A

AAATE

See Association for the Advancement of Assistive Technology.

ABLEISM

Ableism describes prejudicial attitudes and discriminatory behaviors toward persons with a disability. Definitions of ableism hinge on one's understanding of normal ability and the rights and benefits afforded to persons deemed normal. Some persons believe it is ableism that prevents disabled people from participating in the social fabric of their communities, rather than impairments in physical, mental, or emotional ability. Ableism includes attitudes and behaviors emanating from individuals, communities, and institutions as well as from physical and social environments.

HISTORY

The term *ableism* evolved from the civil rights movements in the United States and Britain during the 1960s and 1970s, but prejudice and discrimination against persons with a disability has existed across the globe and throughout history. During the civil rights era, disability activists transformed religious and scientific understandings of disability into a political paradigm. In religious and scientific paradigms, disability is an individual characteristic. The disabled individual bears primary responsibility for enduring or remedying the disability through prayer in the religious paradigm or through medical intervention in the scientific paradigm. Although disabled persons are sometimes isolated from nondisabled persons, the dominant theme in both religious and scientific traditions is that nondisabled persons should behave compassionately toward disabled persons. From the civil rights perspective, often called a minority oppression model, society creates disability by creating physical and social environments hostile to persons different from the majority or "abled" culture. *Ableism* has become a term used to describe "the set of assumptions and practices that promote unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences" (Terry 1996:4–5).

MANIFESTATIONS OF ABLEISM

Discriminatory attitudes and practices that promote unequal treatment of disabled persons share many similarities with the discrimination against other minority groups. Discrimination may be direct or indirect, legally or culturally encoded, based on scientific norms or based on false assumptions. Stereotyped notions of the minority group, whether chosen by an individual or ascribed to an individual by others, may prevent members of the majority group from even perceiving individual characteristics. Common components of ableism include lowered expectations, normalization as beneficence, limitations in self-determination, labeling, and eugenics.

Lowered Expectations

Expectations refer to beliefs about probable future occurrences based on current observations. Expectations of parents, teachers, employers, and others often influence one's self-concept and one's achievement. Research demonstrates correlations between high expectation and high achievement among students in elementary through higher educational settings, as well as correlations between low expectation and low achievement. Moreover, research demonstrates that the younger the person, the stronger the influence of expectations held by others. The consequences of low expectation are particularly pernicious when those forming expectations erroneously evaluate ability and when they assume that low achievement in one performance domain automatically transfers to low achievement in other performance domains. For example, children with speaking impairments are often erroneously assumed to have more difficulty learning than those who are easily understood.

Two areas of lowered expectations receive special attention in the disability literature and in public policy: education and employment. Across continents, many nations prohibit certain forms of discrimination in educational and employment opportunity. In the United States, the Individuals with Disabilities Education Act (1975, 1997) requires schools to provide "free and appropriate education" for all students, and the Americans with Disabilities Act (ADA; 1990) provides employment protections for qualifying persons with disability. In Australia, the Disability Discrimination Act (1992) supports nondiscrimination in education and training and the Disability Services Act (1986) provides that a person with disability has a right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In the United Kingdom, the Disability Discrimination Bill (1995) prohibits employer discrimination against disabled persons in recruitment, employment conditions, training, and promotion. One limitation of these and similar acts in other nations is that they cannot adequately protect persons from unspoken judgments of inadequacy that follow a person throughout childhood and adulthood.

Ableism manifested by lowered expectations in education may be remedied in several ways. Hehir (2002) wrote at length about policies to reduce ableism in schools. He asserted that children with learning disabilities should have access to the rest of the curriculum even if evidence suggests that reading and writing will always be weak. He proposes the elimination of policies in which schools are allowed to a priori exclude the performance of children with disabilities from overall school performance. Laws with this type of exclusion reinforce lower expectations, and consequently lower achievement, of children with disability.

Ableism causing lowered expectation in employment is also pervasive across cultures. Especially in capitalist economies, persons with disability are viewed as expensive labor or not suited for labor at all. The inordinate focus on the characteristics of the disability to the exclusion of that which a person can do exacerbates lower expectations and produces discrimination.

Normalization as Beneficence

Ableism is manifest whenever people assume that normal physical, mental, and emotional behavior is beneficial regardless of a person's actual physical, mental, and emotional attributes. Especially when strong research evidence supports alternate conclusions, the equating of normal with desirable may be harmful to disabled persons. For example, educators and parents may assume that deaf children will better negotiate the hearing world with oral language than with manual language (e.g., sign language). A large body of research, however, demonstrates that deaf children make greater educational achievements when manual, rather than verbal, language skills are emphasized. Language provides organization for the acquisition and utilization of knowledge. It is therefore logical that an emphasis of oral language over manual language would be detrimental to most deaf children. Normalization may be particularly noxious when persons without disability assume positions of power over persons with disability.

Limitations in Self-Determination

Self-determination describes the right and the responsibility of people to make decisions for themselves. Self-determination includes freedom to associate with whomever one chooses, authority to control money owned by or used to purchase services for oneself, autonomy to be the boss of one's own life, and assuming responsibility for the consequences of one's decisions. Self-determination is an internationally endorsed value. The United Nations General Assembly adopted the "Universal Declaration of Human Rights" in 1948. This document affirms that the "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." A problem is that these inalienable rights have often been denied to disabled person. Ableism occurs whenever a group of persons endorse self-determination among most group members but restrict or inhibit disabled persons from making basic life choices. Even when legal codes establish the rights of disabled persons to exercise the same rights of self determination that are afforded to abled persons, disabled persons often are not able to exercise their rights to self-determination in education, employment, transportation, housing, medical decision making, and social interchange. These rights may remain inaccessible to disabled persons due to inaccessibility of physical and social spaces, limited financial resources, and disabling attitudes.

Labeling

Labeling a person as "disabled" requires a judgment, usually by a professional, that an individual's behaviors are somehow inadequate, based on that professional's understanding of community expectations about how a given activity should be accomplished. Professionals typically consider methods used by "abled" person of the same age, sex, and cultural and social environment to accomplish a task to be normal, and all other methods to be abnormal. A problem with this interpretation of disability is the duality of categorization. People are either "disabled" or "abled." "Abled" persons set the criteria for the categorization, and "abled" persons make the judgments that assign people to one of the two categories. The label "disabled" implies inadequacy as a person. The social meaning of a classification often more strongly influences the daily life of a labeled person than the characteristics that cause the person to meet the classification criteria. When a label carries positive social meaning, the labeled individual may experience expanded opportunities. When the label carries negative social meaning, opportunities often contract. The label "disabled" carries negative social meaning. In the United States, the authors of the ADA recognized the seriousness of the negative consequences of being thought of as "disabled." The ADA protects persons thought of as "disabled" equally to persons who otherwise meet the criteria for disability under the act. Few other countries have enacted laws to address disadvantage that results from simply being called "disabled."

Eugenics

Eugenics may be defined as development and improvement of the human race. Eugenic methods include preventing persons deemed deviant and defective from being born, preventing persons born deviant or defective from reproducing, and isolating persons deemed deviant and defective through institutionalization or murder. The systematic killing of disabled children by the Nazi regime in Germany during World War II illustrates an extreme form of ableist behavior. The identification of the human genome (entire genetic makeup of human beings) facilitates selective abortion based on ableism. Selective abortion is a contemporary form of eugenics. Societies that permit abortion for fetuses likely to be born disabled, but do not permit abortion for those likely to be born abled, invalidate the lives of disabled persons.

—Sandra J. Levi

See also Americans with Disabilities Act of 1990 (United States); Disability Discrimination Act of 1992 (Australia); Eugenics; Individuals with Disabilities Education Act of 1990 (United States); Stigma; Stigma, International.

Further Readings

Bartlett, Peter. 1997. "Judging Disability: The Problem of Ableism." Nottingham, UK: Nottingham University, Student Human Rights Law Centre. Retrieved September 24, 2003 (http://www.nottingham.ac.uk/law/hrlc/hrnews/may97/bart.htm).

Disability Rights Education & Defense Fund. 2004. "Country Laws Index." Berkeley, CA: Disability Rights Education & Defense Fund. Retrieved April 4, 2004 (http://www.dredf.org/international/lawindex.html).

Hehir, Thomas. 2002. "Eliminating Ableism in Education." *Harvard Educational Review* 72:1–32.

Ruebain, David. 2000. "What Is Prejudice—As It Relates to Disability and Anti-Discrimination Law?" Berkeley, CA: Disability Rights Education & Defense Fund. Retrieved March 29, 2004 (http://www.dredf.org/international/ruebain.html).

Takayuki, Manakata. 1999. "Human Rights, the Right of Self-Determination and the Right to Freedom." *International Journal of Peace Studies.* Retrieved April 1, 2004 (http://www.gmu.edu/academic\ijps/vol4_1/takayuka.htm).

Terry, Paul M. 1996. "Preparing Educational Leaders to Eradicate the 'isms.'" Paper presented at the Annual International Congress on Challenges to Education: Balancing Unity and Diversity in a Changing World, Palm Beach, Aruba, July 10–12. Obtained from Educational Resources Information Center (ERIC).

United Nations, Office of the High Commissioner for Human Rights. 1948. "Universal Declaration of Human Rights." Geneva: United Nations. Retrieved April 4, 2004 (http://www.unhchr.ch/udhr/lang/eng.htm).

ABU 'L-`ALA AL-MA`ARRI

(973–1057)

Arab poet and freethinker

The renowned Arab poet and philologer Abu 'l-`Ala lost most of his sight to smallpox in his fourth year, and was blind as a youth. His memory developed well, and he retained huge amounts of Arabic literature. Abu 'l-`Ala took up the role of blind poet, having a tiny pension for himself and his sighted attendant. When that income failed, he moved to Baghdad and joined literary circles there, managing briefly to earn a precarious living from writing and public recitation of verses. While his talents were appreciated, they did not save him from some quarrels and humiliations. Within two years, he had returned to Ma`arrat and resumed his life there, in 1010. Extant correspondence shows him active in literary affairs and teaching. As his teeth began to drop out, he complained of his own mispronunciation leading to his amanuensis writing mistakenly. Abu 'l-`Ala actively courted controversy with unorthodox religious views, even writing a book that could be considered as attempting to rival the Qur'an.

—Kumur B. Selim

See also Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

Further Readings

Ibn Khallikan's Biographical Dictionary. 1842–1871. Translated by Mac Guckin de Slane, Vol. 1, pp. 94–98. Paris.

The Letters of Abu 'l-`Ala of Ma`arrat al-Nu`man. 1898. Translated by D. S. Margoliouth. Oxford, UK: Clarendon.

ABU 'L ASWAD AD-DUWALI

(603-688)

Arab scholar

The scholar and innovative grammarian Abu 'l Aswad ad-Duwali lived in Basra, Iraq, and for a short period may have been city governor, under the caliphate of `Ali. In later life, Abu 'l Aswad suffered paralysis and could hardly walk, yet insisted on going to market in person, though he was wealthy. An acquaintance remarked that there was no reason to put himself to this trouble, so Abu 'l Aswad explained why he would continue to appear in public as long as he could: "I go in and out, and the eunuch says: 'He is coming,' and the boy says: 'He is coming,' whereas, were I to continue sitting in the house, the sheep might urine upon me without anyone preventing them." Another reason was that Abu 'l Aswad had lost all real influence after the murder of his patron `Ali, but in public he was still recognized as a man who had been of some consequence.

[QU: Source for the "I go in and out" quote?]

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

Further Readings

Fück, J. W. 1960. "Abu 'l-Aswad al-Du`ali." Pp. 106–107 in *Encyclopaedia of Islam,* new edition, Vol. 1. Leiden, the Netherlands: Brill.

Ibn Khallikan's Biographical Dictionary. 1842–1871. Translated by Mac Guckin de Slane, Vol. 1, pp. 662–667. Paris.

ABUSE AND HATE CRIMES

Abuse and hate crimes are serious problems in the lives of many disabled people. Abuse can take many forms, including: physical, sexual, emotional, medical, and financial abuse, as well as maltreatment and neglect. Physical abuse can include hitting, slapping, and pushing; sexual abuse can involve unwanted touching, sexual contact, or rape; emotional abuse can including bullying, threatening, and intimidating a person; medical abuse can involve overmedicating a person or denying them appropriate medications; financial abuse involves wrongfully using someone else's finances; and neglect may range from failure to provide basic necessities to putting someone at risk through unsafe practices.

Many studies show that disabled people are far more likely than nondisabled people of the same age and gender to be the victims of abuse. However, the studies that have been carried out on disability abuse have often been conducted on small populations of people with specific impairments. For instance, Sullivan, Vernon, and Scanlan (1987) and Elder (1993) reported sexual abuse among Deaf youths at rates higher than 50 percent. Jacobson and Richardson (1987) found that 81 percent of psychiatric inpatients with multiple disabilities had been abused. Pava (1994) studied the vulnerability of vision-impaired people to sexual and physical assault, concluding that one in three of her sample had been targets of either attempted or actual assault. In an Australian study, Wilson and Brewer (1992) reported that people with an intellectual disability were 10 times more likely to experience violent crime victimization than other adults. McCabe, Cummins, and Reid (cited in Chenoweth 1999) found that 20.5 percent of people with an intellectual disability had been raped, compared to 5.7 percent of a control group of nondisabled people.

There is an abundance of literature suggesting that disabled children experience far higher rates of abuse than nondisabled children. Ammerman and Baladerian (1993) concluded that the rate of maltreatment of disabled children is 4 to 10 times higher than nondisabled children. Sullivan and Knutson (1998) examined nearly 40,000 hospital records and reported rates of maltreatment among children with disabilities that were 1.7 times higher than nondisabled children. A later review of school records by Sullivan and Knutson (2000) indicated maltreatment among 31 percent of disabled children compared to 11 percent of the overall school population. A number of studies suggest that abuse is often carried out by people who are known to the victim—family, friends, other disabled people, and even paid caregivers. However, many cases of abuse are not reported to authorities because of the victim's shame, fear of retaliation, fear of not being believed, or reliance on third parties to report the abuse.

Sobsey, Randall, and Parrila (1997) suggested that there may be different patterns of abuse for disabled boys than disabled girls. They reviewed the case files of 1,834 children and found that 62 percent of girls with disabilities and 38 percent of boys with disabilities experienced sexual abuse, 59 percent of girls with disabilities and 41 percent of boys with disabilities had been emotionally abused, and 56 percent of disabled boys were neglected, compared to 44 percent of disabled girls.

Dick Sobsey's (1994) major study, *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* suggested that disabled people are more likely than nondisabled people of the same age and gender to experience abuse and that this abuse is more likely to be prolonged and severe. Sobsey also suggested that a "culture of abuse" often existed in certain institutions. This argument is supported by Furey, Neilsen, and Strauch (1994), who reviewed cases of substantiated abuse and neglect of mentally retarded adults in Connecticut. They found that such abuse and neglect is far more likely to occur in group homes and institutional settings than in private residences. Chenoweth (1996) acknowledged that there may be a "culture of cover-up" in institutions and group homes. However, she emphasizes the importance of other social factors in creating environments where abuses take place, including the dehumanization of residents in institutions, a "paradox of care and abuse within the one system," and the enormous power differentials between people and the system.

The rates of abuse experienced by disabled women are particularly high. Nosek et al. (2001) also stated that 62 percent of physically disabled women in their

QU: Need a reference for Sullivan, Vernon, and Scanlan (1987)]

study reported experiences of sexual abuse. The Disabled Women's Network of Canada surveyed 245 women with disabilities in 1989 and found that 40 percent had experienced abuse, and 12 percent had been raped (Riddington 1989). The most frequent perpetrators in these cases were spouses and former spouses. Less than half of these cases of abuse and rape were reported.

A number of studies suggest that the vast majority of perpetrators of abuse are male and are known to the victim (National Center for Injury Prevention and Control 1998). Perpetrators of abuse include caregivers, family members, other disabled people, health care providers, and acquaintances. The fact that many disabled people have a number of caregivers in their lives, whose work often involves rather intimate tasks, may be one of the factors that puts them at increased risk of abuse. Social and personal boundaries are often at risk of being blurred in the provision of personal assistance (Saxton et al. 2001).

Some of the responses that have been developed to prevent abuse include the following: training programs for both potential victims and caregivers to increase awareness of abuse issues; sex education programs that emphasize choice making, personal rights, and assertiveness training; and staff screening programs involving reference and police checks to weed out convicted sex offenders from caregiving positions (Sobsey and Mansell 1990). It is essential that child protection workers, law enforcement personnel, and educators (particularly in special education settings) be provided with sufficient training to appropriately respond to cases of disability abuse.

Unfortunately, many child protection workers lack knowledge about disability issues. This lack of confidence dealing with disability issues has led to the situation where disabled children are overrepresented among victims of abuse but underrepresented among the caseloads of child protection workers (Orelove, Hollahan, and Myles 2000). As a result, disabled victims of abuse often experience significant difficulty in accessing appropriate services. Over 50 percent of the services studied by Sobsey and Doe (1991) did not provide any accommodations to meet the needs of their disabled clients. Many professionals also report a lack of training in dealing with abuse histories of male clients, which may compound these problems (Lab, Feigenbaum, and De Silva 2000).

DISABILITY HATE CRIMES

Disability hate crimes are criminal acts aimed at a person because of their disability identity, or because of their connection with someone who is disabled. To prove that a crime is actually a hate crime, there must be evidence to demonstrate conclusively that the perpetrator discriminated in the selection of the victim. There are two victims in hate crimes: individuals and communities. Hate crimes not only represent an attack on the rights and freedoms of individuals, they indicate a lack of physical safety for anyone in the community that has been attacked. Because hate crimes have two victims (both individuals and communities), offenders are often given extra penalties for these crimes.

The unique aspect of hate crimes is that they involve "parallel crimes" (Jenness and Grattet 2001:130). That is, there are two crimes embedded in a single act: a crime such as vandalism, theft, arson, murder, or assault, and another crime, a bias crime. To prove that a bias crime has occurred, it is necessary to demonstrate that the offender discriminates in the selection of his or her victim. To prove a disability hate crime exists, discrimination on the basis of real or perceived disability must be a substantial reason for discriminating against this particular individual. Evidence of hate can include words or symbols associated with hate, demeaning jokes about a particular group, the destruction of that group's symbols, a history of crimes against a group, a history of hate crimes in the community, and the presence of hate group literature.

Hate crime legislation typically outlines specific identity categories that are protected from bias crimes. This has led some critics to suggest that there is a hierarchy of protected categories, with race, religion, and ethnicity being the least controversial categories and gender, sexual orientation, and disability being the most controversial (McPhail 2000). In *Hate Crimes: Criminal Law and Identity Politics,* James Jacobs and Kimberly Potter (1998) argued that protecting certain categories of identity generates political conflict, produces an overly negative picture of intergroup relations, and creates recurrent occasions for intergroup conflict. The proponents of hate crimes legislation counter these arguments by arguing that the legislation responds to, rather than creates, intergroup conflict—particularly the violent suppression of marginalized identities and the violence defense of hegemonic identities.

Hate crimes tend to be associated with high levels of violence. Compared to other forms of crime, hate crimes are far more likely to involve physical threat and harm to individuals, rather than property. Victims of a hate crime are three times more likely to require hospitalization than victims of a nonbias assault (Bodinger-DeUriate and Sancho 1992). In one study, half the victims of hate crimes were assaulted. This is a significantly higher rate than the national crime average, where only 7 percent of crimes involve assault (Levin and McDevitt 2002:17). The psychological consequences of hate crimes also seem to be more significant than those for nonbias crimes, in terms of depression, anger, anxiety, and posttraumatic stress (Herek, Gillis, and Cogan 1999; Herek et al., 1997).

Many hate crimes are committed by complete strangers—people who do not know the victim at all. Hate crimes are also often unprovoked (McPhail 2000). This aspect of the crime reinforces the sense that it is not something about the particular individual, but simply the person's shared identity with a collective group, that is the source of the victimization. In fact, this aspect of the crime is often seen as pivotal in establishing that the act was a hate crime rather than another form of crime.

Only a very small minority of disability hate crimes involve organized hate groups. However, it is important to acknowledge that some organized hate groups also overtly display their hostility to disabled people. Some neo-Nazi groups rely on eugenic ideas to debase disabled people and deny the right of disabled people to live. For instance, the white supremacist group Stormfront often discusses the need to "eliminate bad genes" and rid the world of disabled people.

Hate crimes often involve multiple perpetrators (whereas most assaults usually involve two mutual combatants), and often the victims are unarmed while the perpetrators are armed (Bodinger-DeUriate and Sancho 1992). Also, perpetrators of hate crimes often do not live in the area where they commit the crimes. They frequently spend time and money in traveling to unfamiliar areas in order to perpetrate the crime (Medoff 1999). And in most property crimes, something of value is stolen, but hate crimes that involve property are more likely to entail the destruction rather than the theft of that property (Medoff 1999).

Few countries retain national data on disability hate crimes. Often these crimes are not reported to police, or not recorded even if they are reported. Even when crimes against disabled people are neither random nor circumstantial, they are almost never acknowledged as "hate crimes." However, the FBI has published some data on disability hate crimes in America, suggesting that the most common forms of disability hate crimes are assault, intimidation, destruction of property, and vandalism. FBI data on American disability hate crimes from 1997 to 2001 indicate that the most common forms of disability bias crime are simple assault and intimidation, both of which comprise 29 percent of all disability bias crimes. The next most common form of disability bias crime is destruction, damage, or vandalism, which comprised 14 percent of all disability bias crimes.

For a range of bureaucratic reasons, those agencies responsible for reporting hate crimes may not have reported all crimes in their jurisdictions. This is a problem generally with hate crime statistics, and not just disability hate crimes. One of the serious misgivings that has to be voiced about these data is that less than 2,000 of the eligible 17,000 law enforcement agencies have ever filed a report of any sort of hate crime—whether by racial, religious, gender, sexuality, nationality, disability, or other bias (Center for Criminal Justice Policy Research and Justice Research and Statistics Association 2000).

The problems with these data stem from the fact that submitting hate crimes reports is voluntary, not all jurisdictions within states submit reports, and time frames for reporting are uneven—ranging from one month to one year (American Psychological Association 1998). Another problem is that there is a great deal of inconsistency in the location of hate crime units, the nature and amount of training received by responsible officers, procedures for screening and handling cases, and record-keeping systems (Martin 1995). Balboni

[QU: Need reference for (Center for Criminal Justice . . . (2000)]

and McDevitt (2001) suggested that lack of departmental infrastructure, lack of training and supervision, and communication breakdowns between line officers and those responsible for reporting the crimes may inhibit accurate reporting of hate crimes. Green et al. (2001:295) commented, “One cannot compare jurisdictions that use different reporting standards or have different levels of commitment to the monitoring of hate crime.” Potok (2001) argued that the process is riddled with errors, failures to pass along information, misunderstanding of what constitutes a hate crime, and even falsification of data. Despite these misgivings, it must be acknowledged that many police departments are making significant efforts to implement hate crime policies and to monitor the incidence of hate crimes in their jurisdiction. Other factors may contribute to the failure to report hate crimes in such circumstances (Haider-Markel 2001).

—*Mark Sherry*

See also Child Abuse; Violence.

Further Readings

American Psychological Association. 1998.

Ammerman, R. T. and N. J. Baladerian. 1993. *Maltreatment of Children with Disabilities.* Chicago: National Committee to Prevent Child Abuse.

Balboni, and McDevitt, 2001.

Bodinger-DeUriate, C. and A. R. Sancho. 1992. *Hate Crime: Sourcebook for Schools.* Los Alamitos, CA: Southwest Center for Educational Equity.

Center for Criminal Justice Policy Research and Justice Research and Statistics Association. 2000.

Chenoweth, L. 1996. “Violence and Women with Disabilities: Silence and Paradox.” Pp. 21–39 in *Women’s Encounters with Violence in Australia*, edited by J. Bessant and S. Cook. Thousand Oaks, CA: Sage.

———. 1999. “Sexual Abuse of People with Disabilities: Denied Sexuality and Abuses of Power.” Pp. 301–312 in *Disability, Divers-Ability and Legal Change,* edited by M. Jones and L. A. Basser Marks. London: Martinus Nijhoff.

Elder, M. 1993. “Deaf Survivors of Sexual Abuse: A Look at the Issues.” *Moving Forward Newsjournal* 2(1): 1–11.

Furey, E. M., J. J. Nielsen, and J. D. Strauch. 1994. “Abuse and Neglect of Adults with Mental Retardation in Different Residential Settings.” *Behavioral Interventions* 9(4): 199–211.

Green, et al. 2001.

Haider-Markel, 2001.

Herek, G. M., J. R. Gillis, and J. C. Cogan. 1999. “Psychological Sequelae of Hate-Crime Victimization among Lesbian, Gay and Bisexual Adults.” *Journal of Consulting and Clinical Psychology* 67(6): 945–951.

Herek, G. M., J. R. Gillis, J. C. Cogan, and E. K. Glunt. 1997. “Hate Crime Victimization among Lesbian, Gay, and Bisexual Adults: Prevalence, Psychological Correlates, and Methodological Issues.” *Journal of Interpersonal Violence* 12(2): 195–217.

Jacobs, J. B. and K. Potter. 1998. *Hate Crimes: Criminal Law and Identity Politics.* New York: Oxford University Press.

Jacobson, A. and B. Richardson. 1987. “Assault Experiences of 100 Psychiatric Inpatients: Evidence for the Need for Routine Inquiry.” *American Journal of Psychiatry* 144(7): 908–913.

Jenness, V. and R. Grattet. 2001. *Making Hate a Crime: From Social Movement to Law Enforcement.* New York: Russell Sage Foundation.

Lab, D. D., J. D. Feigenbaum, and P. D. De Silva. 2000. “Mental Health Professionals’ Attitudes and Practices towards Male Childhood Sexual Abuse.” *Child Abuse and Neglect* 24(3): 391–409.

Levin, J. and J. McDevitt. 2002. *Hate Crimes Revisited: America’s War on Those Who Are Different.* Boulder, CO: Westview.

Martin, 1995.

McPhail, B. A. 2000. “Hating Hate: Implications of Hate Crime Legislation.” *Social Service Review* (December): 635–653.

Medoff, M. H. 1999. “Allocation of Time and Hateful Behavior: A Theoretical and Positive Analysis of Hate and Hate Crimes.” *American Journal of Economics and Sociology* 58(4): 959–973.

National Center for Injury Prevention and Control. 1998. “Sexual Violence against People with Disabilities.” Atlanta, GA: Centers for Disease Control and Prevention, Division of Violence Prevention.

Nosek, M. A., C. Howland, D. H. Rintala, M. E. Young, and G. F. Chanpong. 2001. “National Study of Women with Physical Disabilities: Final Report.” *Sexuality and Disability* 19(1): 5–39.

Orelove, F. P., D. J. Hollahan, and K. T. Myles. 2000. “Maltreatment of Children with Disabilities: Training Needs for a Collaborative Response.” *Child Abuse and Neglect* 24(2): 185–194.

Pava, W. S. 1994. “Visually Impaired Persons’ Vulnerability to Sexual and Physical Assault.” *Journal of Visual Impairment and Blindness* 88(March-April): 103–113.

Potok, 2001.

Riddington, J. 1989. *Beating the “Odds”: Violence and Women with Disabilities.* Vancouver: Disabled Women’s Network.

Saxton, M., M. A. Curry, L. E. Powers, S. Maley, K. Eckels, and J. Gross. 2001. “Bring My Scooter So I Can Leave You.” *Violence Against Women* 7(4): 393–417.

[QU: Need references for American Psychological Association (1998), Martin (1995), Balboni and McDevitt (2001), Green et al. (2001), Potok (2001), and Haider-Markel (2001)]

Sobsey, D. 1994. *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* Baltimore: Paul H. Brookes.

Sobsey, D. and T. Doe. 1991. "Patterns of Sexual Abuse and Assault." *Sexuality and Disability* 9(3): 243–259.

Sobsey, D. and S. Mansell. 1990. "The Prevention of Sexual Abuse of People with Developmental Disabilities." *Developmental Disabilities Bulletin* 18(2): 51–66.

Sobsey, D., W. Randall, and R. K. Parrila. 1997. "Gender Differences in Abused Children with and without Disabilities." *Child Abuse and Neglect* 21(8): 707–720.

Sullivan, Vernon, and Scanlan, 1987.

Sullivan, P. M. and J. F. Knutson. 1998. "The Association between Child Maltreatment and Disabilities in a Hospital-Based Epidemiological Study." *Child Abuse and Neglect* 22(4): 271–288.

———. 2000. "Maltreatment and Disabilities: A Population-Based Epidemiological Study." *Child Abuse and Neglect* 24(10): 1257–1273.

Wilson, C. and N. Brewer. 1992. "The Incidence of Criminal Victimization of Individuals with an Intellectual Disability." *Australian Psychologist* 27(2): 114–117.

Websites

Abuse of Women with Disabilities, http://www.vaw.umn.edu/documents/vawnet/disab/disab.html#welbourne1983

In Focus: The Risk and Prevention of Maltreatment of Children with Disabilities, http://nccanch.acf.hhs.gov/pubs/prevenres/focus.cfm

National Criminal Justice Reference Service, http://www.ncjrs.org/hate_crimes/summary.html

ACCESSIBILITY

Accessibility is a term with no precise definition. In the disability field, the concept of accessible environments is used to describe environments that are approachable, obtainable, or attainable. Often this means that the environment can be altered to enhance the individual's probability to participate in that environment in a way that is meaningful to the individual. Such environments are thus viewed as accessible. In this sense, issues of access and accessibility are usually not discussed in isolation, but rather in terms of specific environments to which access is desired. Examples of environments where accessibility is discussed are communication systems, education, employment, health care, housing, information technology, medical offices, polling places, public transportation, and websites. This list is by no means exhaustive. Any environment can be deemed as one to which accessibility is desirable.

Accessibility is a distinct characteristic from both participation and the environment. By its nature, *participation* refers either to an act of taking part or to a state of being related to a large whole. *Accessibility* is not an act or a state but a liberty to enter, to approach, to communicate with, to pass to and from, or to make use of a situation. The *environment* is either that large whole or parts thereof or that situation which is accessed. From these distinctions, it is clear then that the elements of accessibility are characteristics of an environment's availability but not characteristics of the environment itself.

By its nature, accessibility is interactive. An environment that is accessible to one person may not be accessible to another. As such, accessibility references issues to the interaction of persons and their environment. Hence, questions can be raised as to whether an environment has been formed or designed in such a way that a person can approach, obtain, or attain some aspect that is desired by that individual. Yet some enhancement of the individual's ability to obtain such access may be desirable. For instance, Braille can make linguistic communication that is usually obtained through sight attainable to persons who are blind, but those persons must know how to use the sense of touch to access Braille. Thus, written communication will not be accessible to persons who are blind if both of these conditions do not obtain—(a) written works must be available in Braille and (b) individuals who are blind must know how to read Braille. However, even the second part raises an issue of accessibility—the access of individuals who are blind to training in Braille. In this sense, accessibility is not a static phenomenon but can occur across different planes.

For more than 30 years in the United States, the concept of accessibility has been legally codified in Section 502 of the Rehabilitation Act of 1973, which created the Access Board. The work of this board interfaces not only with the Rehabilitation Act but also with the Architectural Barriers Act, the Americans with Disabilities Act, and Section 255 of the Telecommunications Act. The board grew out of the creation by Congress in September of 1965 of the

National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacted the Architectural Barriers Act (ABA) on August 12, 1968. The ABA requires access to facilities designed, built, altered, or leased with federal funds. However, there were no design standards to determine the accessibility of facilities.

To address this lack of standards, Congress established the Access Board, originally named the Architectural and Transportation Barriers Compliance Board in Section 502 of the Rehabilitation Act. The board's mandate was to ensure federal agency compliance with the ABA, and it was constituted of representatives from several different agencies. In the Rehabilitation Act Amendments of 1978, Congress authorized the board to establish minimum accessibility standards under the ABA, to ensure compliance with the requirements and to provide technical assistance. In 1984, the board issued the "Minimum Guidelines and Requirements for Accessible Design," which now served as the basis for enforceable design standards. The 1990 Americans with Disabilities Act (ADA) expanded the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. Facilities covered by these guidelines are restaurants and cafeterias; medical care facilities; mercantile establishments; libraries; hotels, motels, and transient lodging; and transportation facilities and vehicles. Under the Telecommunications Act of 1996, Congress authorized the board to develop guidelines for the accessibility of telecommunications products. The board issued its guidelines in 1998. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility to developing accessibility standards for electronic and information technology. The Access Board has established ongoing committees to develop and update its accessibility guidelines and standards, which include those representing designers, industry, and people with disabilities.

Beyond the United States, the concept of accessibility has been a critical element in international disability policy for more than 20 years. Access and accessibility are concepts that are addressed several times throughout the World Programme of Action Concerning Disabled Persons, passed by the United Nations General Assembly in 1983. The World Programme references a concern with cultural, physical, or social barriers that prevent the access of individuals with disabilities to the various systems of society available to other citizens. The concept of accessibility is discussed in conjunction with the definition of equalization of opportunities as the process through which the general systems of society are made accessible to all people. Although addressed several times in the World Programme, accessibility is mainly discussed in terms of those societal elements that should be made accessible to all, such as community services.

Passed by the General Assembly in 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities uses the term *available* instead of *accessible* in the context of defining equalization, perhaps because one of the rules, Rule 5, employs the term *accessibility* a little more narrowly. Accessibility is divided in two main areas: the physical environment and the communication environment. In terms of the physical environment, the Standard Rules offer the possibility of legislation, standards, and guidelines to ensure accessibility to housing, buildings, public transport services, and other means of transportation and outdoor environments. Those designing these environments, such as architects and construction engineers, would, hence, have the means to acquire information on measures to achieve accessibility. The rules urge such consideration at the beginning of the design process.

For information and communication, the importance of access to information about rights, services, programs, and diagnosis is considered of paramount importance. The issue of alternative formats for persons with vision and hearing and other communication issues is raised, along with media and computer accessibility. To ensure such accessibility, the role of persons with disabilities and their organizations is stressed. If the more broad term of *availability* is considered as the concept of accessibility, then the rules offer guidance for accessibility in all the designated target areas for equal participation—education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.

Somewhat more complicated than issues related to accessibility of the physical or built environment is addressing the issue of accessibility to programs, such as access to education. Prior to passage of the Individuals with Disabilities Education Act (IDEA) in the United States, individuals with disabilities were not in school until the idea of access to school as a civil right emerged. Upon passage of the act, progress was made in gaining access to school, in a physical sense. Then, accessibility involved the concepts of mainstreaming and least restrictive environment. The emphasis in each of these approaches to access was the setting, in particular the classroom setting.

While setting remains important, attention is increasingly focusing on curriculum access. To that end, the U.S. Department of Education's Office of Special Education Programs has provided funding to the American Institutes for Research to house a national technical assistance (TA) center called the Access Center. The center strives to improve educational outcomes for elementary and middle school students with disabilities by building the capacity of TA systems, States, districts, and schools, to help students with disabilities learn from the general education curriculum. The center's goals are as follows:

1. Increase awareness of research-based programs, practices, and tools.
2. Strengthen the ability of educators to be informed consumers of programs, practices, and tools.
3. Assist educators to implement and evaluate programs, practices, and tools.

The Access Center has developed a framework for thinking about access to the general education curriculum. It views access is as a multidimensional and dynamic process that involves a combination of instructional practices and supports. Under this approach, the general education curriculum is operationalized in terms of appropriate instructional and learning goals for individual students with disabilities, including appropriate scope and sequence. Appropriate research-based instructional methods and practices that have a track record of helping students with disabilities learn general education content and skills would then be employed alongside appropriate research-based materials and media, as well as supports and accommodations. Finally, appropriate tools and procedures would be used to assess and document whether students with disabilities are meeting high standards and achieving their instructional goals. The center has noted the importance of universal design in providing accessibility.

Whether the discussion focuses on access to programs or to the physical environment, the two approaches for achieving accessibility have been considered to comprise accommodation and universal design. Whereas accommodation involves changing existing environments to enhance accessibility, universal design occurs at the environmental design stage, where products and environments are created to the greatest extent possible to be accessible to persons of all ages and abilities. Often one or both of these approaches are implemented based on practical considerations. When institutions are well established and cannot be redesigned, accommodation solutions may be chosen. When institutions need to be designed or redesigned, principles of universal design may be employed to enhance accessibility.

Accessibility can be viewed as a multidimensional phenomenon. At this time, at least four models attempt to more fully explain the concept of accessibility. The first is the World Health Assembly's adoption in 2001 of the International Classification of Functioning, Disability, and Health (ICF). (The World Health Organization's [WHO] classification systems must be approved by the World Health Assembly, which consists of the member states that belong to the WHO.) The ICF incorporates for the first time in a health taxonomy the systematic consideration of environments, whose accessibility can be evaluated. Broad categories include products and technology, as well as the natural environment and human-made changes to the environment. These encompass many of the areas previously discussed. Also considered, however, are elements of a more sociological nature, such as attitudes and support and relationships. Finally, services, systems, and policies are included. These environments can be characterized as barriers or facilitators. Though it does not employ the concept of accessibility in a systematic way, the ICF does note that accessibility can be dependable or variable, as well as of good or poor quality. Not only that, but environmental access may be limited due to the presence of a certain phenomenon, such as stairs, or the absence of a phenomenon, such as a ramp.

The multidimensionality of accessibility has led to attempts to systematically define access and describe its dimensions. Some of the earliest work in this area was conducted not in the disability field, but in the area of access to health care. In 1981, Pechansky and Thomas defined *access* as a concept representing the degree of "fit" between the clients and the system. Recognizing the multidimensionality of access, Pechansky and Thomas proposed that five dimensions be considered:

1. Availability—Type and extent of services, supports, and resources relative to personal needs
2. Accessibility—Location of the environment
3. Accommodation—The way services and resources are provided relative to persons' abilities to make use of them
4. Affordability—The cost vis-à-vis the resources of individuals
5. Acceptability—The match in attributes and attitudes between providers and clients

This health care model of accessibility has been applied by Simeonnson and colleagues (Simeonnson et al. 1999) to persons with disabilities. They argue that the notion of "fit" is compatible with person-environment interaction. In this manner, accessibility is not only the location of the environment, but it also may refer to interaction with the environmental barriers, such as stairs, referenced earlier.

In a similar vein, Whiteneck and colleagues (Whiteneck, Fougeyrollas, and Gerhart 1997) have proposed five general characteristics of environments that influence how poorly or how well an individual becomes an active, productive member of society. Three terms (accessibility, accommodation, and availability) are used in both models and appear to correspond with each other. Their five dimensions are the following:

1. Accessibility: Can you get to where you want to go?
2. Accommodation: Can you do what you want to do?
3. Resource availability: Are your special needs met?
4. Social support: Are you accepted by those around you?
5. Equality: Are you treated equally with others?

The five characteristics do not constitute a classification of the environment or a ranking of the environment but a classification of different kinds of interactions that the environment has with individuals from the point of view of the environment. Despite the use of the term *accessibility* for one of the interactions, this taxonomy of interactions can be viewed as an attempt to understand the dimensions of how environments interact with individuals or how such environments are accessible towards individuals. In this case, the unit of analysis is the environment, rather than the fit interaction of the Pechansky and Thomas model.

A fourth model derives from the Handicap dimension of the International Classification of Impairments, Disabilities, and Handicaps (World Health Organization 1980) and classifies the dimension of access across planes of interaction, such as who, what, where and when. This system is more like the Pechansky and Thomas approach in that the unit of analysis may be individuals or the environment. The seven dimensions in this model are the following:

1. Orientation: Who—do you have information you wish?
2. Independence: What—do you choose what you wish to do?
3. Mobility: Where—do you go where you wish?
4. Occupation of time: When—do you engage when you wish?
5. Social integration: With whom—are you accepted by others?
6. Economic self-sufficiency: With what—do you have the resources you need?
7. Transition: Change—are you prepared for change?

This model attempts to meet the criteria of universality attempted in the ICF, but would constitute a dimension currently not distinct in it, although some elements may be present.

The dimensions of accessibility as elaborated in the four models have been proposed as potential elements for human rights frameworks relating to disability. However, their theoretical nature and the complexity of performing analyses at the level of interaction may inhibit their use in the short run.

—Scott Campbell Brown

See also Americans with Disabilities Act of 1990 (United States); Communication; Handicap; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Participation; Models; Rehabilitation Act of 1973 (United States); United Nations Disability Convention; United Nations Standard Rules; World Health Organization.

Further Readings

Bickenbach, Jerome E., Somnath Chatterji, Elizabeth M. Badley, and T. B. Ustun. 1999. "Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps." *Social Science and Medicine* 48:1173–1187.

Brown, Scott Campbell. 2001. "Methodological Paradigms That Shape Disability Research." Pp. 145–170 in *Handbook of Disability Studies,* edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

———. 2003. "Vers une taxonomie du handicap et des droits de l'homme" (Towards a Human Rights Disability Taxonomy). *Handicap: revue de sciences humaines et sociales* 100 (October-December): 1–18.

Chapireau, Francois and Alan Colvez. 1998. "Social Disadvantage in the International Classification of Impairments, Disabilities and Handicaps." *Social Science and Medicine* 47:59–66.

Pechansky, R. and C. Thomas. 1981. "The Concept of Access: Definition and Relation to Customer Satisfaction." *Medical Care* 19(2): 127–140.

Schultz, Gary Steven. 1996. "Taxonomy of Rights: A Proposed Classification System of Rights for Individuals with Mental Retardation or Developmental Disabilities." *Journal of Developmental and Physical Disabilities* 8(3): 275–285.

Simeonnson, Rune J., Donald B. Bailey Jr., Donna Scandlin, Gail S. Huntington, and Marcia Roth. 1999. "Disability, Health, Secondary Conditions and Quality of Life: Emerging Issues in Public Health. Pp. 239–255 in *Issues in Disability and Health: The Role of Secondary Conditions and Quality of Life,* edited by Rune J. Simeonnson and Lauren N. McDevitt. Chapel Hill: North Carolina Office on Disability and Health.

United Nations, General Assembly. 1983. *World Programme of Action Concerning Disabled Persons.* No. A/37/51. New York: United Nations.

———. 1993. *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities.* No. A/48/96. New York: United Nations.

Whiteneck, Gale G., Patrick Fougeyrollas, and Kenneth A. Gerhart. 1997. "Elaborating the Model of Disablement." Pp. 91–102 in *Assessing Medical Rehabilitation Practices: The Promise of Outcomes Research,* edited by Marcus J. Fuhrer. Baltimore: Paul H. Brookes.

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

Access Board, http://www.access-board.gov/

Access Center, http://www.k8accesscenter.org/default.asp

Report of the United Nations Expert Group Meeting on Disability Sensitive Evaluation and Monitoring, http://www.worldenable.net/livelihoods/egmny200112.htm

ACCESSIBILITY CODES AND STANDARDS

There are many standards and codes that apply to building design. Accessibility is only one issue that codes address. Accessibility standards and codes have been developed to provide architects and other designers with clear guidance about how to implement accessible design. Accessibility codes are regulations promulgated by governments to implement laws that mandate accessibility. The term *guidelines* is also associated with accessible design, for example, Americans with Disabilities Act Accessibility Guidelines or Fair Housing Accessibility Guidelines. In some cases, guidelines may be more general than standards and codes. For example, a guideline might read, "Provide a space for turning a wheelchair" as opposed to a standard that could read, "Provide a space with a five foot turning diameter."

Accessibility standards that are developed in the United States by the American National Standards Institute (ANSI) A117 Committee are consensus-based documents developed for use as criteria in the design of buildings and facilities. The ANSI A117 Committee is an independent professional organization that oversees the process of developing standards. In Europe, accessibility standards are developed by the International Standards Organization and various public agencies. The European Manual for an Accessible Built Environment was developed to promote standardization in access across Europe. Yet it uses the more general form of a guideline. But in other cases, such as the Americans with Disabilities Act (ADA) and the Fair Housing Act, the term *guidelines* is sometimes used in place of the term *standards*.

While standards and guidelines are often voluntary and nonbinding, regulations and codes are always legal mandates. Standards and guidelines usually focus on the technical criteria for providing accessibility, for example, how much space is needed and the configuration of the space. Regulations, on the other hand, usually have technical criteria but also include rules defining the scope of accessibility—what types of buildings and facilities are covered, how many accessible elements are required, and when exceptions can be made. Regulations can reference standards. On the other hand, regulations do not have to reference standards. In fact, some U.S. state laws require the detailed technical criteria to appear directly in their regulations.

The content, form, and intent of accessibility standards and codes vary significantly from one society to the next. This variation is caused by differences in cultural attitudes toward accessibility, building technologies available, the local built and natural environment, the legal system, and the process for developing standards. Since the regulatory process is political, different interest groups can influence regulations while under development or revision. Consumer advocacy groups work to ensure that the scoping and technical criteria will satisfy the needs of their constituencies, while representatives of the building industry strive to make sure that the codes will not negatively affect their businesses. Design professionals and building officials seek to ensure that the codes will be understandable and enforceable. This process may be more democratic in some societies than others.

In general, accessibility regulations improve the level of accessibility in a jurisdiction. In places where accessibility codes are first being introduced, goals may be modest, whereas in places with a long history of accessibility codes, the goals may be much broader and the criteria much more inclusive and restrictive. The differences in goals can apply within a jurisdiction due to differences across sectors of the building industry or across types of construction. Thus, in the United States new efforts to mandate accessibility to detached single-family homes are focused primarily on homes built with public funding because there is much political opposition to regulating the design of privately built homes. As another example, the ADA Standards for Accessible Design apply only to new construction and those portions of buildings undergoing renovation. In existing buildings, only "readily achievable" modifications to remove barriers to use need to be provided. Readily achievable modifications are a far lower standard.

Accessibility standards may be organized together in one document or dispersed among several. Most accessibility standards are independent stand-alone documents that include criteria for general design issues and specific criteria for many built elements. In some countries, such as in Sweden, criteria for accessibility to different parts of buildings have been incorporated into standards for those elements. The advantage of having an independent inclusive document is that the human and economic resources needed to develop, monitor, interpret, and improve the standards are easier to assemble and organize. When accessibility standards are dispersed in many different documents, each developed by a different industry, expertise is diffused among many different committees. Moreover, the coordination of criteria can be an overwhelming task.

Accessibility standards are generally organized into several parts. The first part is an introductory section that explains the purpose of the document, describes how it should be applied, and provides definitions of technical terms used in the document. The second is often a technical section that covers the main issues of accessibility, for example, wheelchair sizes, clearances for wheelchair maneuvers, and reach limits. Other sections of the document follow with provisions for specific parts of buildings and facilities, for example, parking lots, entrances, interior circulation, and toilet rooms. These sections include technical criteria and usually include any exceptions to the rules.

In the United States, the legal implications of misinterpreting the detailed technical criteria are great, and as a result there is a tendency to provide extensive text and great detail, referred to as the "prescriptive" approach to standards writing. Some U.S. experts feel that the more flexible "performance" standards approach is desirable, leaving room for new and innovative ideas to emerge, and encouraging the development and use of new products. The European Union's guidelines are much more "performance oriented," specifying the objectives to be reached rather than the means. This performance approach is clearly appropriate in Europe where the guidelines have to be used in a very diverse set of legal and built contexts—an approach that works in Italy, for example, may be totally inappropriate in Denmark.

Accessibility codes may include the scope of application, the method by which the code will be implemented, a process for design review and appeal, referenced standards, exceptions, penalties for noncompliance, and other administrative issues. If the accessibility code is a part of a general building code, most of this material will be covered by general sections of that building code. In other cases, there may be a separate administrative process. Many of the states in the United States have a separate accessibility code committee that works independently of the general building code process.

Exceptions and variances are an important part of any standard and code. They define the specific situations where the rule may be waived or altered. There are many examples where the provision of full accessibility, as defined by a standard or code, may be infeasible. For example, historic buildings sometimes cannot be made fully accessible without destroying their cultural value. Building codes usually include provisions that allow some flexibility in renovation of such buildings. Other reasons for exceptions and variances include unusual topography, geological conditions, climate factors, very small size, uninhabited structures, and short-term or temporary structures. In general, blanket exceptions are not usually needed or allowed.

Accessibility standards and codes in the more industrially developed countries are often complex and highly technical. They often represent a significant change in the practice of building design, especially for certain types of buildings such as civic buildings where monumental stairs are traditional. Many countries have experienced difficulties actually implementing accessibility standards, even those with highly educated professional designers and extensive building regulatory apparatus. These countries are gradually adopting new approaches, often modeled on the experience of the United States, Canada, or Western European countries.

At an international level, there are certainly many factors that suggest that there should be differences in standards across countries and within regions of a country. The use of Imperial units of measurement in the United States is clearly an important difference that cannot be ignored. Another factor that encourages differences in standards is attitudes toward disability and rehabilitation practice. Northern European experts criticize U.S. standards for toilet stall sizes because, in the United States, space on either side of a toilet with fold-down bars is neither provided nor allowed. On one hand, the Northern Europeans believe that a toilet stall should be usable for a transfer from either side, whereas the U.S. experts believe that it is important to have the side grab bar mounted on a wall to provide additional stability and support, thus eliminating the possibility of transfer from that side. U.S. code groups have also not been willing to accept the fold-down grab bar that is needed for this type of design as an alternative to the fixed wall mounted bar, believing that many people with severe disabilities will have difficulty moving the bar.

In spite of the need for national or regional differences in standards and codes, consistency of standards around the world would be very useful, especially as international travel and tourism become increasingly popular. To participate in our global culture, people with disabilities need to be able to find facilities that they can use wherever they may travel. Moreover, international standards could be adopted by international agencies and multinational corporations for application to their facilities around the world. International standards would make it easier for less developed countries to make progress in accessibility more rapidly. However, it is important to consider the implications of such a development. There is a tendency to adopt the standards and codes of countries where accessibility laws are more advanced as models.

But this may not be the most appropriate approach for places in the world where accessibility to the built environment is a new idea. The adoption of an unrealistic standard or code could easily lead to widespread lack of compliance and therefore no progress at all. Countries that do not have an educational and regulatory infrastructure developed to ensure that standards and codes will be implemented should consider a different approach, one that is more realistic, easy to communicate, and easy to enforce. Thus, at this point in time, international standards should probably include a minimal set of "must have" requirements. They could have more extensive optional requirements. But they should be performance oriented and designed for flexible application to different local conditions.

—Edward Steinfeld and John P. S. Salmen

See also Fair Housing Act Amendments of 1988 (United States); Home Modification; Housing: Law and Policy.

Further Readings

Salmen, J. 2001. U.S. "Accessibility Codes and Standards: Challenges for Universal Design." In *The Universal Design Handbook*, edited by W. F. E. Preiser and E. Ostroff. New York: McGraw-Hill.

Steinfeld, E. 1977. "Major Issues in Developing Building Standards." In *Barrier-Free Environments*, edited by Michael Bednars. Stroudsburg, PA: Dowden, Hutchinson and Ross.

———. 2003, January. "Recent United States Experience—Moving toward an Accessible Society for All." *Proceedings of the International Conference on the Elimination of Architectural Barriers,* Pamplona, Spain.

Wijk, M. 1990. *European Manual for an Accessible Built Environment*. Utrecht: IG-Nederland.

Websites

ADA Technical Assistance Centers, www.adata.org/

U.S. Access Board, www.access-board.gov

U.S. Department of Justice ADA site, www.usdoj.gov/crt/ada/adahom1.htm

ACCESSIBLE INTERNET

Accessible Internet is the manner of creating websites that are as usable as possible by web surfers with disabilities. To access a website, individuals with disabilities rely on assistive devices, such as screen reader software, which translates information on a computer screen into automated audible output, and refreshable Braille displays. However, there has been continuous concern surrounding the issue that the information that disabled persons receive from a website may not be equivalent to the information that individuals without disabilities get. With rapid advances in Internet technology, assistive technology has had considerable difficulty in keeping up with web browsers with special features: electronic forms, HTML tables, style sheets, multimedia presentations, applets and plug-ins, scripting language, and more. Therefore, the designer of the website needs to provide the information carried by the special features in the formats/methods that assistive devices can easily use. For example, a screen reader cannot describe a picture, but it can convey the text information to the user who has visual impairments. Thus, the provision of special feature information by web designers is imperative for the most efficient use of assistive technology within Internet technology.

Section 508 of federal law has established design standards for federal websites to be compatible with existing and future assistive devices. However, these standards do not apply to private sector websites, which might not be prepared for products of assistive technology. The proposal of Section 508 was first initiated in 1996, when the U.S. Department of Justice asserted that the Americans with Disabilities Act (ADA) would apply to the coverage of websites. Two years later, former President Bill Clinton signed into law the Rehabilitation Act Amendments of 1998, which included the legislation component of Section 508. According to Section 508, federal websites must be made accessible to individuals with disabilities (federal employees and the general public), unless an "undue burden" is imposed on the department or agency. In addition, the Architectural and Transportation Barriers Compliance Board (Access Board) was required to establish and publish technical standards, among others, for federal websites to ascertain compliance with Section 508. In December of 2000, the Access Board published final rules, and the enforcement provisions of Section 508 took effect in June 2001. Many state governments are following the federal example. Nearly every state now has some sort of web accessibility policy, and more than 20 states have accessibility laws modeled on Section 508.

The Access Board's standards are based on access guidelines developed by the Web Accessibility Initiative of the World Wide Web Consortium. Issues such as the usability of multimedia presentations, image maps, style sheets, scripting languages, applets and plug-ins, and electronic forms are addressed within these standards. The provisions do allow the use of such advanced web technology or enhancement technology but require that equivalent information be provided in a format compatible with assistive technology.

A website, required to be accessible by Section 508, would be in complete compliance if it met the standards of paragraphs (a) through (p) of the final rules' Section 1194.22. Most of these provisions ensure access for people with vision impairments, although some provisions address the needs of individuals with both visual and hearing impairments. Paragraph (a) requires that a text equivalent for every non-text element, such as photographs, images, and audio presentations, be provided. For example, when audio presentations are exhibited on a web page, text, in the form of captioning, must accompany the audio, to allow people who are deaf or hearing impaired to comprehend the content. Furthermore, when an arrow image is used to indicate a navigational action such as "move to the next screen" the image must be accompanied by actual text that states the purpose of the image. Similar to audio presentations, when an image is used to represent page content, the image must have a text description accompanying it that explains the meaning of the image.

Paragraph (c) does not prohibit the use of color to enhance identification of important features, but it does prohibit its use as the single method for indicating important information on a web page.

Moreover, paragraph (d) does not prohibit the use of style sheets that allows website designers to create consistent appearing web pages that can be easily updated. Instead, it requires that these web pages employing style sheets can be read accurately by browsers that do not support style sheets, as well as browsers that have disabled the support for style sheets.

Paragraphs (e) and (f) address image maps that provide different "links" to other web pages, depending on where a user clicks on the map. Client-side image maps, as opposed to server-side maps, can display links related to the map in a text format that can be read with the use of assistive technology. By contrast, a server-side map cannot. Therefore, when a server-side map is only available, a web page designer must add the equivalent text link.

Paragraphs (g) and (h) permit the use of tables but require that the tables be coded according to the rules for developing tables of the markup language used. If row and column headers are not identified for data tables, some assistive technology cannot accurately read the content. HTML table codes must be used to associate data cells and header cells for data tables that have two or more logical levels of row or column headers.

Paragraph (i) addresses the use of frames, a common technique used by web designers to create different "portions" or "frames" of their screen that serve different functions. This provision requires that frames be titled with text to identify and assist in navigating the frames by labeling them as "navigation bar" or "main content."

Paragraph (l) handles the use of special programming instructions called "scripts." When pages use scripting languages to display content, or to create interface elements, the provision requires web page authors to ensure that all the information placed on a screen by a script shall be available in text format for assistive technology.

Paragraph (n) requires that people with disabilities have access to interactive electronic forms. When electronic forms are designed to be completed online, the form must allow people using assistive technology to access the information, field elements, and functionality required for completion and submission of the form, including all directions, feedback, alerts, and cues.

Some provisions apply to individuals with hearing impairments or to overall individuals. Paragraph (b) provides that real-time captioning of an audio be provided. However, providing captioning does not preclude posting a transcript of the speech for people to search or download, although the real-time captioning is usually preferred over the delay in providing a transcript. In addition, paragraph (j) sets limits on the blinker or flicker rate of screen elements (a frequency greater than 2 Hz and lower than 55 Hz). Furthermore, paragraph (m) requires that web pages that provide content, such as Real Audio or PDF files, also provide a link to a plug-in that will meet the software provisions. Moreover, paragraph (o) mandates that a method be used to facilitate the easy tracking of page content that provides users of assistive technology the option to skip repetitive navigation links. Finally, paragraph (p) dictates that when a timed response is required, the user be alerted and given sufficient time to indicate more time is necessary in order to respond.

Congress established the Compliance Office to monitor federal law relating to employment of and access to public services and accommodations by disabled persons. One compliance case illustrates a growing demand for accessible websites for people with disabilities. In October 2002, the Atlanta-area people with disabilities complained about numerous problems they experienced with accessibility in the Metropolitan Atlanta Rapid Transit Authority (MARTA) website, including difficulties in obtaining schedule and route information in an accessible format. This information was available on the MARTA website, but people who used screen readers to access the site could not get complete access to schedule and route information. It was ruled that although MARTA provided information to people with visual impairments over the telephone, this service was not equivalent to that provided over the Internet to nondisabled passengers.

Web pages accessible to individuals with disabilities offer practical advantages that go beyond simple access. On March 13, 1998, President Clinton issued an executive order ensuring that the federal government assume the role of a model employer of adults with disabilities. The order addressed the concern that people with disabilities are markedly less likely to be employed, even though they received comparable levels of education to people without disabilities. For example, less than half of the people with significant disabilities who have a college education are employed. In the same year, Congress passed the 1998 Government Paperwork Elimination Act, which required that federal agencies make electronic versions of their forms available online when practicable, and allow individuals and businesses to use electronic signatures to file these forms. Electronic forms are a popular method used by many agencies to gather information or to permit a person to apply for services, benefits, or employment. Because Section 508 requires all electronic forms to be made available to individuals with disabilities, accessible web pages may have enhanced employment opportunities for disabled persons. Furthermore, accessible Internet may also have enhanced the productivity of federal employees with disabilities.

Advantages offered by accessible web pages are not limited to federal employees or federal job seekers with disabilities. Because accessible format often means better structured code that follows the standards of the World Wide Web Consortium, the compliant code can give better search engine rankings by separating the content of pages from the code required to style or present the pages. The ratio of information to overall code on the page increases, which becomes more attractive to search engines. The code also makes atypical web browser devices, such as Internet-able cell phones or PDAs (personal digital assistants), to assist in more effectively using the site. Again, this is due to the separation of content. In addition, the site is more effective as a communications tool. Accessible Internet makes its site more available to dial-up Internet users, since accessible standardized code is often smaller in size. Being accessible can also help increase customer base. Currently, there are 30 million Americans ages 21–64 with disabilities, comprising almost 20 percent of the U.S. population. The disabled are the country's largest minority group and collectively possess a disposable annual income of more than $175 billion. Although the Section 508 requirement does not apply to private sector websites, they will soon follow suit to address the growing trend of use of Internet and the diversity of Internet users.

Section 508 does not require that assistive technologies be provided universally. The standards of Section 508 focus only on compatibility with existing and future assistive devices. Provision of assistive technologies is still governed by the reasonable accommodation requirements contained in Sections 501 and 504 of the Rehabilitation Act. However, Section 508 does not require that assistive devices be purchased, although it does require that covered electronic and information technology be capable of having such devices added at some later time as necessary. Therefore, Section 508—accessible web page design—is insufficient to ensure accessible Internet. Access to a computer is a prerequisite for the use of the Internet. But unlike persons without disabilities, they need alternative computer access tools for physical reasons. Examples of input methods include alternate keyboards, interface devices, joysticks, keyboard modifications, keyboard additions, optical pointing devices, pointing and typing aids, switches with scanning, scanners, and optical character recognition, trackballs, touch screens, voice recognition, and arm and wrist supports. Examples of output assistive devices include Braille embossers and translators, refreshable Braille displays, monitor additions, screen enlargement programs, and talking and large-print word processors in addition to screen readers and speech synthesizers mentioned earlier.

A recent study suggests that Internet use among persons with disabilities has beneficial impacts on health-related quality of life. It has been found that, after controlling for sociodemographic factors (e.g., race and education), a higher level of Internet use, among persons with spinal cord injuries, was associated with a higher quality of life, such as a higher self-perceived health status, a better health status compared to 1 year ago, less severe depression, a higher social integration score, a higher occupation score, more frequent contacts with friends, more business contacts, and higher levels of satisfaction with life. The study also found that there were significant differences in Internet access among specific subgroups, indicating more barriers among persons with less education and among African Americans and Hispanics.

In conclusion, accessible web page design enables people with disabilities to use the Internet—and assists in the better overall utilization of the Internet for everyone. However, accessible Internet cannot be completed without the availability of assistive technology. The finding of disparity in Internet use among specific groups may indicate the need for assistive devices. Moreover, accessible Internet is important because it can be related to better quality of life among persons with disabilities, in addition to practical matters such as better employment opportunities. Research commissioned by Microsoft and conducted by Forrester Research of Cambridge, Massachusetts, suggest that 60 percent of U.S. adults ages 18–64 and 57 percent of working-age computer users could benefit from accessible technology for vision, hearing, dexterity, or other impairments.

—Kyusuk Chung

See also Assistive Technology; Communication: Law and Policy; Computer Software Accessibility; Computer Technology; Information Technology; Rehabilitation Act of 1973 (United States).

Further Readings

Drainoni, M. L., B. Houlihan, S. Williams, M. Vedrani, D. Esch, E. Lee-Hood, and C. Weiner. 2004. "Patterns of Internet Use by Persons with Spinal Cord Injuries and Relationship to Health-Related Quality of Life." *Archives of Physical Medicine and Rehabilitation* 85(11): 1872–1879.

Federal Register. 36 C.F.R. Part 1194. "Electronic and Information Technology Accessibility Standards." December 21, 2000.

Websites

"Information Technology Technical Assistance and Training, Section 508," http://www.ittatc.org/laws/508.cfm

National Center for the Dissemination of Disability Research, information by topic: alternate formats, assistive technology, web accessibility and design, http://www.ncddr.org/index.html

National Organization on Disability, information on assistive technology, http://www.nod.org/section.cfm?id=92

ACCIDENTS

Accidents occur everywhere and have always been a common feature of the human experience. Every year, large numbers of people across the world are injured and permanently disabled in accidents. Others are temporarily disabled and have to spend months, sometimes years, in therapy to regain their previous function. Despite the best intentions, accidents can occur anywhere: in the home, during transportation, in the hospital, on the sports field, and at work.

Road accidents are one of the largest contributors, in both the first and developing worlds, to the numbers of disabled people. The numbers of cars on the road increased steadily over the twentieth century and continues to rise into the twenty-first century. Despite ever improving safety features, large numbers of people are disabled in road accidents each year. Speeding is often the cause of accidents. This is not a recent phenomenon; before the Road Traffic Act of 1930, which abolished the speed limit, the courts and the police in Britain tried to cope with the hundreds of thousands of speeding cases each year as drivers exceeded the limit of 20 miles per hour. The Royal Society for the Prevention of Accidents was formed in 1916 as a response to the number of road accidents from the increasing numbers of cars on the road. A speed limit was reintroduced in Britain in 1934.

Besides vehicular speed, the nature of the vehicle can alter accidents. Motorcycles are particularly dangerous, and in the United Kingdom alone 28,000 motorcyclists per year are currently injured as a result of accidents. During World War II, 23,000 British servicemen were injured in motorcycle accidents. Other users of the road—bicyclists, horse riders, and pedestrians—are all regularly involved in accidents. In New York City in 1992, there were 3,250 bicycle-motor vehicle collisions, of which 17 were fatal. In the same year, there were 13,599 pedestrian-motor vehicle collisions, of which 294 were fatal, and 298 pedestrian-bicycle collisions, leading to 2 fatalities.

As well as the incidence of death, such accidents result in a wide range of injuries and often permanent disability. In an attempt to limit some of this damage, in some countries such as Australia, it is mandatory for children riding bicycles to wear protective helmets. Accidents involving buses are also responsible for large numbers of people becoming injured, although many countries are making seat belt use in buses mandatory to reduce the injury rate. Equally, safety features on cars including seat belts, side-impact reinforcement, and airbags have contributed to fewer injuries that result in permanent disability. Externally, cars have been fitted with bumpers that cause less damage to pedestrians who may be hit. Preventive measures such as campaigns on the dangers of drink driving, enforcing speed limits and using cameras to catch traffic law violators, and educating children about road safety have raised awareness but seem to have little effect on the numbers of people disabled in car accidents. The World Health Organization has estimated that by 2020 road accidents will be one of the top three causes of death and disability.

Accidents on the sports field have long been the cause of disabilities. Since the rise of modern organized sports in the latter half of the nineteenth century, all sports, especially those involving contact, such as American football or U.K. rugby, have witnessed crippling injuries, disability, and death. One well-known person disabled in a sports accident was actor Christopher Reeve (1952–2004), star of the *Superman* films, who in 1995 fell off his horse in a jumping competition and was rendered tetraplegic. Sports such as horse riding are by their very nature dangerous and account for a high number of disabling injuries in any national statistics, as do traditionally dangerous outdoor sports such as mountain climbing, rappelling, and alpine sports. Since the 1970s, the number of sports that deliberately court danger, the so-called extreme sports, has grown rapidly and resulted in a concomitant number of injuries.

Sports accidents are not limited to adults; many children are injured in sports accidents, often causing disability. Contact sports are often more likely to be the sports in which people are injured, so rules have been changed and safety equipment introduced to reduce the incidence of accidents and severity of injuries on the sports field. However, such action does not eradicate injury. In ice hockey, for example, a 1994 survey found that 12 percent of players suffered accidents resulting in shoulder injury and 11 percent in knee injury, which can cause temporary disability and often result later in replacement surgery. In Ontario alone, 79 players had accidents that led to permanent disability or death, although with better safety regulations and improved on-site medical treatment, this number was reduced to 26 by 1992.

The home is a site for many accidents, and falls in particular are the cause of many disabling injuries. The success of home improvement programs on television has resulted in many people doing their own home maintenance, which has resulted in many accidents and permanent disability. In the United Kingdom, each year 3,900 people require hospital treatment as a result of accidents relating to home improvement activities, while 70 people are killed (50 alone from ladder-related accidents) and nearly 250,000 are hospitalized. Accidental fire caused by poor wiring or malfunction of electrical items in the home can cause disabling burns. For example, poorly wired or old electric blankets cause 5,000 house fires in the United Kingdom every year, which leads to 20 deaths and 200 disabling injuries.

Children can be disabled in the home by falls or from burns from boiling water, for example. In Britain, children celebrating Guy Fawkes Night on November 5 have become blind through accidents involving fireworks. In 2001, fireworks were responsible for 1,362 injuries, of which 469 required hospital treatment and 73 resulted in permanent injury.

Accidents involving procedures or medication can occur in hospitals, and these can cause permanent disability. These include brain damage caused by problems during birth, or in some cases people are given the wrong medication while in a hospital. It was estimated in 2002 that 2,610 American children died from infections caught while staying in hospital, while between 44,000 and 98,000 Americans died from preventable medical accidents.

Accidents involving ordnance left over from war or accidents involving noncombatants such as children occur every day. Since the end of the twentieth century, the focus of this problem has been land mine accidents. Land mines can be hidden in most types of ground, and they are designed to disable as opposed to kill. Unfortunately, they are difficult to clear and many civilians, particularly children, have been disabled by land mines. At present, it is estimated that there are 110 million active land mines buried across the globe. As a result of this huge number of active mines, more than 70 people are killed each day, and 300,000 children under the age of 16 are disabled each year. In less developed nations, where land mines are often located, problems of disability are exacerbated because there is little money for artificial limbs and aids to assist those who have lost limbs as a result of land mines.

Work is hazardous. In some occupations, the threat of accidents is very real, particularly in industries such as construction and mining where heavy equipment is used. Industrial accidents are associated with the modern age of factories, mines, and foundries. In the twentieth century, work was still dangerous and many people were still disabled as a result of accidents at work. Some disablement, such as “beat knee” or later “vibration white finger,” was caused by constant and repetitive work with machinery in the mining industry, or long-term exposure to dangerous materials such as asbestos. There was little in the way of safety equipment to prevent accidents, and long-term exposure to dangerous chemicals could cause severe disablement and death. Before factory owners were called on to make their workplaces safer, many workers were injured in accidents. When permanent disability was the result, often that worker was doomed to a life of poverty as there was often little in the way of compensation for their injury. In Britain, while the National Insurance Act of 1911 allowed workers to insure themselves against injury, the 1937 Workers Compensation Act was a more beneficial piece of legislation for those with permanent disabling conditions. In some cases, disabled people were seen as perfect for certain types of work. In World War II in factories in Britain, deaf people were employed in the very noisy occupation of shell filling because it was believed that no further damage could be done to their hearing. In less active occupations, the risk of falling, strains, or even stress can cause debilitating conditions that can mean that a person is unable to work and has to rely on state support.

Safer work environments and better compensation for workers were an aspect of the twentieth century. Despite that, there is still a potential for accidents whether it be in the home, as a result of a fall, or in some countries at war with each other, from the lurking and ever present threat of land mines. Accidents also continue to happen because of the natural fallibility of both technology and humans.

—Julie Anderson

See also Burns; Spinal Cord Injury; Sports; Traumatic Brain Injury.

Further Readings

Cooter, Roger and Bill Luckin, eds. 1997. *Accidents in History: Injuries, Fatalities and Social Relations*. Amsterdam: Rodopi.

Davis, Robert. 1993. *Death on the Streets: Cars and the Mythology of Road Safety* Hawes, UK: Leading Edge.

Monin, Lydia and Andrew Gallimore. 2002. *The Devil's Gardens: A History of Landmines*. London: Pimlico.

Sellers, Christopher C. 1997. *Hazards of the Job: From Industrial Disease to Environmental Health Science*. Chapel Hill: University of North Carolina Press.

Websites

Land mine information, http://www.oneworld.org/landmines/landmine_background.html and http://www.icbl.org/lm

Royal Society for the Prevention of Accidents (UK) history, http://www.rospa.com/cms/index.asp

ACCOUNTABILITY

Persons with disabilities, as well as the general public, are increasingly demanding greater accountability from politicians, government bureaucracies, teachers, public school systems, physicians, and health care organizations. The term *accountability* is widely used by the public in diverse and changing contexts, which conveys different meanings of the term at various times and places. Although there are numerous definitions of accountability, in general, it is commonly understood to mean the giving of an explanation for the discharge of responsibilities entrusted to individuals or organizations. In short, accountability is a reckoning, or a justification of conduct.

To have accountability, three mechanisms are required: the identification of the specific responsibilities given to an individual or organization, the provision of information about the actions that were or were not taken, and the availability of appropriate sanctions. Accountability provides a set of constraints on actions or omissions because someone or some organization is held responsible. Accountability also implies an implicit or explicit set of criteria against which comparisons are made, and then penalties or rewards are applied.

Individuals and organizations frequently deal with multiple, overlapping, and sometimes conflicting accountability systems. Some of the more common types of accountability systems include political, legal, bureaucratic, economic, moral and ethical, and professional accountability.

Political accountability refers to the democratic process by which national, state, and locally elected officials periodically submit their past actions to an electorate. Democratic control is based on ballot counts and the overall preferences of the voters. If a political official is viewed as having increased the public's well-being through appropriate actions and services, he or she will be elected to office again, if not, the person will be voted out of office.

Legal accountability systems are generally based on the relationships between an individual or organization and an outside controlling party. The outside party may be an individual or group in a position to impose legal sanctions or assert formal contractual obligations. Typically, these outsiders make the laws and other policy mandates, which the individual or organization is obligated to enforce or implement. Legal accountability relationships emphasize compliance and external oversight of performance. These systems typically use contracts, audits, inspector generals, oversight hearings, and court proceedings.

Bureaucratic accountability refers to large government and private sector organizations that require subordinates to both formally and informally answer to their superiors. The functioning of bureaucratic accountability systems require an organized and legitimate relationship between superiors and subordinates in which the need to follow "orders" is unquestioned. Subordinates are under close supervision for meeting standards of performance, and they must follow explicit organizational directives, rules, regulations, and standard operating procedures. In these systems, the relationship is hierarchical and based on the ability of supervisors to reward and punish subordinates.

Economic accountability refers to the market relationship of consumers and providers. The marketplace operates on a supply-and-demand basis, with both consumers and providers expected to economize if buying and to maximize profits if selling. One type of economic accountability is corporate accountability. This type of accountability requires managers and board members of for-profit corporations to prudently and wisely use the human and capital resources of the firm to return a profit to the corporation's owners and stockholders.

Moral and ethical accountability systems are standards of good behavior that arise from conscience, religious beliefs and norms, and concerns for the general welfare of society. These systems reflect concerns with the concepts of how or by what means individuals and organizations choose a course of action and how they subsequently defend it.

Professional accountability refers to the relationships among peers with similar training and expertise. This type of accountability employs peer group pressure almost exclusively to discipline and reward its members, although licensing is the formal device for entry and expulsion from the profession. It relies on specific performance standards derived from professional norms and prevailing practices of peers. Because professionals have special knowledge and expertise, they are generally given much discretion, have a high degree of job autonomy, and are self-regulated.

Professions such as medicine, law, clergy, and university teaching are self-regulated for a number of reasons. Members of these professions tend to be carefully recruited and supervised. To be in good standing within the profession, members are required to follow and adhere to codes of ethics and practice standards (e.g., the American College of Physicians–American Society of Internal Medicine requires its members to advocate and assist medically disabled patients to obtain their appropriate disability status and to complete all disability evaluation forms factually, honestly, and promptly). To enforce their standards, these professions have their own review boards, which police individual members. Last, members of these professions have a fiduciary responsibility to place their clients' needs ahead of their own self-interest.

Professionals tend to have high prestige and power in society because of indeterminacy and uncertainty. Many of the tasks performed by professionals cannot be easily broken down or otherwise routinized (indeterminacy). Similarly, many professionals deal with areas of high uncertainty or risk for their clients.

Professional accountability in medicine is particularly difficult to determine. Accountability is problematic because of asymmetric information, difficulty in evaluating the outcomes of care provided to patients, and the ever-changing complex nature of health care medical errors that tend to frequently occur. Asymmetric information exists when one party to a transaction possesses more information than the other. Because of their years of training and experience, physicians have a much greater knowledge of health care and health than patients do. It is very difficult for patients to judge whether they received appropriate and efficacious care from their physicians. Some medical conditions are self-limited and patients will get well regardless of what physicians do or do not do. Conversely, other medical conditions are incurable and physicians can do nothing to stop them from progressing. Last, because of increasingly new and complex medical technologies, drugs, and treatments, and the sheer volume of care provided, medical errors commonly occur.

Attempts to hold physicians accountable for the care they provide are probably as old as the medical profession itself. For example, the 4,000-year-old Babylonian Code of Hammurabi, one of the world's oldest known collections of laws, contains several statutes that set fees for surgical operations and establish penalties for surgical errors. Specifically, a physician was held liable when a patient died as a result of an operation or lost an eye because of his surgical intervention. Penalties varied according to the social status of the patient. The penalty for death or loss of an eye in the instance of an upper-class person was having the physician's hand cut off, but only compensation was required from the physician in the cases of commoners or slaves. This is the earliest recorded instance in history of the legal consequences for medical malpractice.

The Hippocratic Oath, written more than 2,000 years ago, presents the first known ethical standards for physicians. In the oath, the Greek physician Hippocrates, the father of Western medicine, outlines the physician's duties and responsibilities. The oath is divided into two parts. The first part specifies the duties of the physician toward his teacher and his obligations to transmit medical knowledge; the second part gives a short summary of medical ethics. Some of the ethical duties of the physician include keeping patients from harm and injustice, not dispensing deadly drugs, not giving a woman an abortive remedy, not indulging in sexual contact with patients, and not divulging confidential patient information. To this day, many physicians graduating from medical schools throughout the world recite the oath or some modification of it.

An important figure in modern professional accountability in medicine was Ernest A. Codman. In the early 1900s, Codman, an eminent Boston surgeon, was one of the first to apply outcomes management concepts to medical care. Specifically, he developed a system of tracking the long-term outcomes of hospital patients to identify clinical success and failure (e.g., medical complications and preventable deaths) to improve the care of future patients. He also believed that this information should be made public so that patients could be guided in their choices of physicians and hospitals. Unfortunately, his ideas were not accepted by the medical community of the time. And his work was forgotten for decades.

Since the 1980s, there has been a large movement in the United States to measure and improve the quality of health care and increase the accountability of physicians, health care plans, and health care institutions. A number of factors were responsible for this movement. Large computer systems became widely available, which could cheaply and quickly analyze millions of individual patient insurance claim records. Government and business groups were increasingly concerned with the rising costs of health care, and they believed that improving the quality of care would help keep costs down. And many managed care organizations wanted to closely monitor the costs and quality of care provided by the physicians they employed, and to hold them directly accountable for it.

As a result of these efforts, a number of medical quality indicators have been developed including various measures of clinical outcomes, operational performance, and patient satisfaction with care. Today, the federal government, many state governments, and several private sector firms compile, publish printed reports, and post on the Internet medical quality indicators of individual physicians, hospitals, managed care organizations, and nursing homes.

—Ross M. Mullner

See also Consumer Satisfaction; Health Management Systems; Hippocrates.

Further Readings

Donaldson, Molla J. 1998. "Accountability for Quality in Managed Care." *Journal on Quality Improvement* 24(12): 711–725.

Emanuel, Ezekiel and Linda L. Emanuel. 1996. "What Is Accountability in Health Care?" *Annals of Internal Medicine* 124(2): 229–239.

Gorlin, Rena A., ed. 1999. *Codes of Professional Responsibility: Ethics Standards in Business, Health, and Law.* Washington, DC: Bureau of National Affairs.

Ribnick, Preston G. and Valerie A. Carrano. 1997. "Health Care Accountability: Communicating Quality to the Public." *Journal of Nursing Care Quality* 11(6): 9–13.

Rodwin, Marc A. 1994. "Patient Accountability and Quality of Care: Lessons from Medical Consumerism and the Patients' Rights, Women's Health and Disability Rights Movements." *American Journal of Law and Medicine* 20(1–2): 147–167.

Tuohy, Carolyn Hughes. 2003. "Agency, Contract, and Governance: Shifting Shapes of Accountability in the Health Care Arena." *Journal of Health Politics, Policy and Law* 28(2–3): 195–215.

Websites

Foundation for Accountability, http://www.facct.org
Health Grades, Inc., http://www.healthgrades.com
National Committee for Quality Assurance, http://www.ncqa.org

ACTIVISM

Activism is a term used to characterize the activities of people with disabilities who are engaged in advocacy actions intended to advance their policy agenda at the local, state, or national levels. Activism refers to the active participation of people with disabilities in visible efforts to address the issues that concern them. Activism in the disability community can be distinguished from other forms of advocacy because it includes direct action and confrontational tactics. Conceptually, advocacy goals and strategic tactics can be placed along a continuum ranging from those that emphasize a high degree of confrontation and visibility to those that rely on them minimally. For example, acts of peaceful civil disobedience in which people with disabilities block traffic in a street or the entrance to an inaccessible store involve a high degree of confrontation and visibility. In the middle of the continuum would be less confrontational tactics, such as town meetings or rallies. Tactics such as signing petitions or building coalitions have a low degree of confrontation.

Activists in the disability community often refer to a sense of urgency for increasing the level of confrontation necessary to achieve their goals, as "time to escalate." Most disabled activists try to use tactics that generate media attention for their cause, which increases public sympathy for their predicament. However, using more confrontational actions also increases the likelihood of police repression and legal action against the group members. These are risks that advocates consider as they engage in the advocacy process.

The history and development of disability services and policies have been significantly marked by the critical role that a number of individual activists have played in promoting change. Of course, the actions of the leaders are almost always accompanied by the actions of many others who remain unknown but whose involvement is critical to the success in achieving a particular aim. The history of activism associated with the advancement of policies and services for individuals with disabilities in the United States can be categorized in two distinct periods.

The first period was led by professionals and other well-intended individuals who took upon themselves the task of starting institutions or services to help individuals with disabilities. Examples of leading activists of this time in history include Thomas Gallaudet, who opened the first American asylum for the education of the deaf in 1918 in Hartford, Connecticut; Francis Fauquier, who opened the first facility for mentally disabled individuals in Virginia in 1773; and Dorothea Dix, who advocated for the creation or expansion of asylum facilities for the mentally disabled from 1840 to 1870. With few exceptions (e.g., Helen Keller, Clifford Beers), individuals with disabilities themselves did not lead the efforts for reform during this period, being considered for the most part incapable of such a task.

The role of individuals with disabilities in charting their own destiny became the most important change during the second period of activism in the United States. Inspired in part by the civil rights movement during this period, individuals with disabilities themselves took the lead in organizing and leading the fight for reform. Examples include Ed Roberts, who was one of the founders of the independent living movement, and Judy Heumann, who founded Disabled in Action in 1970 to address barriers faced by people with disabilities. A vanguard of leaders with disabilities took direct action in several forms at historic moments thereby helping to create, energize, and sustain the disability rights movement. More recently, people with intellectual disabilities established a national organization called Self Advocates Becoming Empowered (SABE) to promote the closure of state-operated mental retardation institutions in the United States.

In this second period of activism, the broadness and complexity of social and policy changes gave rise to a variety of advocacy and social activist groups. During the 1970s, people with disabilities organized themselves to establish the first center for independent living in Berkeley, California. Federal funds for these community-based organizations were later expanded. This expansion was a direct result of disabled activists confronting the political unwillingness and perhaps even the ineptitude of the federal government that delayed, for several years, the enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973. On April 1, 1977, in various cities across the United States, disabled activists organized protests at the federal offices of the Department of Health and Human Services. The confrontational protest that occurred in San Francisco, California, stands out in history due to its length and the impact it had on social and political change. Wheelchair users, people who were deaf or blind, and people with developmental and other disabilities organized themselves to exercise their collective power and political might. The protesters held the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the 1973 Rehabilitation Act.

Disability rights activists usually learn and practice direct action as part of single-issue, grassroots community organizing. For example, during the 1980s in the United States, many grassroots activists organized to gain access to accessible mainline public transportation through a group called ADAPT (American Disabled for Accessible Public Transit, now also called American Disabled for Attendant Programs Today). Their struggle for "lifts on buses" at both the national and local levels emphasized that disabled people had a civil right to access public transportation. By the end of the decade, these disabled activists had won a victory in the courts and access to mainline buses on the streets. They helped drastically change public opinion about civil rights for people with disabilities. They used the media effectively to portray the images of disabled individuals being arrested or being pushed to the ground by the police. They also chained themselves to buses and often engaged in civil disobedience. ADAPT developed a reputation across the country as the radical wing of the disabled movement that actually helped change the perception of people with disabilities as uninvolved and apathetic to their issues. These were people who were wiling to die for their cause.

Activism is a cornerstone of democracy and, as such, epitomizes the role of the citizen as willing and entitled to act in benefit of the common good. Critical characteristics of a first-rate citizen are being informed in order to make sound decisions and being willing to join with others to act on relevant issues. In many ways, good citizenship is associated with social activism as a commitment for improving society for all its members. Typically, grassroots activism occurs within members of the educated middle class who have a sense of entitlement and are savvy about lobbying and advocating for their rights. Unfortunately, poor people with disabilities have been denied full citizenship rights for many years and have been segregated and marginalized from the decision-making forums of society.

A long history of oppression and discrimination against a particular group of people can lead to negative societal beliefs and low expectations about the group's capacity to transform the group's social reality. Individuals with disabilities have to overcome such a history, as well as self-defeating perceptions of their own inferiority and inadequacy, to become activists. It is precisely through active involvement in community change efforts that most people with disabilities develop their critical awareness and some radicalize themselves. In some cases, the fight for justice and equality becomes the reason to be, the reason to overcome barriers and discrimination. There is an obvious parallel with the perceived conditions that led to the civil rights movement in the United States.

Effective social change requires both critical reflection and understanding of the issues affecting a particular group, as well as careful planning of actions intended to generate the most impact with the least cost to the groups involved. Activism is focused on producing shock and getting attention to the issues. Good activists are always reviewing the impact of their actions and planning their next step accordingly. Typically, the activists' actions prepare the context for negotiations and compromises, and the actual agreements are usually reached in private meetings and with only a few representatives.

The members of the coalition or group leading the change effort have to be prepared to overcome unanticipated challenges, delays, and attacks, setbacks, or diminishing resources. The strengths of the activists lie on their numbers, their resilience, and the fact that often their conditions are so desperate that they have nothing more to lose and a lot to gain by engaging in a particular struggle. In many developing countries, this kind of activism is leading to gradual improvements in services and policy changes to protect the rights of people with disabilities. Disabled organizers have learned effective strategies for social activism from community organizing, labor movements, civil rights movements, and other national efforts intended to promote social justice and political change. These models indicate that to achieve desired change, people with disabilities have to become actively and visibly involved in the struggle and that they should be ready to take some risks.

—Fabricio Balcazar and Rene Luna

See also ADAPT; Advocacy; Citizenship and Civil Rights; Consumer Control; Justin Dart; Empowerment and Emancipation; Independent Living; Ed Roberts.

Further Readings

Albrecht, G. L. 1992. *The Disability Business: Rehabilitation in America.* London: Sage.

Charlton, James. 1998. *Nothing about Us without Us: Disability, Oppression and Empowerment.* Berkeley: University of California Press.

Oliver, M. 1993. *Disability, Citizenship and Empowerment,* Milton Keynes, UK: Open University Press.

Websites

Disability World, bimonthly webzine, www.disabilityworld.org

World Institute on Disability, www.wid.org

ACTIVITIES OF DAILY LIVING

Activities of daily living (ADLs) are most broadly described as those tasks that are commonly completed by most persons in a culture, often habitually or done repeatedly at regular intervals, and often serve as prerequisites for other activities (e.g., laundering clothes or taking them to the dry cleaners in order to have clean clothes to wear to work or for leisure activities). ADLs may be perceived as routine, but they may in fact be quite creative endeavors (e.g., choosing clothes to wear to create a certain "look," or cooking a meal in which ingredients are selected for complementary flavors and color). In particular, ADLs are important for the roles they serve in maintaining social life and connections with other persons.

ADLs are distinguished from productive activities such as paid employment, volunteerism, and education and also from leisure, recreational, and social activities. ADLs are sometimes divided into basic or personal activities of daily living (BADLs or PADLs) and instrumental activities of daily living (IADLs). The distinction maybe somewhat vague and academic although ADLs (or PADLs or BADLs) are more often activities that are related to taking care of one's own body while IADLs are more often activities that support others in addition to self and are often thought to be more "complex" in nature. Whether ADLs are distinct categories or simply two ends of a continuum remains open to debate, particularly among those involved in development of instruments that measure a person's performance on these activities.

ADLs (or BADLs or PADLS) include, but are not limited to, activities such as washing oneself, bathing and showering, bowel and bladder management, caring for one's own well-being and comfort, communication and communication device use, dressing, eating, feeding, functional mobility, personal devise care, personal hygiene and grooming, sexual activity, sleep/rest, and toilet hygiene. IADLs include activities such as caregiving, care of pets, child rearing, community mobility, financial management, health management, procuring and caring for necessities, procuring and maintaining a home, meal preparation and cleanup, and safety procedures.

It should be clear from the preceding lists that deciding whether an activity is an ADL or IADL can be quite arbitrary. For example, meal preparation could be regarded as part of self-maintenance, and communication and communication device use are just as often considered as ADLs as IADLs. In addition, while the concept of ADLs is distinct from productive, educational, and leisure activities, the categorization of particular activities is less clear. For example, some ADLs and IADLs may be performed for remuneration (such as grooming, home maintenance, child care) or for leisure (such as cooking, shopping). While activities may be broadly categorized as ADLs and IADLs, whether a particular activity is considered as such for a particular individual is much more dependent on the context and meaning of that activity for that individual.

Society often has expectations of how ADLs should be performed, and they are often used to describe what a person can or cannot do, what they need assistance with. These culturally accepted forms of performance are often based on how able-bodied persons might complete the task. This is of particular consequence because unacceptable performances of ADLs and IADLs are all too frequently invoked as indicators of disability. Particularly in Western cultures, inability to perform ADLs, particularly self-care activities, without assistance is a strong indication of disability.

The social disability model challenges this view. Social disability theory helps us to recognize that in the same way able-bodied persons may use a computer to order and have groceries delivered to their homes, or may choose to drive to work instead of taking public transportation to have more time and energy for work, a person with a disability may choose to have a personal assistant help with morning self-care activities to have more time and energy to be gainfully employed. Typically, however, the latter example is viewed as an indication of dependence while the former example is viewed as independence, even though all of these "time and energy saving" strategies require the assistance of other individuals.

Determining independence in ADLs is often narrowly defined as completing a task completely by oneself, which ignores the often highly social components to ADLs such as asking someone to stir a pot while more ingredients are added by another, having someone set the table while another finishes preparing the meal, receiving assistance with bringing groceries into one's home, or assistance with folding sheets after being laundered. Defining what "basic" components of ADLs should be completed alone, by an individual, in order to be considered independent are quite arbitrary and reflect goals and values of both the individual and the larger society. Often task completion is related not to independence but rather to notions of intimacy.

ADLs have also become linked to definitions of disability and dependence through the development of a wide, and ever-growing, range of assessments that rate a person's ability to perform ADLs independently or how much assistance they require to complete an ADL. In general, the items on assessment tools, which reflect only a small and rather impoverished number of ADLs, are commonly referred to as limited data sets. Often for reasons of time, cost, and efficiency, the number of items included is kept to a minimum and focus only on those activities that are not influenced by societal gender roles. For example, IADLs such as home maintenance and shopping are often thought to be more closely associated with women's roles. In addition, the ADLs selected for use within medical systems may be more a reflection of service delivery concerns rather than what is most important to the person and his or her family. Thus, the activities that have come to most commonly define ADL assessments (PADL or BADL) include eating, bathing, dressing, toileting, bowel and bladder control, functional mobility (transfers, walking, stair climbing), and sometimes grooming, and IADL assessments generally include telephone use, shopping, laundry, meal preparation, housework, and sometimes reading, driving, finances, and medication management.

ADL and IADL instruments are frequently designed to meet pragmatic goals, such as assessing the outcomes of treatment programs; to predict successful living in a home or community setting, need for assistance, or the need for nursing home care; and to evaluate the impact of impairments on daily life. Observational or self-reported scores of performance of ADLs are often used as a description of an individual's "functional status," or as a measure of "disability." ADLs are even used as a large component of, or even as a substitute for, quality of life, sometimes referred to as health-related quality of life. However, disability scholars have pointed out that "disability" is essentially a political term, connoting a status that arises from discriminatory actions of an able-bodied society that fails to take full account of the rights of all citizens and creates barriers to full inclusion.

A broader way of thinking about ADLs is as a person-task-environment transaction. A person-task-environment (PTE) transaction approach does not consider whether a person is dependent in ADL but under what conditions can a person successfully complete ADLs in a manner that he or she finds personally acceptable and satisfying. By viewing performance of ADLs as PTE transactions, the strengths and limitations of a particular individual, the specific components and requirements of the particular task, and the supports and barriers within the physical and social environment in which the person is performing the task are all considered of equivalent status in determining how successful and satisfying any particular ADL performance is. From this perspective, there are not prescribed or generally acceptable ways to perform or complete ADLs, but rather ways that are unique and personally acceptable. Instead of asking, "Can a person dress independently?" or "How much assistance does he or she need with cooking?" the question becomes, "Under what circumstances can or does this person get dressed or cook in a way that he or she finds most satisfying?" Thus, one person may choose to employ a personal care attendant to complete ADLs that are viewed as laborious in order to have enough time and energy to do the things that are most important, while another person chooses to adapt the environment, methods, or use assistive devises to complete the same tasks.

—Trudy R. Mallinson

See also Aids for Activities of Daily Living; Self-Sufficiency.

Further Readings

American Occupational Therapy Association. 2002. "Occupational Therapy Practice Framework: Domain and Process." *American Journal of Occupational Therapy* 56(6): 609–639.

Barile, M. 2003. "Globalization and ICF Eugenics: Historical Coincidence or Connection? The More Things Change the More They Stay the Same." *Disability Studies Quarterly* 23(2): 208–223.

Lawton M. 1971. "The Functional Assessment of Elderly People." *Journal of the American Geriatric Society* 19(6): 465–481.

Marfisi, C. 2002. "Personally Speaking: A Critical Reflection of Factors Which Blur the Original Vision of Personal Assistance Services." *Disability Studies Quarterly* 22(1): 5–31.

World Health Organization. 2001. *International Classification of Functioning, Disability and Health.* Geneva: World Health Organization. (http://www3.who.int/icf/onlinebrowser/icf.cfm).

ACUPUNCTURE

Acupuncture has been practiced in China for at least 2,500 years and is an essential component of traditional Chinese medicine (TCM). This practice involves the insertion of fine needles just beneath the skin's surface at specific points along clearly defined paths to treat a variety of different medical conditions. These paths, which are usually called channels or meridian, pass through every organ and are interconnected through a network of branches and collaterals. They all carry intrinsic life energy called *qi* (pronounced chee). Because of its emphasis on interconnectedness, acupuncture takes a holistic and nonlinear approach to treating health problems. In the past four decades, acupuncture has gained increasing acceptance in the United States and other Western nations and is now used increasingly by itself or as a complementary therapy in combination with Western medicine. Acupuncture is generally used to treat disability in two ways: to alleviate disabling symptoms (e.g., treating nausea in people undergoing chemotherapy) and to strengthen the body overall (e.g., creating an appropriate immune response in people living with HIV/AIDS or lupus).

TCM views the body as an integrated whole, with mind, body, and spirit as one indivisible entity. This medical system stresses finding and healing the underlying cause of ill health rather than treating individual symptoms. For example, while a Western doctor may prescribe the same medication for all of his or her patients complaining of chronic indigestion, an acupuncturist would first seek to discern the distinct energy imbalance in each patient and treat that accordingly. As a result, acupuncture treatment is unique and specific to each individual patient. Many believe that this holistic, patient-centered approach makes acupuncture particularly useful for treating the complex, chronic medical conditions associated with disability.

Fundamental to acupuncture and TCM is the concept of yin-yang. According to this theory, we find the opposing forces of yin and yang in all of nature. Yin energy is dark, damp, cool, earthy, and female, while yang energy is light, dry, warm, celestial, and male. Yin cannot exist without yang and vice versa. In addition to being interdependent, they are also the source of each other's genesis. Yin and yang are often described as "divisible but inseparable."

Qi arises from the interplay and interdependence of yin and yang. It travels along an interconnected series of 12 major meridians and eight related collaterals called vessels to nourish every part of the body. On the skin, at least 350 points exist that allow an acupuncturist direct access to these meridians.

When yin and yang are in balance in the human body, an individual will be in good health, adaptable to many stresses, and able to fight off most pathogens. When yin and yang are unbalanced as a result of environmental, physical, spiritual, mental, or emotional stress, *qi* can become unbalanced, weak, and/or blocked. As a result, ill health occurs. According to TCM, people with chronic illness and/or disability are particularly vulnerable because they often face a multiplicity of stressors. For example, the stresses caused by multiple sclerosis, HIV, and Type II diabetes typically result in a yin deficiency along one or more vital meridians in most individuals.

When an individual goes to an acupuncturist, he or she will be diagnosed through a process called the four examinations: (1) observation of the patient's overall demeanor and appearance with specific emphasis placed on the condition of the tongue; (2) inquiry about health including questions about pain, sleep, dizziness, appetite, thirst, and elimination; (3) listening to the patient's voice and breathing and checking for abnormal or strong body odors; and (4) palpation of the patient's body with specific emphasis placed on the pulse. In acupuncture, 12 different types of wrist pulses are observed that correspond with each of the 12 meridians. Acupuncturists have 28 different descriptive terms to accurately describe each pulse.

From the four examinations, the acupuncturist determines which energy channels and corresponding organ systems have unbalanced, blocked, or deficient *qi* and then inserts acupuncture needles into appropriate points along the appropriate channels in the patient's body. Sometimes an acupuncturist may also pass a small electric current through the needle in a process called electroacupuncture. The acupuncturist may also use other elements of TCM including *moxibustion* (the burning of the herb moxa close to the skin), herbs, dietary suggestions, and massage.

Although archeological evidence suggests that acupuncture has existed for at least 4,000 years, its recorded history begins with *The Yellow Emperor's Internal Classic,* the first text to outline acupuncture practice, compiled around 300 BCE. Two other texts form the backbone of acupuncture's early development and dissemination. In about 282 CE, Huang-fu Mi described the major acupuncture points, many of which are still in use today in *The Systematic Classic of Acupuncture and Moxibustion.* Last, around 1000 CE, Wang Wei-Yi compiled all existing knowledge of acupuncture, accurately charted the energy meridians, and described them in *The Manual of Illustrated Points for Acupuncture or Moxibustion.* He also commissioned two bronze figures with acupuncture points clearly marked and named, making it possible for acupuncture to be widely taught, researched, and disseminated for the first time. As a result, the practice of acupuncture traveled to other Asian countries including Korean and Japan. The term *acupuncture* (*acu* = with a needle + *puncture*) was actually coined by Dutch physician Willem Ten Rhyne when he visited Nagasaki, Japan, in 1684.

Although some Western awareness of acupuncture has existed for centuries, it did not capture the Western imagination until 1971 when *New York Times* journalist James Reston was stricken with acute appendicitis while in China, covering Henry Kissinger's work toward normalization of that country's relationship with the United States. Chinese doctors operated on Reston using acupuncture instead of Western methods of anesthesia. When he returned to the United States, he wrote of his experience, peaking the interest of the American public.

Western medicine has been cautious in acknowledging the effectiveness of acupuncture, because *qi* and energy meridians cannot be detected through its methods. Much research has been devoted to finding a way to prove the mechanisms of acupuncture through Western methods. Current theories suggest that acupuncture works by directly altering the body's biochemical, bioelectrical, and/or neurological systems. While acupuncturists do not dispute these findings, they interpret them differently: They perceive these measurable changes as a manifestation of the correct flow of *qi* rather than a beginning and end result.

With increasing acceptance has come broader acknowledgment from government organizations. The World Health Organization compiled a list in 1979 of more than 40 medical conditions that lent themselves to acupuncture treatment. In 1996, the U.S. Food and Drug Administration shifted the classification of acupuncture needles from experimental to standard medical devices and approved their use by licensed practitioners. In 1997, the National Institutes of Health used stringent guidelines to create a consensus statement based on a review of all existing literature on acupuncture and clinical trials. The statement deemed acupuncture an effective therapy for treating postoperative and chemotherapy-based nausea and alleviating postoperative dental pain. The statement also noted that acupuncture could be an effective complementary therapy to Western medicine for certain types of pain, addiction, stroke rehabilitation, and asthma.

Acupuncture is used for people living with disability to relieve disabling symptoms and to strengthen an individual's overall body and immune response. Acupuncture's common uses for symptom relief fall into at least five categories. First, it can relieve nausea in people undergoing drug treatments such as cancer or HIV/AIDS chemotherapy. Second, it is used to alleviate dizziness characteristic of people with Meniere's disease, anemia, and other chronic conditions. Third, acupuncture is used as treatment for peripheral neuropathy in people with HIV/AIDS and Type II diabetes. Fourth, acupuncture is often employed to treat symptoms and cravings associated with nicotine, cocaine, or heroin withdrawal. Fifth, acupuncture is used to alleviate chronic pain for many disabling conditions including fibromyalgia, osteoarthritis, and carpal tunnel syndrome.

Use of acupuncture to strengthen the overall well-being of an individual tends to require a systematic long-term series of approaches and techniques. It is often used in three ways. First, it may be used in conjunction with Western medicine to treat the energy imbalances that TCM believes exist in certain mental illnesses such as major depression and bipolar disorder. Second, it may be used to strengthen specific organs that are severely taxed by specific pathogens, for example, treatment of the liver and related meridians for people with hepatitis C. Finally, it can be used to strengthen and/or balance the overall immune system for people facing HIV/AIDS and autoimmune diseases such as lupus or multiple sclerosis.

—Martha E. Lang

See also Complementary and Alternative Medicine; Disability in Contemporary China; Experience of Disability: China.

Further Readings

Bannerman, R. H. 1979. “Acupuncture: The WHO View.” *World Health* (December): 27–28.

Kaptchuk, Ted J. 2000. *The Web That Has No Weaver: Understanding Chinese Medicine.* New York: McGraw-Hill.

Liang, Shou-Yu and Wen-Ching Wu. 1997. *Qigong Empowerment: A Guide to Medical, Taoist, Buddhist and Wushu Energy Cultivation.* East Providence, RI: Way of the Dragon.

Maciocia, Giovanni. 1989. *Foundations of Chinese Medicine: A Comprehensive Text for Acupuncturists and Herbalists.* Oxford, UK: Churchill Livingstone.

National Institutes of Health, Office of the Director. 1997. “Acupuncture.” *NIH Consensus Statement* 15(5). NIH Consensus Program (http://consensus.nih.gov/cons/107/107_intro.htm).

Stux, Gabriel and Richard Hammerslag, eds. 2001. *Clinical Acupuncture: Scientific Basis.* Berlin: Springer Verlag.

Xinnong, Cheng, ed. 2002. *Chinese Acupuncture and Moxibustion,* rev. ed. Beijing: Foreign Language Press.

Websites

Medical Acupuncture, “Scientific Basis of Acupuncture Research Articles,” http://users.med.auth.gr/~karanik/english/abstm.htm

“Resources for Patients, Practitioners & Students,” http://www.acupuncture.com

ACUTE AND CHRONIC CONDITIONS

This entry discusses acute and chronic conditions in the context of ability and disability. The focus of the discussion is the nature of different conditions and how they affect function. Clinical or case examples illustrate acute and chronic conditions that affect people and how they interact with their environment. Other entries in this encyclopedia elucidate many issues that directly relate to specific conditions and their functional impact; therefore, the examples found herein are for illustration only.

A *condition* in the context of ability and disability can be described in terms of physical, cognitive, or behavioral changes that affect one’s ability to participate in functional activities. For example, osteoarthritis of the knee results in anatomic and physiological changes to the joint that render it less capable of bearing an axial load such as when bearing weight. The resultant loss of mobility renders the person less able to walk long distances or remain standing. The functional outcome of this limitation is less mobility independence. If this limitation is concurrent with other limitations (such as shortness of breath due to cardiovascular disease), then the person’s independence might be impaired such that he or she would be considered disabled using standard societal definitions.

Using this definition, an acute condition is one that has an immediate effect on the individual. The type, degree, and severity of the condition may then produce functional limitations. The time course for an acute condition is generally short in duration, with most authorities such as the Centers for Disease Control and Prevention in the United States considering an acute medical condition as one lasting three months or less. Such definitions are predicated, however, on the immediate and accurate identification of the condition. For example, an individual with buttock pain present for 11 months that multiple physicians have failed to identify and treat adequately is evaluated by a consulting expert and found to have specific pathology affecting the piriformis muscle in the buttock. Shortly after the initiation of a treatment program for the specific problem, the condition completely resolved, rendering her fully functional. The condition cannot therefore be considered chronic in nature, but rather the result of inadequate identification of the acute condition.

It is for this reason that purely time-based considerations relating to acute conditions must be considered in their context. Some conditions will present themselves immediately or, with rapid progression, affect the individual, then abate, leaving the person fully functional at the conclusion of the condition. Others will affect the individual at the outset, with residual impairments that extend beyond the period of illness or injury. Polio would serve as an example of an acute illness that produces limitations that persist beyond the period of the infection.

In the United States, disability resulting from an acute condition can be measured in terms using temporary partial disability, temporary total disability, permanent partial disability, or permanent total disability based on the degree and severity of the impairment and its affect on the person's employability during the period of acute illness or injury. European systems offer a similar approach to temporary incapacity, with most systems considering the transition from acute to chronic disability occurring on or around the first anniversary of the onset of the disabling condition. Differing systems exist for the determination of income replacement when substantive improvement cannot be expected beyond the 360-day period of temporary disability. Most programs will use some formula for the determination of benefits at the determination of maximum improvement but may differ widely from state to state (as in the United States) or from country to country (as in the European Union).

From a biopsychosocial perspective, a more appropriate definition of an acute condition is one that manifests itself rapidly with demonstrable changes in function and one that in most circumstances will improve with appropriate identification and treatment. Some conditions, such as pneumonia or meningitis, will manifest themselves rapidly and result in either death or recovery with appropriate treatment. Other conditions represent the more immediate manifestations of a chronic condition (see below). Defining disability in acute conditions revolves around the duration that the impairment results in functional limitation.

A chronic condition can therefore be considered one for which there may be neither rapid onset nor rapid resolution. Some chronic conditions, such as spinal cord injuries, manifest different limitations during their acute and chronic phases. With many other conditions, chronic manifestations can be present even during the acute phase of the condition. For example, suffering behaviors can be identified in some individuals who are experiencing acute low back pain. This likely relates to that person's pain threshold and any other psychosocial factors or life stressors that might exist concurrent to the acute episode. Similarly, an acute psychosis may demonstrate features that represent an underlying and more chronic psychiatric condition. The goal of treatment of the acute condition is to reduce or eliminate the potential conversion to a chronic condition with resultant functional impairments.

Other conditions progress gradually over months or years and only become manifest or clinically evident when functional ability begins to decline. Various neurodegenerative conditions manifest themselves slowly over time, with functional limitations dependent on where in the course of the condition that person might be. Some chronic conditions have an exacerbating-remitting course, with acute phases interspersed with more chronic manifestations. Malaria, once considered virtually eradicated but increasingly evident in developing countries, is a good example of a condition with an exacerbating-remitting course superimposed on chronic disease-related manifestations. Therefore, as with acute conditions, chronic conditions do not require a specific time interval before being manifest, nor are they necessarily predictable in how they impair the individual. Nor does a chronic condition necessarily impair function. There are many chronic conditions, such as psoriasis, for which there are no specific functional limitations. The goal of treatment and rehabilitation of chronic conditions is to minimize the impairments that are due to the condition and when necessary to establish compensatory strategies (through the use of assistive devices, prostheses, or alternate methods to subsume the same activity).

The physical and functional manifestations of acute and chronic conditions can help differentiate their respective impact on the individual. Acute mycoplasma pneumonia will result in fatigue, lethargy, and respiratory manifestations. These acute changes will result in an immediate loss of endurance and strength, and they may result in shortness of breath that limits the individual's function. Once treatment is initiated, the condition will generally improve such that the functional limitations abate. In contrast, chronic obstructive pulmonary disease (COPD) results in similar feelings of fatigue, lethargy, and shortness of breath. Treatment for this condition is directed toward minimizing the impact of the condition and resultant impairments but generally does not change the underlying condition. With chronic conditions, there is a higher likelihood that treatment is more commonly directed toward palliative measures or treatments directed toward minimizing the impact of the condition rather than its elimination.

Other conditions, such as spinal cord injury, will manifest different functional impacts at different phases of the condition. Acute spinal cord injury results in significant hypotension that limits a person's ability to go from lying to sitting. This substantially limits rehabilitative efforts, necessitating aggressive measures to maintain blood pressure. In chronic spinal cord injury, a condition termed *autonomic dysreflexia* can occur (depending on the type and level of the paralysis) that results in overactivity of the autonomic nervous system. This overactivity causes severe increases in blood pressure that can be life threatening if left untreated. Aggressive measures must be taken to ensure that blood pressure does not rise uncontrolled. This example illustrates how treatments can differ substantially during the acute and chronic phases of the same condition.

Behavioral as well as physical manifestations can also be differentiated between acute and chronic conditions. Acute pain is most often associated with tissue trauma. As the tissues become traumatized, inflammatory mediators are released, initiating transmission by peripheral pain fibers to the central nervous system. After modulation at the spinal cord, the signal is then transmitted to the brain where pain is sensed. A simple example of this would be spraining one's ankle. Acute pain is usually described as local or regional in nature (i.e., the hip does not hurt if the ankle has been injured) and can be identified by appropriate diagnostic testing. The pain response associated with the acute event results in protective reactions that reduce function to an even greater degree. In the circumstance of an ankle sprain, weight bearing is limited both due to the original injury and as a protective mechanism to reduce further injury. Once the acute condition has either resolved or been treated, the functional limitation resolves. Chronic pain by contrast results from multimodal changes that occur both at the site of injury and more centrally. Additional behavioral changes are commonly associated with chronic pain. Due to the neurochemical and behavioral changes manifest in chronic pain, the same protective mechanisms fail to apply to the injured area or the whole person, resulting in continuing and persistent limitations.

The resultant physical or cognitive limitations of acute and chronic conditions impair the individual's ability to interact with his or her environment. Using the framework of the International Classification of Functioning, Disability, and Health (ICF), acute and chronic conditions represent only one of three dimensions that result in disablement. Specifically, an acute or chronic condition impairs body functions and structures. The result of that condition is the restriction of personal activities (dimension 2) that limits the person's ability to participate (dimension 3) in his or her environment.

Traumatic brain injury (TBI) is an example of a condition that manifests acute and chronic features and for which the functional limitations result in a loss of ability to participate in the environment. The acute phase of the condition is often manifested with spastic paralysis and profound cognitive impairment (dependent on the severity of the TBI). As a result, there is an immediate loss of bodily functions that include mobility impairments as well as cognitive alterations that limit the injured person's ability to interact with the environment.

In the chronic phase, there is some improvement of bodily and cognitive function such that the limitations experienced in the acute phase are less profound, or where compensatory strategies have been found for lost bodily functions. For example, a person with TBI would manifest limitations at the level of the person that consisted of right upper and lower limb weakness, speech limitations, and slowed cognitive processing and memory. This would result in activity-specific limitations (previously considered as an "impairment") including dressing, grooming, and toileting. As a result of these person-level limitations, the individual with a TBI would be less able to participate in activities requiring his direct involvement, such as driving a motor vehicle. Other functions, such as using an adapted computer for access to educational resources or memory augmentation, would not be impaired and could partially ameliorate other person-level limitations. The societal context of the person and activity level impairments relate to the external implications of the limitations. Using the ICF as the framework, these society-imposed "limitations" relate to access to public spaces, social service resources, and vocational opportunities. Exposure to negative societal attitudes and pity among "able-bodied" persons represent additional external factors that impair the ability or the person with TBI to interact within a social context.

It is therefore evident that acute and chronic conditions represent powerful contributors to the occurrence of disability. Acute conditions impair an individual's ability to engage in functional tasks during the period of incapacity. Some acute conditions produce long-term residual impairments that affect the individual well beyond the acute episode of illness or injury. Chronic conditions may represent the continuum of a condition from the acute to the chronic state, or may gradually affect function as the condition progresses. Both acute and chronic conditions result in limitations that can be defined at the tissue or organ level. These physiological or cognitive limitations will result in either temporary or longer-lasting activity deficits that can be expressed in functional terms. The disability that results from acute and chronic conditions results from internal and external factors that contribute to that person's ability to participate fully in his or her environment.

—Anthony Margherita

See also Accidents; Health; Pain; Spinal Cord Injury; Traumatic Brain Injury.

Further Reading

Coster, W. J., S. M. Haley, P. L. Andres, L. H. Ludlow, T. L. Bond, and P. S. Ni. 2004. "Refining the Conceptual Basis for Rehabilitation Outcome Measurement: Personal Care and Instrumental Activities Domain." *Medical Care* 42(January, Suppl. 1): I62–I72.

Fougeyrollas, P., L. Noreau, H. Bergeron, R. Cloutier, S. A. Dion, and G. St-Michel. 1998. "Social Consequences of Long Term Impairments and Disabilities: Conceptual Approach and Assessment of Handicap." *International Journal of Rehabilitation Research* 21(2): 127–141.

Go, B. K., M. J. DeVivo, and J. S. Richards. 1995. "The Epidemiology of Spinal Cord Injury." In *Spinal Cord Injury: Clinical Outcomes from the Model Systems,* edited by S. L. Stover, J. A. DeLisa, and G. G. Whiteneck. Gaithersburg, MD: Aspen.

Heinemann, A., J. Linacre, B. Wright, B. Hamilton, and C. Granger. 1994. "Prediction of Rehabilitation Outcomes with Disability Measures." *Archives of Physical Medicine & Rehabilitation* 75:133–143.

Minaire, P. 1992. "Disease, Illness, and Health: Theoretical Models of the Disablement Process." *Bulletin of the World Health Organization* 70:373.

Meerding, W. J., C. W. Looman, M. L. Essink-Bot, H. Toet, S. Mulder, and E. F. Van Beeck. 2004. "Distribution and Determinants of Health and Work Status in a Comprehensive Population of Injury Patients." *Journal of Trauma* 56(1): 150–161.

Verbrugge, L. M. and A. M. Jette. 1994. "The Disablement Process." *Social Science & Medicine* 38(1): 1–14.

World Health Organization. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

European Commission, "Definitions of Disability in Europe," http://europa.eu.int/comm/employment_social/index/complete_report_en.pdf

National Center for Health Statistics, definition of *health condition*, http://www.cdc.gov/nchs/datawh/nchsdefs/healthcondition.htm

▣ ADAPT

ADAPT, the American Disabled for Attendant Programs Today, also called American Disabled for Accessible Public Transit, is a grassroots network of disability rights activists within the United States. Unlike many advocacy organizations, there are no monetary dues or membership cards. Individuals "join" ADAPT by becoming active within the ADAPT community. While the overall structure of ADAPT is informal, activities function at both local and national levels. There are more than 40 active local groups within 25 states and the District of Columbia. Each local ADAPT group develops its own style and structure, with decisions typically made through group consensus at meetings. Local groups often take on particular local issues but are united in a shared vision at the national level. For over the past decade, ADAPT's mission has focused on expansion of community-based attendant services and supports.

The origins of ADAPT trace back to Atlantis Community, located in Denver, Colorado. Atlantis Community was founded in 1975 as the second independent living center, following the establishment of the first in 1972 by Ed Roberts and fellow disabled students at the University of California, Berkeley. Simultaneous struggles for community-based independent living services and social justice prompted Wade Blank to found Atlantis Community. Blank was working in a nursing facility known as Heritage House with young disabled residents. After being fired for his advocacy to integrate the youths back into the community, Blank "freed" nine young disabled individuals from Heritage House, initially providing personal assistance services himself at no cost. Access to public transportation became an essential issue for this group in order to live independently in the community. On July 5–6, 1978, Wade and 19 disabled activists, using tactics of civil disobedience in the tradition of other civil rights movements, blocked buses with their wheelchairs and bodies and brought traffic to a standstill on the corner of Broadway and Colfax in Denver: American Disabled for Accessible Public Transit was born (this was the original name for the acronym ADAPT).

Demonstrations branched out nationally and intensified. Between 1983 and 1990 alone, ADAPT organized more than 20 protest actions in nearly every major U.S. city. The American Public Transit Association (APTA) and the Urban Mass Transit Administration (UMTA), now the Federal Transit Administration (FTA), were the targets. "We Will Ride!" was the rallying cry. The Urban Mass Transit law, passed in 1970, required wheelchair-accessible lifts on public buses, but regulations for implementation were delayed by the transit industry for more than 20 years.

ADAPT continued to gain public awareness through tactics of civil disobedience until regulations were finally issued in 1990 with the passage of the Americans with Disabilities Act (ADA). ADAPT played a key role in applying pressure within Washington to pass the ADA. In one of the largest disability rights protests to date, the "Wheels of Justice March" brought more than 600 demonstrators to the Capitol in March of 1990. ADAPT national leader Mike Auberger addressed the crowd, "We will not permit these steps to continue to be a barrier to prevent us from the equality that is rightfully ours. The preamble of the Constitution does not say 'We the able-bodied people.' It says, 'We the People'" (Shapiro 1993:133). With those remarks, dozens of protesters threw themselves out of their wheelchairs and began crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day, 150 ADAPT protesters gathered in the center of the Capitol rotunda. Locking their wheelchairs together, they engaged in a sit-in until police carried away the protesters one by one. With the combined efforts of many individuals and organizations, the ADA moved quickly through Congress and was signed into law by President George H. W. Bush on July 26, 1990. On the second anniversary of the ADA, a plaque was dedicated by the city of Denver at the intersection of Broadway and Colfax, honoring the names of "The Gang of Nineteen"; a large mural on the inside wall of the transit station now memorializes the legacy of Wade Blank.

Following the victory around accessible transportation in 1990, ADAPT refocused its political objectives. Returning to foundational roots, ADAPT decided to tackle the issue of community-based personal assistance services. The acronym ADAPT was creatively reconfigured to stand for American Disabled for Attendant Programs Today. Many individuals active within ADAPT have lived, or still live, in nursing homes or other institutions. The struggle for community-based personal assistance services lies at the heart of the independent living movement. ADAPT has raised awareness concerning the "institutional bias" that exists within the United States long-term care system. Medicaid is the primary funding source of long-term care services within the United

States. Approximately 75 percent of Medicaid spending on long-term care funds services in nursing homes and other institutions. Nursing home services are mandatory for states participating in the Medicaid program, while community-based attendant supports and services are optional.

To correct the institutional bias in the delivery of long-term care, ADAPT has worked with legislators at the national level to introduce a number of pieces of legislation. The first bill (H.R. 2020 of the 105th U.S. Congress) was introduced on June 24, 1997, in the House of Representatives by Newt Gingrich. The bill was titled the Medicaid Community Attendant Services Act, commonly referred to as MiCASA. The MiCASA proposal required states to provide the option of community-based attendant services for individuals entitled to nursing facility or intermediate care facility services under the Medicaid program. Cost-effectiveness limits were embedded, so that aggregate spending on community-based services did not exceed what would have been spent on institutional services. Also, transitional money was proposed for states to change their systems of delivery. MiCASA was referred to the House subcommittee on Health and Environment and garnered bipartisan support from 77 cosponsors. Congressional hearings were held in March 1998; however, the bill did not make it out of committee.

Subsequent versions of the legislation were reintroduced in the 106th, 107th, 108th, and 109th U.S. Congresses in both the Senate and House of Representatives. These versions became known as the Medicaid Community-Based Attendant Services and Supports Act, or MiCASSA. Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) and Representative Danny Davis (D-IL) were among the members of Congress instrumental in developing MiCASSA with ADAPT. While each version has become more politically savvy, using federal reimbursement incentives, the general goals of the original version have not drastically changed. However, later versions of MiCASSA have embraced a more cross-disability perspective of disability, for example, incorporating mechanisms to address the needs of individuals who may require more support. In addition to MiCASSA, ADAPT has also been successful in getting another piece of legislation introduced known as "Money Follows the Person." This legislation also aims to rebalance the institutional bias in long-term care through demonstration projects that would allow individuals to move from institutional to community-based settings of their choice. While MiCASSA and Money Follows the Person have obtained administration and bipartisan support, they have not passed through Congress.

ADAPT continues to use tactics of civil disobedience to raise awareness of MiCASSA. Since 1990, more than 45 major actions have been organized by ADAPT around issues of community-based attendant services and supports. Examples of recent actions include the "Stolen Lives Campaign," in which more than 500 demonstrators converged on the White House to demand a presidential apology for individuals who have been forced to live in institutional settings due to lack of available community-based supports, and the 144-mile "Free Our People March" from Philadelphia to Washington D.C. on the 20th anniversary of the Civil Rights March of 1963. Under the leadership of Bob Kafka and ADAPT at the national level, individuals with diverse disabilities and ages have united in solidarity. Hundreds of individuals have participated in direct actions at the national level and hundreds of disability-related organizations at the local, state, and national level have signed on in support of MiCASSA. ADAPT's efforts have successfully led to some enactment of principles within MiCASSA through systems change grants under the Clinton and Bush administrations. As a single-issue grassroots organization, ADAPT has been extremely successful in uniting the disability community; and if the history of ADAPT is telling, the fight will continue until the rallying cry of "Free Our People!" is heard.

—Joe Caldwell and Larry Biondi

See also Advocacy; Americans with Disabilities Act of 1990 (United States); Independent Living; Ed Roberts.

Further Readings

Johnson, M. and Shaw, B. 2001. *To Ride the Public's Buses: The Fight That Built a Movement.* Louisville, KY: Advocado Press.

McDonald, G. and M. Oxford. 2003. *History of Independent Living*. (http://www.acils.com/acil/ilhistory.html).

Shapiro, J. P. 1993. *No Pity: People with Disabilities Forging a New Civil Rights Movement.* New York: Random House.

Websites

ADAPT, http://www.adapt.org
ADAPT Action Report, http://freeourpeople.org

ADLs

See Activities of Daily Living

ADOPTION AND FOSTER CARE

Most children with disabilities are raised in the homes of one or both of their biological parents, but some grow up in other environments including adoptive and foster care homes. Although historically children with disabilities were considered not to be adoptable, by the end of the twentieth century that had changed. Greater recognition of the rights of persons with disabilities combined with the decreased adoption availability of healthy infants helped public attitudes to become more favorable toward adoption of special-needs children—those who were older, of minority race or ethnicity, who were members of sibling groups of three or more, or who had disabilities. These more favorable attitudes were reflected in federal laws in the United States such as the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980. This legislation expedited the adoption process by establishing adoption exchanges, training adoption workers, and offering financial subsidies for adoptive families, all of which promoted the adoption of children with special needs, including disabilities. In 2000 in the United States, 11.8 percent of all adopted children ages 5 to 17 had at least one disability, in contrast to only 5.2 percent of biological children.

Children with many types of disabilities have been adopted. Some disabilities are mild and correctable, whereas others are severe and life threatening. Although severity of disability and prognosis for a very limited lifespan are deterrents for some potential adopters, at least one-third of women currently seeking to adopt consider adopting a child with a severe physical or mental disability, and approximately 5 percent actually prefer to adopt this kind of special-needs child. As an example, in the 1980s and 1990s in the United States, the AIDS pandemic began to orphan children, some of whom were HIV-positive and therefore at high risk for both disability and early death. Many of these children were placed with foster families, became available for adoption, and were adopted. Although the number of pediatric AIDS cases in the United States is declining, worldwide it is increasing rapidly, and U.S. families who adopt internationally are at some risk for unknowingly adopting an HIV-infected child.

Children with disabilities become available for adoption in two ways. Some are relinquished voluntarily by their birth parents with the disability as a contributing factor, and others are removed involuntarily because of abuse and/or neglect. For example, several studies have yielded estimates that approximately 20 percent of children with Down syndrome are voluntarily relinquished for adoption by their birth parents, almost always immediately after diagnosis. This relatively high percentage results in a fairly large number of children with Down syndrome available for adoption, and some individuals and agencies have specialized in finding homes for them. Nonetheless, infants with Down syndrome are much in demand and agencies frequently report that potential adoptive families may need to wait for several years before one becomes available.

Many children with disabilities are adopted by their foster families, especially since 1997 in the United States when Public Law 105–89, the Adoption and Safe Families Act, was enacted. This legislation is quite complex, but it and state regulations and policies related to it have resulted in a number of improvements in children's welfare: The amount of time that children spend in foster care waiting for reunification with birth parents has decreased and the number of adoptions from foster care has increased, in some states by as much as 50 percent or more in just one year. Nationally, foster care adoptions grew from approximately 31,000 children in 1997 to 50,000 in 2001. Because many children in foster care have disabilities, it is anticipated that increasing the number of adoptions from foster care will also increase the number of adoptions of children with disabilities.

From the adoptive parent perspective, the rewards of adopting children with disabilities seem to far outweigh the difficulties. Many parents speak of the life-changing experiences of their adoptions and report positive changes in their marriages, their other children, and their understanding of life meaning. Parents also describe that they are proud of their child's achievements and that they delight in their child's positive characteristics such as an affectionate nature, a contagious sense of humor, and an optimistic outlook on life. One indication of the success of adoptions is that many families choose to do it again. It is not unusual for families to have adopted more than one child with a disability, and some families described in published research studies have, over their lifetimes, adopted more than 20 children with disabilities.

Nonetheless, there are also challenges in adopting children with disabilities. Along with rewards, many parents report problems, including a variety of negative child characteristics; worry, anxiety, or guilt relating to the child; an increase in family disharmony as a result of the child's adoption; and lack of emotional bonding to and from the child. Medical emergencies may be a common occurrence, and dealing with service providers can be a chronic source of stress.

Because many adopted children with disabilities have suffered neglect and physical and/or sexual abuse in their families of origin, psychological and behavioral issues related to these experiences arise and can cause problems such as oversexualized behaviors or a victim mentality. Identity issues also arise, sometimes exacerbated if the adoption is transracial or transethnic. However, there is no indication that disability, in general, is related to adoption disruption (termination before finalization) or dissolution (termination after finalization). Many studies, however, do confirm that both adoption dissatisfaction and disruption or dissolution are predicted by the children's behavioral disorders. Externalizing or acting-out behavior, in particular, is linked to adoption breakdown.

The adoption process consists of several phases. Family recruitment is often the first step because there are more children with disabilities waiting to be adopted than potential adoptive families for them. Children who are older and have emotional or behavioral problems in addition to other disabilities are particularly hard to place. Photo books and media presentations of waiting children are useful strategies, as are national recruitment efforts with children frequently adopted across state lines. Many potential adoptive families have initial preferences for the type of child they would like to adopt, but to expedite placements, agency workers may encourage parents to consider children who do not match those preferences, a practice called "stretching." Many successful adoptions result from some stretching, but disrupted and dissolved adoptions are likely to be poor matches between child and family.

Although there is no typical or ideal family for a child with disabilities, some characteristics are usually found in successful adoptive families. These include familiarity with child rearing and with disability; a family-centered approach, including high cohesiveness; and flexible parenting style. Neither higher parental education nor greater family income appear to be positively related to good outcomes, and some studies have actually found that families with lower incomes and less education are more successful, perhaps because their expectations for child achievement are less likely to be unrealistically high.

The adoption process is not complete even after placement and finalization. Postadoption services are essential for families adopting children with disabilities, and use of these services is known to be associated with low disruption. Postadoption service providers can help families identify, locate, and obtain assistance of a financial, educational, therapeutic, or medical nature. Issues related to child and family adjustment change as the child and the family enter different life stages, and access to ongoing or periodic treatment is important.

Although a permanent placement is the ultimate goal for all children, including those with disabilities, it is not always achievable. At the beginning of the twenty-first century in the United States, more than a half million children are in foster care, with an average stay of almost three years. Although some of these children will return to their families of origin, and some will be adopted, others will remain in the foster care system throughout their childhood. Years in foster care usually result in multiple placements, which put the child at additional risk for emotional and behavioral problems.

Research has shown that a majority of foster children have developmental delays and a variety of disability conditions. For children with extensive special needs including psychiatric care, treatment or therapeutic foster care has emerged as a viable option to residential care. Therapeutic foster parents are experienced and mature, and they are trained to be responsive to many of the difficulties that the children require. Typically, there are consultant clinical/psychiatric services available and utilized. Although the majority of children in foster care have multiple risk factors for poor outcomes, an enduring relationship with at least one supportive adult is protective. Thus, it is important that children in foster care be returned to biological homes if possible or be placed for adoption as soon as is feasible. If they remain in foster care until the age of majority, the transition to adulthood, including coordination with agencies serving adults with disabilities, needs to be managed.

—Laraine Masters Glidden

See also Behavioral Disorders; Children, Youths, and Adolescents; Developmental Disabilities; Down Syndrome; Early Childhood Intervention; Parenting and Disability.

Further Readings

Dumaret, Annick-Camille, Catherine de Vigan, Claire Julian-Reynier, Janine Goujard, Dominique Rosset, and Ségolêne Aymé. 1998. “Adoption and Fostering of Babies with Down Syndrome: A Cohort of 593 Cases.” *Prenatal Diagnosis* 18:437–445.

Glidden, Laraine M. 1989. *Parents for Children, Children for Parents: The Adoption Alternative.* American Association on Mental Retardation Monograph No. 11. Washington, DC: American Association on Mental Retardation.

———. 2000. “Adopting Children with Developmental Disabilities: A Long-Term Perspective.” *Family Relations* 49:397–405.

Gordon, Jeanne N., William Ganger, and Kristin Gist. 2002. “Developmental Delay in Young Children in Child Welfare by Initial Placement Type.” *Infant Mental Health Journal* 23:496–516.

Marshner, Connaught, ed. 1999. *Adoption Factbook III.* Washington, DC: National Council for Adoption.

Websites

National Council on Adoption, http://www.adopt.org

North American Council on Adoptable Children, http://www.nacac.org

ADVERTISING

Advertising is defined as a paid, mass media-driven attempt to persuade selected audiences. Advertising messages, whether carried on traditional media (television, radio, newspaper and magazines) or nontraditional channels (e.g., Internet, kiosks in malls, signs in malls), are designed to provide the public with brand information, change their perception about a particular product, or motivate them to take action.

Although the definition seems simple, advertising is anything but simple. In the United States alone, more than $300 billion is spent each year on advertising campaigns targeted to various market segments. According to the National Organization on Disability (NOD) (Cheng 2002), the disability community is a market segment worth $220 billion in collective spending power each year. The 54 million people making up this segment represent 20 percent of the U.S. population. It is not surprising therefore that advertising and disability are linked. According to a 1999 report (Farnall and Smith 1999), more than 100 corporations producing general consumer goods were including people with disabilities in their television advertising campaigns. *Advertising Age,* a major trade publication in the advertising industry, addressed the connection between people with disabilities and major corporations by claiming it is just “good business sense” to use ability-integrated advertising. While these facts might be interpreted as an acceptance of people with disabilities in advertising executions, it is important to remember the percentage of people with disabilities in advertising is approximately 2–3 percent, well below the population percentage.

The debate over the social impact of advertising is particularly appropriate to this discussion. Advertising is first and foremost a business activity designed to improve the bottom line for companies, yet some research on advertising featuring people with disabilities supports the idea that there can be societal benefits to positive portrayal in advertising. Other social science studies have found either no effect or negative impact such as when the portrayal included physically disabled females interacting with nondisabled males.

The history of advertising targeting people with disabilities is fraught with many of the same ethical issues (stereotypical representations, absence from the media) other minorities have encountered. And the power of a message that is intended to persuade cannot be overlooked in a discussion of that history.

HISTORICAL DEVELOPMENT

The association between advertising and the disability community can be segmented into two major periods approximately separated by passage of the 1990 Americans with Disabilities Act (ADA). Prior to the ADA, advertising featuring people with disabilities was either promoting a product developed specifically for that target and placed in disability media or designed to raise money for various causes. About the time Congress was considering passage of the ADA, marketers began to acknowledge the economic potential of the disabled community. Consequently, the appearance of disabled characters in consumer goods advertising mushroomed and ability-integrated advertising became much more commonplace.

Examples of Early Advertising

A search of the archives of the National Museum of Advertising History at the Smithsonian Institute uncovered a limited number of examples of early-twentieth-century advertising containing images of people with disabilities. The examples that were found fit into one of two groups. The first group of ads dates back to the 1920s and is the most unflattering portrayal of people with disabilities. It is characterized by line drawings of disfigured bodies just waiting for replacement limbs and raucous posters of sideshow attractions such as General Tom Thumb and the Fiji Mermaid. Often these same posters exaggerated the physical differences of the celebrity, such as one poster that enlarged the head of the famous general to make his body appear even smaller than his 3-foot frame.

The other group of ads could be labeled as charity advertising. Typical of this group are the “poster child” print ads for nonprofit organizations and the heart-breaking TV spots aired during the telethons of the 1970s. In these advertising executions, the visuals usually featured a child in a wheelchair or with braces and crutches. The voice-over copy was usually dramatic and poignant. In its most bold form, the copy portrayed a person whose life needed to be changed and who was condemned to a pitiful existence without contributions.

Fortunately, the trend in charity advertising shifted away from that approach to a more positive theme in the 1990s. For example, in 1995 the National Easter Seals fund-raising event moved away from the old-style “telethon” to a 20-hour televised program featuring more entertainment and theme segments on acceptance of children and family members with disabilities. In 1998, the marathon event was dropped completely by the group.

Transition to Ability-Integrated Advertising

The phrase “ability-integrated advertising” refers to the practice of including roles for people with disabilities in advertising for products that are not exclusively intended for the disability community. There is some disagreement among experts about which national company was the first to recognize the potential of including people with disabilities in its overall promotional efforts. Some researchers claim that discount retailer Target Stores was the first major marketer to insert people with disabilities in its print ads. Others point to a 1983 CBS television promotional spot featuring a paraplegic wheelchair racer.

No matter who led the charge, the number of print ads and television commercials with disabled roles increased to the point of being noticed in the late 1980s and early 1990s. Major manufacturers including Levi’s Jeans, McDonald’s, Kodak, Kellogg’s, Mattel, and Plymouth were including representations of people with disabilities in their advertising campaigns. Marketers were beginning to recognize and address a market estimated in 1985 to be 43 million strong. The use of disabled actors and actresses in the ads also suggested that society might be ready to start to look at people with disabilities as individuals able to lead normal lives and as promoters and consumers of products.

MARKETING STRATEGIES FOR ABILITY-INTEGRATED ADVERTISING

The inclusion of people with disabilities in advertising has not occurred without some pitfalls both in execution and strategy. Organizations such as the Media Access Office (MAO) and NOD provide advertising strategies and guidance to producers, directors, agency creative directors, and talent. In addition, organizations such as the National Easter Seals Society (NESS) have stressed the need to portray people with disabilities in positive, yet realistic, situations.

Examples of advertising from general products companies that successfully communicated the positive, realistic approach focused on normal characters in daily life experiences. The executions were emotional, but not too emotional. Plot lines included such things as one child learning sign language from his computer so that he could communicate with the "new kid" on a school bus who happened to be deaf or two brothers who wake up to the smell or sound of their mother preparing sausage (one brother was deaf), or the famous Nike ad portraying a man with an artificial limb getting knocked around in a street basketball game. Of course, humor was also used as in the campaign for Airtouch Cellular featuring blind actor Rick Boggs. In all these examples, the ad worked because it did not pity the person with the disability or depict that person as achieving unrealistic feats.

Execution Pitfalls

It is not surprising that advertising executions do not always succeed in the area of positive portrayal for the disabled. Even with the best of intentions, it is easy to fall into one of the negative stereotypical portrayals of people with disabilities such as the "supercrip" or "one to be cared for." When writers, producers, and directors include characters with disabilities only to make sure that the group is represented, there is a greater chance the ad will actually alienate disabled consumers instead of embracing them.

In the relatively short history of disability-integrated advertising the faux pas most often cited is the use of non-disabled actors to play disabled roles. Many have been guilty of that error, but no case better illustrates how easily it can happen than the Maryland Planning Council on Developmental Disabilities campaign. In 1988, a Baltimore agency produced a set of 30- and 60-second TV spots for the council featuring a nondisabled actor portraying a man in a wheelchair. The agency said a last-minute rewrite at the request of the council changed the script from one in which the actor got up from the wheelchair to one in which the actor did not reveal his ability to walk. The casting had already been done. The spots brought an avalanche of letters to professional publications and the council from activist groups and individuals who were aware of the production.

Examples of other campaigns that used disabled actors but still failed to capture the desired effect include a series of actor Christopher Reeve ads for an investment company, a retailer that showed a disabled shopper receiving help from the store's staff, and a shoe manufacturer's use of insensitive language about people with mobility impairment in its shoe ads.

ORGANIZATIONS SUPPORTING ADVERTISING EFFORTS

There are a number of private companies and consultancies that have experience in helping companies target consumers with disabilities. But on a national scale three not-for-profit organizations lead the way.

National Organization on Disability

The NOD has a much broader mission, but it also provides support through its website for marketers interested in reaching people with disabilities. NOD efforts in this area include articles offering marketing strategy tips, information, and resource lists, and even partnership programs with corporate sponsors interested in the disability community. One recent example of sponsorship programs was the 2004 special advertising section in *Motor Trend* magazine. The 15-page spread was the largest mass-market effort to publicize automotive industry achievements in the field of mobility equipment.

Media Access Office

The purpose of the MAO is "to actively promote the employment and accurate portrayal of persons with disabilities in all areas of the media and entertainment industry, ensuring that the industry recognizes people with disabilities as part of cultural diversity" (California Governor's Committee 2004). The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals established the MAO in 1980. In addition to promoting ability-integrated advertising, this group works with writers, producers, and directors to advocate the use of actors with disabilities in disabled roles and promote a more positive portrayal of people with disabilities in the entertainment industry. Programs and services of the MAO include casting, talent development, talent support, project development, community education, and awards.

NESS Equality, Dignity, and Independence Awards

The emergence of ability-integrated advertising was a positive step toward gaining respect for the disability community. For 10 years, a primary force in supporting this role was the NESS. From 1989 to 2000, NESS recognized and encouraged realistic media portrayals of people with disabilities by presenting EDI Awards to members of the media, entertainment, and advertising industry. In the advertising category, both print and broadcast executions were judged with the best receiving recognition. In 1989, only five entries were received in the advertising category. By 1992, the number of entries had increased by 300 percent.

—Olan F. Farnall

See also Easter Seals; Poster Child; Telethon.

Further Readings

California Governor's Committee on Employment of People with Disabilities. 2004. "Media Access Office." Los Angeles: Governor's Committee. Retrieved October 5, 2004 (http://www.disabilityemployment.org/med_acc.html).

Cheng, Kipp. 2002. "What Marketers Should Know about People with Disabilities." Washington, DC: National Organization on Disability. Retrieved April 25, 2004 (http://www.nod.org/content.cfm?id=925).

Farnall, Olan. F. 2000. "Invisible No More: Advertising and People with Disabilities." Pp. 307–318 in *Handbook of Communication and People with Disabilities: Research and Application,* edited by D. Braithwaite and T. Thompson. Hillsdale, NJ: Lawrence Erlbaum.

Farnall, Olan F. and Kim Smith. 1999. "Personal Contact versus Media Exposure as Predictors of Reactions to People with Disabilities." *Journalism and Mass Communication Quarterly* 76(4): 659–672.

Haller, Beth and Sue Ralph. 2001. "Profitability, Diversity, and Disability Images in Advertising in the United States and Great Britain." *Electronic Disability Studies Quarterly* 21(2). Retrieved May 5, 2004 (http://www.dsq-sds.org/_articles_html/2001/Spring/dsq_2001_Spring_03.html).

Nelson, Jack A. 2003. "The Invisible Cultural Group: Images of Disability." Pp. 175–184 in *Images That Injure: Pictorial Stereotypes in the Media,* edited by P. M. Lester and S. D. Ross. Westport, CT: Praeger.

Panol, Zenaida S. and Michael McBride. 2001. "Disability Images in Print Advertising: Exploring Attitudinal Impact Issues." *Electronic Disability Studies Quarterly* 21(2). Retrieved October 1, 2004 (http://www.dsq-sds.org/_articles_html/2001/Spring/dsq_2001_Spring_06.html).

▣ ADVOCACY

Advocacy refers to actions taken to express one's view, to further a cause or belief and/or to exercise rights. Advocacy is used by people with disabilities (as individuals or organized groups) to increase their influence and obtain their rights. Advocates, people who take advocacy actions, may focus their actions on themselves, other individuals, families, organizations, communities, and/or public policies. Self-advocacy activities are those practices that involve individuals taking the initiative to request, pursue, obtain, and, if necessary, demand particular things they need in their daily lives to attain and exercise their rights. Community-based or other systems-level advocacy efforts target larger shared concerns that individuals may have with organizations or social movement building. Examples of advocacy of this nature include community outreach and education, community organizing, and public policy initiatives. Systems-directed advocacy can cover a wide range of disability-related issues such as education and youth services, transportation and housing, health care and personal assistance, and human and civil rights.

Within the disability rights movement (DRM), self-advocacy has been a key strategy in changing social conditions. In the context of the DRM, the term *self-advocacy* has sometimes been used as synonymous with the movement through which people with disabilities seek human, civil, and legal rights. In using self-advocacy as synonymous with the DRM, it becomes difficult to differentiate among other terms such as *advocacy, community movement,* and *self-help organization.* This entry will consider *self-advocacy* as advocacy that entails those individual actions directed at attaining better conditions for the self and *advocacy* as actions often taken by groups directed at improving conditions for others, groups, communities, and larger social systems. Advocacy and self-advocacy have become important means by which people with disabilities (along with their allies and families) have been able to gain rights. Another meaning of self-advocacy that is common in the DRM, especially among individuals with intellectual disabilities, is advocacy done by people with disabilities themselves.

A *social or community movement* occurs when a number of individuals work together to address important social problems with the purpose of producing social change. These efforts often involve increasing access to opportunities, civil rights, and stronger government support for exercising group member civil rights. Social movements rely on collective efforts by individuals, groups, and/or organizations that share similar values and common goals. Community movements are considered "bottom up" efforts that can produce changes in the structure and mindset of societies. Five defining elements of social movements include that they are joint efforts, have a common goal to produce change, are organized, continue across time, and use a combination of actions both within and external to existing institutions.

Within the DRM, structured settings in which people with disabilities meet and discuss common issues as well as plan advocacy actions are organizations known as *self-help organizations.* The primary goal of self-help organizations is to provide members with a supportive social network that can offer both instrumental and emotional support. Self-help organizations also tend to have a defined mission of change and strategies to obtain that change. The group's purpose may range from personal change to social change, or it may include both approaches to advocacy, self and system, as part of its change agenda. Members of self-help groups are often trying to address a particular issue and may join the group in an effort to gain personal control. Self-help groups operate within informal settings in which marginalized individuals who have similar concerns, experiences, or living conditions can give and receive support. Self-help organizations are often organized in a nonhierarchical manner with group members leading the group; professionals rarely have an active role in the group unless they participate as members or nondirective advisers. Membership is usually open to anyone who has the focal problem, situation, or identity in common with other group members.

Across time, self-help organizations have served diverse purposes and taken a variety of forms to achieve their goals. Different types of self-help organizations include local self-help groups, local advocacy and program centers, local single-issue advocacy groups, public policy groups, single-issue national advocacy groups, national membership organizations, national coalitions, federations of groups, national single-disability organizations, regional organizations, and international organizations.

Self-help organizations can be viewed along two dimensions, political and personal, with high and low gradations of foci on either dimension. Successful self-help organizations can take at least three forms: (1) a primary emphasis on political issues, (2) a prominent emphasis on personal issues, or (3) a significant dual emphasis on both. Organizations that reflect this latter dual focus on personal and political issues include centers for independent living, which have both national and local agencies; each branch of the organization may differ on its emphasis depending on whether it is a national or a local organization. Members of these organizations are both highly involved in political advocacy as well as seek and provide individual assistance and support through the organization.

Other organizations have a high political component and a moderate to low individual element such as Self-Advocates Becoming Empowered, the national federation of statewide advocacy organizations of, by, and for people with intellectual disabilities. Organizations such as these tend to be more focused on policy issues and engage in actions such as lobbying of policy makers. Other organizations have a strong personal component with a less active political agenda. These types of organizations tend to focus on individual needs. For example, a local chapter of People First for people with intellectual disabilities or another single-disability organization (i.e., an organization dedicated to only one form of disability) may focus exclusively on personal issues such as social support and interpersonal relationships. Within this high-low two-dimensional framework, there might be organizations that have both low political and individual agendas.

These organizations might be starting up, dying down, or in transition. Given the nature of grassroots organizing, it is typical for self-help organizations to be in this stage briefly at certain points in their development. Self-help organizations may shift their emphasis throughout time. The high-low two-dimensional framework includes all combinations of emphasis on the political and the personal and recognizes that today's personal concern may become tomorrow's political issue. It is dynamic in that the mix of personal and political can vary at different times in the life cycle of a self-help organization.

It may be that self-help organizations that recognize the personal as political and vice versa are most successful. For example, an individual who participates in self-help organizations might engage in political activities because it becomes personally rewarding to speak on behalf of others. In this context, the personal experience is affirmed because it has broader implications. Thus, when individuals in a self-help organization integrate the personal and political, the self-help organization may become stronger and serve multiple purposes.

All self-help organizations provide environments in which people have the opportunity to organize, develop self-advocacy skills, and receive support. These environments allow individuals to obtain public (e.g., taking a political stand) and private (e.g., establishing friendships) goals.

THREE INTERRELATED CONCEPTS

The focus of advocacy actions by advocacy, social movement, or self-help organizations can be placed on a continuum of different levels or units of analysis. This continuum includes actions that are directed at the self to actions directed at society. Examples of advocacy at the individual or family end of this "levels of analysis" continuum of advocacy include a parent who advocates at a school to obtain needed supports for his or her child and a disabled person who advocates at a rehabilitation services center for better service provision. In the middle of the continuum, at the community level, a group of residents may advocate for accessible parking. On the other end, actions taken to change legislation or public policy such as building codes or services are considered advocacy at a systems level. It is critical to note that placing advocacy actions on this continuum does not mean that advocacy efforts do not overlap or flow between these levels. Indeed, advocates and their organizations often move along this continuum. For example, a person with a disability may advocate for himself or herself as a self-advocate; however, while the person can advocate on an individual level (e.g., for adequate personal attendant care) he or she can also advocate at a systems level (e.g., lobbying legislators).

Advocacy serves as an empowering force through which people with disabilities obtain social change. In the 1970s, an international disability social movement emerged based on self-advocacy and advocacy efforts. The social movement known as the DRM began when people with disabilities started organizing themselves with the intent of speaking out and demanding their rights. For people with disabilities, the process of forming self-help organizations provided an infrastructure for self-advocacy development by providing a setting in which people could share their experiences and knowledge and receive support.

As part of the empowerment and self-determination movement, different organizations and groups of individuals drafted their own definitions of self-advocacy. For example, in 1991 People First, an advocacy organization of and for people with intellectual disabilities, defined self-advocacy as

> independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that

> affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is supporting each other and helping each other gain confidence in themselves to speak out for what they believe in. (Dybwad 1996:2)

Definitions of self-advocacy reference common factors such as empowerment, self-determination, self-help, independence, and integration. In addition, they call for a reconceptualization of what it is to be a person with a disability by pushing for a change in society's view of disability from a medical and individual impairment to a socially created experience. The advocacy and self-advocacy efforts that have occurred over time across disabilities and specific historical developments led to the community movement known as the DRM.

HISTORY

Early Origins

People with disabilities have organized for centuries. Historians have been able to trace the existence of self-help organizations to medieval China and Europe. There, people with disabilities, especially those who were blind, were marginalized by society and then organized for self-protection and economic support. In China, informal organizations became guilds and associations composed exclusively of blind people. In at least one guild, members earned a living by singing and entertaining. The guild was self-governed, and all the members of the board were blind except the secretary. Board members decided on all issues including recruitment of new members and discipline of members. Children who entered the guild learned skills for specific trades. As members acquired skills, they ascended the hierarchy of the guild.

During the Middle Ages in Europe, blind people also formed guilds for the purpose of self-protection. Group membership provided status and a means of expression, participation in the community, and demonstration of self-sufficiency. Guilds were known as "free brotherhoods of the blind." In Paris, a group called the "Congregation and House of the Three Hundred" was formed composed of blind men and women. These early associations provided members emotional support and sometimes access to economic self-sufficiency. Despite these early associations, later historical events impeded the further development of these organizations. Nonetheless, the existence of these associations is important to be noted; men and women with disabilities who participated in these organizations were self-advocates of their time.

In the 1800s in the United States, advocates spoke out and demanded changes, particularly in laws and education. One of the first organizations to promote collective advocacy was the National Association for the Deaf, which advocated for the right to include sign language as part of education for people with hearing disabilities at a time when mainstream society opposed sign language. Similarly, in the nineteenth and first half of the twentieth centuries, there was an increase in the population of psychiatric hospitals. Initially, mental institutions were conceptualized as places to care for mentally ill individuals. However, they quickly became a means for social control. Mental institutions were often used as means to discipline and alienate those who were different.

Fortunately, successful advocacy strategies brought the problem of institutionalization to the public's attention. In 1866, Elizabeth Packard was committed to a psychiatric hospital against her will. She wrote a book on her experience and advocated for the creation of the Packard Law, which stipulated that a jury must decide whether to commit a person to a psychiatric hospital against his or her will. In the early 1900s Clifford Beers, a former inmate at a psychiatric hospital, authored a book on his experience. His book, *A Mind That Found Itself,* made public the experience of abuse while committed to a mental hospital. These instances of advocacy through written experiences reflect early efforts and success in changing public views towards mental illness.

Modern Advocacy Organizations

The first modern advocacy organization for the blind, the National Federation of the Blind, was founded in 1940. Around this time, parents of people with intellectual disabilities also began to organize to advocate for services for their children. After World War II, as the population increased, there was an increase in the number of children with disabilities. Other single-disability organizations arose such as the National Association for Retarded Children (formerly named the National Association of Parents and Friends of Mentally Retarded Children; *Children* was later replaced with *Citizen* and now the organization's name is the acronym ARC.). The ARC pushed forward the concerns of parents of children with intellectual disabilities including their children's exclusion from public education, the dearth of community and residential services, and dissatisfaction with extant conditions for employment of people with intellectual disabilities. The ARC has served as a leader in advancing public policy for people with intellectual disabilities including steps toward deinstitutionalization. Its success may be linked to the high social status of its members and effective, grassroots social action strategies.

During this same time period, a group of ex-patients publicly criticized institutions by bringing attention to issues of human rights violations in mental institutions. In doing so, ex-patients formed self-help groups and demanded changes in policy. In the mid-1960s, the mental health patients' movement slowly emerged. Simultaneously, the population of psychiatric hospitals was dropping due largely to the availability of medications that helped people live in the community, literature that increased social beliefs toward mental illness, and concomitant shifts in public policy. Interplay among science, culture, society, and government began to produce changes that remain today. Literary examples that worked to induce these changes include Thomas Szasz's *The Manufacture of Madness* (1970) and Ken Kesey's *One Flew over the Cuckoo's Nest* (1962).Within the policy arena, President John F. Kennedy signed laws regarding mental health issues. For example, the 1963 Community Mental Health Act contributed to having people live and receive treatment in the community. In addition, the Kennedy administration contributed to setting the stage for attention to intellectual disabilities. Influenced by a sister with intellectual disabilities, Kennedy advanced the cause of providing public school services for people with disabilities by commissioning a presidential panel on mental retardation and creating a bureau for special education.

A group of parents filed a lawsuit to get their children with disabilities educated. Their advocacy efforts led to the passing of the federal law known as The Education for All Handicapped Children in 1975. Signed by President Gerald Ford, it guaranteed education in "the least restrictive environment" for children with disabilities. The original law has been revised over the years and has since been renamed the Individuals with Disabilities Education Act or IDEA.

The independent living movement was one of the first movements that provided tangible gains for people with disabilities by demonstrating that people with disabilities were capable of living and being leaders in their communities. In the early 1970s, the Berkeley Center for Independent Living opened. Centers for independent living (CILs) are nonresidential, not-for-profit organizations that do advocacy, service, and educational activities. CILs are cross disability, and the majority of the members on the board of directors are people with disabilities.

Similarly, in the 1970s, a group of individuals with intellectual disabilities founded People First, the first self-advocacy group for people with intellectual disabilities. The name was developed as an initial step in speaking out and demonstrating a sense of identity defined first by their humanity and second by their disability. The purpose of People First is to help members learn to advocate for themselves. The 1974 convention of People First in Oregon provided a setting to discuss issues in self-advocacy and served as a propelling force for the self-advocacy movement. As a result, many organizations flourished. By 1994, approximately 11,600 people with intellectual disabilities were involved in self-advocacy groups. Early issues addressed by advocates centered on public transportation, lack of accessible and affordable housing, institutionalizing of the poor, inclusion of students with disabilities in the classroom, and changing the understanding of disabilities.

In the mid-1970s, diverse advocacy groups led by ex-patients and mental health consumers were formed. These groups used strategies such as awareness raising, organizing, and political action techniques to effect change. The most radical of the groups viewed psychiatry as the oppressor and were suspicious of professional advocates. Others viewed some professionals who supported change as valued collaborators. The differences of opinion were often strongly held, which sometimes made it difficult to establish synergy among mental health advocacy groups.

Mental health advocates championed changes in policies through a variety of approaches, and various advocacy groups were created such as the National Alliance for the Mentally Ill (NAMI), founded in 1979. NAMI originated as a network of mutual support groups and expanded to include national public education efforts as well as legislative lobbying at the local, state, and federal levels. NAMI is an advocacy and education organization that now has hundreds of affiliates and represents thousands of families. Advocacy organizations such as NAMI have increased awareness of mental health issues and affected policy and legislation. Early impacts on legislation resulted in the right of a person with a mental disability to receive treatment, in the least restrictive environment, protected from intrusive procedures and from involuntary commitment without appropriate procedures.

ADVOCATE DEVELOPMENT AND ADVISORY

Since the initiation of the DRM, people with disabilities have obtained and been more able to exercise their rights through advocacy efforts. Many have initiated their advocacy activities as a result of personal experiences with disability whether as a person with a disability or as a family member or other loved one of a person with a disability. Other individuals have initiated advocacy activities from a shared interest in promoting equality. Some researchers have suggested stages of advocate development ranging from starting to be involved to being highly involved. Balcazar, Keys, Bertram, and Rizzo (1996) identified three developmental stages: beginner, involved, and activist. At the beginner stage, a person belongs to an organization and acts as a relatively passive member, receiving few services and taking few advocacy actions. In the involved stage, a person is a more active member of at least one organization, obtains services as needed, and takes more advocacy actions to address personal needs. An activist, however, likely belongs to several organizations including those at the state and/or national level and has taken leadership roles in at least one advocacy organization. An activist also works to obtain services for local group members and takes a significant number of advocacy actions on a regular basis. By understanding advocate development, advocacy actions can be tailored according to the expertise, interests, and activity level of advocates. Advocacy training can be developed that are appropriate to participants' present level of involvement.

Many recognize a need to enhance and support advocate development in order to affect policy and society. Advocacy training programs have been designed to enhance the skills of advocates with the intention of maximizing the roles of people with disabilities and family members. Many advocacy training programs have been developed. One example is Partners in Policy Making. Partners is a training program designed to empower people with developmental disabilities and their families to pursue their cause. By introducing trainees to disability policy, advocacy skills, and state-of-the-art services, Partners in Policy Making promotes involvement in positive and progressive advocacy activities by program graduates. The program has been very successful in developing advocacy leaders in many states in the United States.

Advocacy training programs offer participants intensive training in advocacy skills and provide an opportunity for diverse people to become advocates. In a study with participants of different levels of advocacy activity, researchers found that advocates that already had a high level of participation in advocacy activity increased their participation the most and their family members with disabilities received three times more services when compared to people with medium or low levels of participation. In addition, researchers found that people can move beyond personal interest to address the needs of others similar to themselves. Results from this study shed light on the benefits of advocacy involvement and training.

In one program, participants in advocacy training programs delineated supports and barriers to successful advocacy. Participants identified elements such as empowered voices, networking, courage, and leadership as essential factors for successful advocacy efforts. Participants also outlined barriers to advocacy including lack of time, lack of financial resources, and the interference of emotions. By identifying and sharing the supports and barriers that advocates encounter, advocacy development trainings can build a sense of universality among advocates. That is, these training programs can increase participants' awareness that others share struggles and benefit from supports similar to their own. Universality can lead to greater solidarity among disability advocates. It can motivate participants to enhance their skills and collaborate to develop and share strategies to combat barriers to effective advocacy.

In general, individuals who participate in self-advocacy efforts become empowered, or gain greater control over things that affect their lives. Models of empowerment suggest that self-advocacy and advocacy provides a setting for people to become empowered by gaining awareness of society and self, emphasizing one's strengths, taking action, engaging in collaborative relationships, and effecting social change. Through participation in advocacy activities, including advocacy trainings, individuals gain a sense of awareness of their roles as advocates. For example, people with intellectual disabilities who participate in self-advocacy activities learn that social and physical structures are often discriminatory. They see that changes to systems must occur to meet and integrate individuals with disabilities to society. Once individuals become aware of barriers that impede the integration of people with disabilities, individuals are often more able to acknowledge that people with disabilities are persons with strengths and capable of contributing to society. In addition, individuals who participate in advocacy efforts are able to take action and gain greater control over their lives. Furthermore, members of self-advocacy groups gain peer and public support and a sense of self-confidence.

ADVOCATE ADVISERS

The DRM pushes for a shift from a traditional deficit model of disabilities to a social model that is strengths based, supportive, and collaborative. Collaboration occurs when members of different groups work together for a common cause or bring in nonmembers as consultants to provide specific expertise or guidance. For example, many self-advocacy groups of people with intellectual disabilities include a nondisabled member as an adviser. Advisers are usually community members or professionals who work in the disabilities field. The role of the adviser is to facilitate and provide assistance in various areas. Advisers are not experts but rather collaborators. It is important to note that advisers are not necessary for a self-advocacy organization and that there are advantages and disadvantages of having an adviser. One advantage of having an adviser is that it permits groups to access to knowledge or expertise that may be less available within their current membership. One disadvantage is that some advisers can act beyond their advisory role and counteract member's advocacy by promoting disempowering relationships between the adviser and organization members.

To facilitate collaboration between an advocacy organization and advisers, it is important for advisers to be committed to the philosophy and realization of empowerment and self-determination. Effective advisers work to facilitate personal and collective changes, incorporate creative ideas, and recognize individual worth, equality, and skills of organization members. The role of advisers and nondisabled advocates is not without controversy: There is the potential for many to not fully understand their role within the DRM and to not fully appreciate the social role of people with disabilities.

CHALLENGES TO ADVOCACY MOVEMENTS

In addition to controversy over the role of advisers and participation of able-bodied individuals, there are several other challenges to the success of advocacy efforts. Many times, advocacy efforts have had difficulty finding a common cause given the broad scope of disabilities and individual needs related to this diversity. A second barrier might be that different models of disability are used as a basis for action and change. Differences among these approaches can present a barrier for a successful advocacy. For example, some people may incorporate the medical model and work within this framework to increase access to traditional services. However, others may feel that the legal rights model is a more adequate framework and work within this framework to change the services available and how they are delivered. Thus, those following the more traditional approach would ask for individual student services offices in universities to provide more readers or individual supports to make texts more readily available to blind college students in a timely manner. Others, noting the inadequacy for print access through these offices on campus, might focus instead on developing a policy with publishers or a law for them. For example, all publishers would make computer-readable versions of texts and journals available to blind students at a reasonable cost. These variations in perspectives on disability can affect the tactics and strategies used for advocating as well as present a challenge if consensus is not reached.

ADVOCACY TACTICS AND STRATEGIES

There are diverse tactics and strategies that advocates adopt to pursue change. As mentioned earlier, differences in these strategies might present challenges in pushing forward any particular agenda. However, many agree that the milestones reached in the contemporary DRM were obtained through the use of multiple advocacy strategies including the most action oriented of all, activism. Advocacy practices are geared toward changing services, promoting inclusion in society, and influencing legislation and policy. Advocacy efforts can be speaking out in the community, serving on boards and committees, communicating with decision makers, lobbying, writing letters, and participating in the development and implementation of programs, among many other tactics. There are also many tactics available to advocates such as peer advocacy, parent advocacy, professional advocacy, and self-advocacy.

An illustrative example of using multiple advocacy strategies occurred in 1973 when Section 504 of the Rehabilitation Act was passed. This act prohibited discrimination against disabled individuals from organizations receiving federal financial assistance. Regulations were passed thanks to cross-disability advocacy efforts. Multiple advocacy tactics were used ranging from single phone calls to a sit-in at federal buildings. Different advocacy approaches such as writing letters, lobbying, and media appearances made the promulgation possible. Another example of the success of multiple advocacy tactics is that of individuals with psychiatric disabilities issuing a public statement, called the "Highlander Statement of Concern and Call for Action on March 25, 2000." In this statement, a call for a mental health system founded on self-determination, respect, ethical behavior, and humane services and supports was made. Similar cross-disabilities, multifaceted advocacy efforts helped pass the Americans with Disabilities Act of 1990 (ADA). There are fundamentals elements necessary to obtain a successful advocacy effort: Set goals, develop a strategy, gather information including asking questions, and use other support establish your place in the process. Using these advocacy elements can bolster the effectiveness of the effort.

CONCLUSION

Overall, anecdotal accounts and research have established that appropriate advocacy strategies are effective in implementing change and can provide benefits at many levels, including to individuals, communities, and societies. Through advocacy, empowered groups have greater potential to have an impact on society and terminate the long history of unequal treatment against individual with disabilities. Advocacy, self-help, and social movement activities will continue to be integral to attaining social justice for people with disabilities in the twenty-first century.

—Yari Colon, Christopher Keys, and Katherine McDonald

See also Advocacy, International; Advocacy Movements: France; Advocacy Movements: Germany; Empowerment and Emancipation; Individuals with Disabilities Education Act of 1990 (United States); Lobbying; Parental Advocacy; People First.

Further Readings

Albrecht, Gary L., Katherine D. Seelman, and Michael Bury, eds. 2001. *Handbook of Disability Studies.* Thousand Oaks, CA: Sage.

Balcazar, Fabricio, Christopher Keys, Joyce Bertram, and Thomas Rizzo. 1996. "Advocate Development in the Field of

Developmental Disabilities: A Data-Based Conceptual Model." *Mental Retardation* 34:341–351.

Chandler, Susan Meyers. 1990. *Competing Realities: The Contested Terrain of Mental Health Advocacy.* New York: Praeger.

Charlton, James. 1998. *Nothing about Us without Us: Disability, Oppression and Empowerment.* Berkeley: University of California Press.

Cone, Alicia. 1999. "Profile of Advisors to Self-Advocacy Groups for People with Mental Retardation." *Mental Retardation* 37:308–318.

Driedger, Diane. 1989. *The Last Civil Rights Movement: Disabled Peoples' International.* New York: St. Martin's.

Dybwad, Gunnar. 1996. "Setting the Stage Historically." Pp. 1-17 in *New Voices: Self-Advocacy by People with Disabilities,* edited by G. Dybwad and H. Bersani. Cambridge, MA: Brookline.

Dybwad, Gunnar and Hank Bersani, eds. 1996. *New Voices: Self-Advocacy by People with Disabilities.* Cambridge, MA: Brookline.

Kurtz, Linda. 1997. *Self-Help and Support Groups: A Handbook for Practitioners.* Thousand Oaks, CA: Sage.

Matson, Floyd. 1990. *Walking Alone and Marching Together: The History of the Organized Blind Movement in the United States, 1940–1990.* Baltimore: National Federation of the Blind.

Miller, Alison and Christopher Keys. 1996. "Awareness, Action and Collaboration: How the Self-Advocacy Movement Is Empowering Persons with Developmental Disabilities." *Mental Retardation* 34:312–319.

Websites

Gallaudet University, www.gallaudet.edu
National Alliance for the Mentally Ill, http://www.nami.org
National Federation of the Blind, www.nfb.org

ADVOCACY, INTERNATIONAL

Advocacy refers to actions taken to express one's view, to further a cause or belief and/or to exercise rights. Advocacy is the practice, in this context, by people with disabilities (as individuals or groups), to increase their influence and independence. Self-advocacy activities are those practices that involve individuals taking the initiative to demand and pursue particular things they need in their daily life. Community-based or systemic advocacy efforts dovetail with organization and movement building. These efforts may include community outreach and education, community organizing, and public policy. They can cover a wide range of disability-related issues such as education and youth services, transportation and housing, health care and personal assistance, and human and civil rights. It is with the latter notion of advocacy and its connection to organization and movement building that this entry is concerned, although there are many connections between self-advocacy and community-based advocacy.

PHILOSOPHY AND PRACTICE

The philosophy and practice of advocacy, self-help, and social movement building have evolved out of an emerging consciousness of political activists worldwide that is informed both by their own particular local experiences and the reach of the international disability movement. They incorporate the interconnected principles of empowerment and human rights, integration and independence, self-help and self-determination. The meaning of these concepts and where they programmatically lead can, not surprisingly, be different and, more noticeably, can have different strategic movement or organizational importance. This reflects the divergent and often conflictual politics of the movement's activists.

DISABILITY RIGHTS AS A NEW SOCIAL MOVEMENT

The building of a disability movement rooted in self-help organization and advocacy reflects many of the traits of other new social movements that emphasize identity. These social movements focus on new forms of social and collective action, involve personal intimate needs, and are not centralized but loose and diffuse. There has been much debate among activists and scholars about how similar the disability movement(s) is to other new social movements such as women's, human rights, landless peoples', and environmental movements. In arguing that the disability rights movement is a new social movement, two British disability rights scholars, Mike Oliver and Gerry Zarb, argued that the critical traits of new social movements mirror those of the disability rights/advocacy movement: "To varying degrees and in varying ways the new movements also seek to connect the personal (or cultural) and political realms, or at least they raise psychological issues that were often submerged or ignored." Oliver and Zarb (1989:237) go so far as to make the assertion, "Hence, the disability movement will come to have a central role in counter-hegemonic politics and the social transformation upon which this will eventually be based." This assertion contrasts with the lack of interest most sociologists who study social movements have shown in the advocacy, community movement, and self-organization of people with disabilities.

CONTEXT OF ADVOCACY, MOVEMENT, ORGANIZATION

Out of the different and often hard realities of everyday life, advocacy organizations of people with disabilities have appeared in virtually every country in the world. These organizations form the core of the international disability rights movement. Although this development touches only a relatively small portion of people with disabilities, it nevertheless parallels the process of consciousness and organization that has given rise to many kinds of community-based advocacy and self-help organizations and social movements.

Many of these organizations started as a response to the simple need for survival—food, shelter, and work—and their goals were limited to economic self-help and self-sufficiency. Others started as political groups that wished to mobilize people with disabilities in their communities, cities, countries, or regions. These groups and purposes have gradually merged. All seek to link their work with the struggle for self-determination and human rights. With few exceptions, this struggle is their common denominator.

Although the development of disabled persons advocacy and self-help organizations has been uneven, it is undeniable. Within the past 25 years, self-help groups have formed in leprosy communities in southern Africa, in refugee camps in Kampuchea and Mexico, and on remote islands in the Philippines, Palau, and Fiji. A village in the mountains of Mexico has become the center of a self-organization of and by people disabled from drug-related violence and has attracted hundreds of people with disabilities from throughout the country.

Advocacy activists have made different choices over the years on how and what to organize around. In southern Africa, activists took a perspective that national and regional federations had to be organized that would in turn promote locally based economic development projects. For example, the National Council of Disabled Persons Zimbabwe fostered the establishment of a supermarket in a township outside Bulawayo and collective gardens outside Harare. In Southeast Asia, various individuals who had returned from international conferences banded together to form chapters of Disabled Peoples' International because they understood all policy and services were mandated by a number of connected politicians in their countries' capitols. Indeed, Disabled Peoples' International–Thailand quickly established a national presence by staging demonstrations criticizing the Thai government for dismissing a deputy cabinet member who used a wheelchair. In many places in the third world, the lack of rehabilitation services and mobility aids for those with physical disabilities created both an impetus to organize and goals of newly formed groups. In Nicaragua, one of the first things the Organization of Disabled Revolutionaries (ORD) did after the Sandinista revolution was to set up a wheelchair production and distribution system using locally available materials in their wheelchair design. Other activists, especially in the United States and Japan, out of a perceived overarching need to create community and employment, opted to concentrate on establishing centers for independent living.

HISTORY

Most of these groups are relatively new, small, and fragile. Most exist with little or no funding. As indicated, the 1980s were the first time people with disabilities and their supporters founded a large number of advocacy organizations. The National Council of Disabled Persons Zimbabwe, initially registered as a welfare organization, became a national disability rights group in 1981. The Organization of the Revolutionary Disabled was set up in the wake of the Sandinista victory in 1979. The Self Help Association of Paraplegics of Soweto was started in 1981 as an economic development project. The Program of Rehabilitation Organized by Disabled Youth of Western Mexico also began in 1981 as a rural community-based rehabilitation program. DPI-Thailand was established in 1983, and the Southern Africa Federation of the Disabled was formed in 1986 as a federation of nongovernmental organizations (NGOs) of disabled persons. It was during this time that many disability rights and advocacy groups were established including the Disability Rights and Education Defense Fund, ADAPT (American Disabled for Accessible Public Transit, also called American Disabled for Attendant Programs Today), and France's Groupement Francais de Personnes Handicapees. Also begun during this period were England's British Council of Disabled Persons and Disability, Greater London Action on Disability, and Disability Awareness in Action, Cuba's Asociacion Cubana de Limitados Fisicos Motores, and many European advocacy groups.

Often these organizations have reached across borders to establish similar groups in neighboring countries. For example, members of DPI-Thailand, based in Bangkok, made numerous trips to Vietnam, Laos, and Kampuchea to spread the philosophy of disability rights and to initiate activities. There have been international exchanges between Hong Kong and the People's Republic of China. Some of these NGOs have very close connections to the governing party. Close connections have historically been the case in Vietnam, Mozambique, Angola, Cuba, Indonesia, Nicaragua, and the Peoples Republic of China among other countries, particularly in the third world. In other instances, disability rights and advocacy-oriented NGOs have been allied with opposition forces in their countries such as in Brazil (with the Workers Party), South Africa (with the African National Congress), and Japan. In most cases, disability rights and advocacy-oriented groups have stayed out of national politics, focusing instead on narrow disability issues.

A TYPOLOGY OF ORGANIZATION

Reviewing the various structures and strategies of international advocacy groups, we could group them by the following typology: (1) local self-help and advocacy groups, (2) national advocacy organizations and coalitions/federations, and (3) worldwide organizations.

Local Self-Help Groups

Local self-help groups vary from small collectives of people providing peer counseling and moral support to small plot gardening and agricultural ventures to larger projects involving a significant level of support, production, and revenue. Some are cross disability, cutting across many different kinds of disabilities, and others focus more on persons with a single disability or cluster of similar disabilities. The experiences and lessons from the hundreds of self-help groups are diverse. The peer relationships and friendships, material aid and support, and sense of control they engender have significantly contributed to the health and sustenance of hundreds of thousands of people. These groups are the easiest to establish but the hardest to maintain. In South Africa, for example, there are more than 175 revenue-generating self-help projects, most associated with Disabled People South Africa. Most employ fewer than 30 people and yield little revenue. However, the projects generate a minimal level of food or income for their members, which often is the margin between life and death. The largest and best known is the Self-Help Association of Paraplegics/Soweto (SHAP) established in 1981 by a group of Soweto paraplegics (primarily spinal cord injured).

Probably the most important local advocacy groups are centers for independent living (CILs). The first CILs appeared in the United States in the early 1970s, and there was a large increase in the number of CILs in the 1980s and early 1990s in the United States (now more than 400) as well as Japan (now exceeding 100) and Europe (where there are dozens in Northern Europe and England). Activists in Brazil set up Latin America's first CIL in Rio de Janeiro (Centro de Vida Independente). Later, in the late 1990s, CILs spread to a number of cities throughout Latin America. Efforts to establish CILs in Africa and Asia have been sporadic and less successful.

National and Regional Advocacy Organizations

National and regional advocacy organizations have local chapters throughout or across countries, and their membership participates in advocacy and program activities as well as in organizational business.

Most of the national advocacy groups are quite democratic, although there is a strong tendency to follow the same leadership over extended periods of time. Most countries have such organizations, although examples offer divergent pictures. For example, the constitution of the National Council of Disabled Persons Zimbabwe (NCDPZ) spells out the organization's mission: "[to] promote full integration into Zimbabwean society of all disabled persons and active participation by the disabled in the planning and decision-making processes that affect their own lives." The work of NCDPZ involves advocacy, grassroots organizing, services, and leadership development training. NCDPZ has been able to obtain funding from foundations located in Northern Europe. These foundations support specific programs or purchases, such as personal computers or agency vans. Another national organization is the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people. BCOPD was set up in 1981 by disabled people to promote their full equality and participation in UK society. By 2003, BCOPD included 126 groups run by disabled people in the UK. Between them, their member groups have a total membership of around 350,000 disabled people throughout England, Wales, and Scotland and is affiliated with Disabled Peoples' International.

An example of a regional organization is the Southern Africa Federation of the Disabled (SAFOD), which represents disability rights groups from a number of countries in Southern Africa including Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe. The aims of SAFOD are to provide a forum for disability rights activists to meet, share common concerns, and coordinate regional projects. SAFOD has a secretariat in Bulawayo, Zimbabwe, with a small staff headed by a secretary general. SAFOD is a member organization of Disabled Peoples' International. SAFOD is governed by an executive committee, elected at each biannual general assembly and drawn from the national organizations. It also widely circulates its newsletter, *Disability Frontline*. The creation of SAFOD eventually led to the founding of the Pan-African Federation of the Disabled for the entire continent more than a decade later.

International Advocacy Efforts

There are a growing number of disability rights organizations that do international exchange work. Some, such as Mobility International, based in Eugene, Oregon, provide opportunities for advocacy activists to visit other countries. These exchanges have been successful in spreading the experiences of independent living, peer counseling, self-help projects, and an awareness of the politics of disability across many cultures. Worldwide organizations such as Disabled Peoples' International and the World Institute on Disability (WID) focus on international advocacy, networking, public policy, research, and training. WID has developed educational and leadership training programs throughout the world from Latin America to the former Soviet Republics. Many of WID's staff have spent considerable time outside the United States promoting disability rights. WID has convened international forums and foreign exchanges on personal assistance, leadership training, and disability rights philosophy. Other important international organizations in Europe include the Institute on Independent Living in Stockholm and Disability Awareness in Action based in London, which has established contacts in 158 countries, most of which are in underdeveloped countries and whose newsletter, *Disability Tribune*, reaches readers throughout the world. There has been a great deal written about Disabled Peoples' International, the most important of these organizations.

FUTURE DIRECTIONS IN ADVOCACY AND COMMUNITY ORGANIZATION

The disability rights movement has always situated self-control and community control at the center of its agenda. The history of the movement has been the growing consciousness and activism of greater numbers of people with disabilities. For the first time in history, millions of people with disabilities have seen or heard about other people with disabilities who are struggling for a better life. This is a beacon of hope for many. The practice of empowerment means and has meant creating, increasing, and improving the options available to people with disabilities in their everyday lives.

There is an abundance of challenges and a scarcity of choices. The dilemma most people with disabilities throughout the world face is how to use their meager resources to attend to this condition. So the most obvious challenge is the most elementary: how people with disabilities secure the basic needs to survive. For the vast majority of the 375 million people with disabilities living in the third world, meeting basic needs can be a matter of life and death. For those of us living in the developed world achieving a level of self-sufficiency goes directly to the question of quality of life. In the course of grappling with an array of complex and burdensome issues, the fundamental challenge is how the movement develops politically. What kind of analysis and political program will its leaders and activists bring to their struggle? What is the strategic goal of the disability rights movement? Is it strictly human rights, or is it liberation and freedom? There are many questions with many answers. The answers will strongly inform the future of disability advocacy and community organization.

—James Charlton

See also Advocacy; Disability in Contemporary Africa; Disabled Peoples' International.

Further Readings

Charlton, James. 1998. *Nothing about Us without Us: Disability, Oppression and Empowerment.* Berkeley: University of California Press.

Driedger, Diane. 1989. *The Last Civil Rights Movement: Disabled Peoples' International.* New York: St. Martin's.

Helander, Einar, Padmeni Mendis, Gunnel Nelson, and Ann Goerdt. 1993. *Training the Disabled in the Community: A Manual on Community-Based Rehabilitation for Developing Countries.* Geneva: World Health Organization/UNICEF/ILO/UNESCO.

Hurst, Rachel. 1995. "Choice and Empowerment: Lessons from Europe." *Disability & Society* 10:1–7.

IEEIR Interchange. 1993. "Culture and Disability in the Pacific." University of New Hampshire, International Exchange of Experts and Information in Rehabilitation, Institute on Disability.

Ingstad, Benedicte and Susan Reynolds Whyte, eds. 1995. *Disability and Culture.* Berkeley: University of California Press.

International Disability Rights Monitor. 2003. New York: Published jointly by Disabled Peoples' International and the Center for International Rehabilitation.

Leamon, Dick and Yutta Fricke. 1991. *The Making of a Movement.* SAFOD Evaluation. Bulawayo, Zimbabwe: Southern Africa Federation of the Disabled.

Oliver, Mike and Gerry Zarb. 1989. "The Politics of Disability: A New Approach." *Disability, Handicap, & Society* 4:219–240.

Williams, Eugene. 1989. "Surviving without a Safety Net in Brazil." In *Ideas Study Visit Report. International Exchange of Experts and Information in Rehabilitation.* Oakland, CA: World Institute on Disability.

Websites

Disabled Peoples' International, www.dpi.org
Disability World, www.disabilityworld.org
World Institute on Disability, www.wid.org

ADVOCACY MOVEMENTS: FRANCE

The topic of French advocacy movements for the disabled is explored in this entry from two perspectives: first, the chronology and history of movements that have emerged from the disabled world and, second, the political and social situation of these movements. The phrase "disabled world" is justified by the fact that in recent times the representation of disabled persons and the effort to enhance their visibility in society were, with some few exception, more the work of parents and support circles than of the people who were directly concerned. *Movements* is an intentionally broad term even though most of the initiatives that have been and are being taken fall within the framework created by the French law of 1901 concerning associations.

Three historical waves can be identified. The earliest goes back in part to the first appearance of large numbers of work-related accidents in the nineteenth century and stimulated the creation in 1921 of the National Federation of Injured Workers (the French acronym is FNAT) and also others such as the National Union of the Disabled and Injured Workers (UNIAT), focused essentially on the protection of rights. Another contributing factor was the wounded veterans of World War I (1914–1918). These veterans founded dozens of organizations with a generally similar mission, for example, the National Union of the War-Wounded and Rehabilitated, but were also committed to the defense of very specific categories of the injured such as those with lung trauma, those with head injuries requiring surgery, and wounded agricultural workers.

These two great losses of life, marginalizing the economic activity of thousands of people, caused disability to be transformed from purely natural status to a form of socialization, in which society was seen as the agent that produced this multitude of injured persons. As a consequence, there emerged the idea that relief from, and compensation for, these prejudices was a collective responsibility, requiring a solidarity organized through the medium of social security. This right to compensation and the desire to recover a place in community life would form the basis for the claims of FNAT, of the *gueules casées* (a nickname that referred to severe facial injury), and with a similar thrust, of tuberculosis patients, who considered themselves the victims of a blight that was social in nature and not simply a health issue.

Numerous groups of disabled people, or the "diminished" as they called themselves at the time, were created, although in quantitative terms relatively small numbers of people were involved. Along with FNAT and federations and unions for war veterans, there appeared Auxilia (1924), dedicated to the retraining of the hospitalized disabled; Ladapt or League for the Rehabilitation for Work of the Physically Disabled (1929), whose name spells out its program; and Clair-Vivre, a residential village for the rehabilitation of tuberculosis patients (1924), soon followed in the mid-1930s by the Association of the Paralyzed of France (APF) and the Marine Cross associations (which would become the Marine Cross Federation for Assistance in Mental Health in 1952).

This is not an exhaustive list. To be emphasized is the degree to which these movements and organizations were principally concerned with physical disability, except for the Marine Crosses. These movements were more the achievement of those affected than would be the case in the period that followed. It should also be noted that institutions that went back to the French Revolution and were not the creations of disabled people themselves continued their work, but they were fundamentally concerned with children and therefore addressed chiefly disabled children with prominent distinguishing features such as blindness, deafness, or mental retardation.

The second wave dates from the period after World War II. The great majority of the initiatives were the work of families and addressed the mentally disabled or "handicapped" as they were then known, or at least disabilities that caused difficulties or slow progress at school. In the face of the inertia of the public school system and the scarcity of appropriate institutions, parent groups formed, initially less to constitute a lobby than to create schools and training facilities, supplemented, as required, by lifelong vocational support structures. The families became the administrators. This is the case with the White Butterflies, regional or local associations that in 1960 joined to form the national Union of Associations of Parents of Maladjusted Children (UNAPEI).

Between 1950 and 1970, initiatives multiplied and it would be fruitless to attempt an enumeration. An exemplary case is the APAJH, initially created as the Association for Assistance and Vocational Placement for Disabled Adolescents (AAPAJH, 1962), then renamed Association for Vocational Placement and Assistance for Disabled Youth (APAJH, 1963), and last, Association for Disabled Adults and Youth (APAJH, 1981). This evolution illustrates that the connection between disabled adults and youngsters is a recent development. It also shows that two years after UNAPEI (1962), the French term *inadapté* (maladjusted) was dropped in favor of *handicapé* (handicapped or, more currently in English, disabled). The FNAT would become the FNATH and, last, the associations would become increasingly polyvalent and ambitious, tending to take the form of large national entities, powerful in the face of the authorities, rich in endowments and staff numbers.

This was also the path followed by associations that were formed between the wars (Ladapt, APF). Today, a group called the Committee of Understanding encompasses upwards of 50 national associations, and it is politics that effectively determines the dozen or so that are counted as heavyweights, such as those named above. In the course of this period, roughly the 30 years after World War II—three glorious decades for France because of economic expansion, full employment, implementation of far-reaching social policies, and the importance of the government's economic advisory committee—the overwhelming majority of associations wished (UNAPEI) or were obliged (APAJH) to manage their own operations. There were some exceptions such as the National Federation of the Ill, Disabled and Paralyzed (FNMIP, 1945), which engaged in the protection of rights, training, and advocacy but administered no facilities or services of its own.

In chronological terms, we may speak of a third wave of newly established movements or organizations concerned with disabled people. Here it is not so much a flood of new creations as a gradual emergence in the sense that antiestablishment groups coalesced, opposed both to existing institutional and legislative arrangements, and to earlier associations. These groups in general count fewer members in comparison with the others, adopt theoretical stands, and are inspired by movements already under way outside France. This rather heterogeneous assembly ranges from highly politicized movements such as the "mean crips" (*handicaps méchants*) of the mid-1970s to associations of disabled researchers (GIHP), which would eventually become an association of services, in particular as concerns adaptive transportation for the disabled. In the central range of the spectrum is the move toward emancipation from specialized institutions, such as Living Upright (*Vivre Debout*), which would lead to the creation of the association's first group living facility in 1977, and the initial establishment in France of Disabled People International (DPI).

From this hasty overview, reference may be made to the typology proposed by Catherine Barral (1998):

> The French association landscape has taken shape around three broad tendencies: associations that administer specialized facilities dominate the picture in terms of number, reputation, and representativity; a second group is made up of associations of the trade union kind, such as FNATH . . . ; the third type is represented by user-advocate associations on the model of consumer rights movements.

But to this typology, which readily permits each of the groups of associations to be situated in social and political terms, should be added an analysis that identifies the relationship between this nebula of associations and the authorities. In the case of every association that administers any kind of service or facility, financing comes in very large part from public funds or at least nonprivate sources. In fact, there is a near equilibrium today between state funding and, increasingly, funding by regional collectivities and funding from social security agencies. Self-generated funding or independent revenues are of only marginal importance. These associations thereby assume a public mission, what in France is called "subsidiarity": What is normally considered a responsibility of the state is delegated by it to private organizations.

This situation has very specific features in France. What is less specific is the degree to which the authorities respect but also restrain these agencies: They are partners; they cannot oppose the establishment, or only to a limited degree. One example will suffice, the drafting of new legislation to replace that of 1975, in which associations that ran their own operations played the primary role, silencing the voices of those that refused any special legislation. In the reform of 2004, there was a moment when the government's approach to disability satisfied no one. The associations gathered under the heading Committee of Understanding could have required the lawmakers to rewrite the legislation completely but they preferred, as in the past, to settle for amendments.

But it would be wrong to give the impression that the organizations administering their own operations were incapable of evolution and innovation. They have developed a number of alternatives to the single route of specialized establishments. They do, however, remain hegemonistic when confronted with movements and associations that seek to position themselves differently, preferring to play on the generalized principle of nondiscrimination and a strengthened desire for democratic recognition.

In conclusion, all French organizations are today confronted by what comes from beyond, in particular European developments and recommendations that will become more constraining as Europe refashions itself into a tighter union. The European constitution, if adopted, will further this process.

—Henri-Jacques Stiker

See also Advocacy; Disability Law: Europe; European Union Policy.

Further Readings

Barral, Catherine. 1998. "Les associations nationales des personnes handicapées face à l'emploi." In *L'insertion professionnelle des personnes handicapées en France*, edited by Alain Blanc and Henri-Jacques Stiker. Paris: Desclée de Brouwer.

Barral, Catherine, Florence Paterson, Henri-Jacques Stiker, Michel Chauvière, eds. 2000. *L'institution du handicap, le rôle des associations, XIXe-XXe siècles.* Rennes, France: Presses Universitaires de Rennes.

Blanc, Alain, and Henri-Jacques Stiker, eds. 1998. *L'insertion professionnelle des personnes handicapées en France.* Paris: Desclée de Brouwer.

"De l'infirmité au handicap, Handicaps et inadaptations." 1990. *Les Cahiers du CTNERHI* 50.

Guillaume, Pierre. 1986. *Du désespoir au salut: les tuberculeux aux 19e et 20e siècles.* Paris: Aubier.

Prost, Antoine. 1977. *Les anciens combattants et la société française 1914-1939.* Paris: Fondation nationale des sciences politiques.

Stiker, Henri-Jacques. 1977. *Corps infirmes et sociétés*, 2d ed. Paris: Dunod.

ADVOCACY MOVEMENTS: GERMANY

The German disabled people's disability rights movement began at the end of the 1970s in West Germany. Disabled people in East Germany (then German Democratic Republic) had to wait until the reunification of Germany in 1989 before they could be actively involved. After the catastrophe of national socialism and the horrible experiences of compulsory sterilization and euthanasia earlier in the twentieth century, followed by decades of silence about these atrocities and also decades of being put away in institutions and homes, German people with disabilities started to set up their own groups. The time seemed to be ripe: Disabled people profited from the political, societal, and cultural changes that had been initiated by student revolutions at the end of the 1960s. Ever since, Germany has been gradually turning into a more liberal, pluralistic, and individualistic society. "Self help" was the key concept of these and the following years.

Undoubtedly, when the disability rights movement started, disabled people in Germany could look back on a long tradition of self-help organization, which can be traced back to the beginning of the twentieth century. Blind and deaf people as well as war victims of World War I (1914–1918) were among the first who had their own interest groups. An early self-help organization of the physically disabled was founded by Otto Perl (1882–1951) in 1919. After World War II (1939–1945), organizations of war victims grew even bigger and were quite successful in political lobbying. Since the end of the 1950s, parents of disabled children began to build up their own disability-related organizations and services. The Bundesvereinigung Lebenshilfe (Confederation Help to Life) for mentally disabled children, founded in 1958 in Marburg, is one prominent example of a parent group.

Despite these activities, until the late 1970s a cross-disability rights movement did not exist in Germany. But the end of that decade saw the emergence of something new: So-called cripples' groups sprang up in several places. Their members came together solely because of their disabilities, but their specific impairments did not matter. Principally, the meetings were open for all people who defined themselves as being disabled. In contrast to the already existing organizations, the new groups did not exclude nondisabled people from their ranks. These new groups founded the "Krüppelzeitung" ("cripples' newsletter") and adopted a radical position: the "cripples' standpoint," which had been formulated by Franz Christoph (1953–1996), a major activist of the new movement. This philosophy was directed against professionals and experts, who took charge of and oppressed disabled people, and against do-gooders, and what was viewed as their denigrating compassion. The new disability standpoint was full of angry protest against the ideologies of partnership and integration propagated by the traditional disability organizations. Instead, the new disability rights movement followed the example set by the women's liberation movement and women's consciousness-raising groups. Its aim was to accept and value disability as a specific form of life. Radical changes in living conditions were demanded as political rights and not as charity.

After that first phase in which angry young men and women with disabilities protested, for example, against the charity approach officially adopted in Germany for the 1981 International Year of Disabled Persons, a more pragmatic period followed. During the 1980s, German activists in the disability rights movement were busy organizing peer counseling services, giving each other legal advice and psychosocial support, protesting against inadequate public transport, and political lobbying. They built up their own infrastructure, consisting of counseling and advocacy facilities as well as job creation programs all over the country.

Gradually, the "cripples' movement" turned into the independent living movement in which the principle of self-representation continued to play an important role. The magazine *die randschau* (*from the margin*) became the new mouthpiece. Inspired by the American philosophy of independent living, German disabled people started their own independent living centers. Consequently, personal assistance became an important issue. In 1990 the nationwide umbrella organization Interessenvertretung Selbstbestimmt Leben (Interest Group Independent Living) was founded. A further field of intensive campaigning were bioethics and the effects of genetic engineering and reproductive technologies on the lives of disabled people. Female activists especially were involved in this issue. Disabled women also managed to build up their own feminist networks, and they gained a self-confident voice within the movement. Furthermore, the 1990s saw people with learning difficulties starting their own networks. A new phase began when the issue of equal rights and opportunities was put on the agenda.

Since the beginnings of the 1990s, the legal approach has dominated and both old and new disability organizations have started to work more closely together instead of competing against each other. In 1994, the disability rights movement was successful in using for its own aims the reform of the German constitution, which had been made necessary by the reunification of Germany. Since that year, an amendment to the constitution forbids discrimination on the ground of disability. Other laws, such as the Rehabilitation and Participation Law (2001) and the Federal Equal Rights Law (2002), have been formulated with the active contribution of disability rights activists. In 2003, the official German program of the European Year of People with Disabilities was organized by a prominent activist of the disability rights movement, and a summer school on critical disability studies took place. It seems as if disabled people finally have taken their place in German society, but at the same time discrimination continues and new issues arise on the disability agenda requiring new approaches and policies.

—Anne Waldschmidt

See also Advocacy; Franz Christoph; *Cripple*; Independent Living.

Further Readings

Aktion Grundgesetz, ed. 1997. *Die Gesellschaft der Behinderer*. Reinbek, Germany: Rowohlt.

Miles-Paul, Ottmar. 1992. *Wir sind nicht mehr aufzuhalten. Behinderte auf dem Weg zur Selbstbestimmung*. Munich: AG SPAK.

Waldschmidt, Anne. 1992. "Against Selection of Human Life—People with Disabilities Oppose Genetic Counselling." *Journal of International Feminist Analysis*, Special Issue: Issues in Reproductive and Genetic Engineering, 5(2): 155–167.

Wunder, Michael and Udo Sierck, eds. 1982. *Sie nennen es Fürsorge. Behinderte zwischen Vernichtung und Widerstand*. Hamburg: Verlagsgesellschaft Gesundheit.

AESOP

(Seventh- or sixth-century bce; possibly legendary)

Greek fabulist

Although the fables attributed to Aesop, such as "The Ant and the Grasshopper" and "The Tortoise and the Hare," are as well known as any of Hans Christian Andersen's tales, little is known of this early poet or even whether he existed. Aesop was connected with the Greek island of Samos in some way, either by birth or later residence. The sources for Aesop's life are very late, written many centuries later, thus unreliable. One tale tells us that he was born mute but granted not only speech but also eloquence by the goddess Isis. Another dubious piece of information—dubious because it was recorded so many centuries later—is that Aesop was lame or hunchbacked. Robert Garland, in a *The Eye of the Beholder* (1995:11), tenuously identified as Aesop a disfigured man in conversation with a fox on a charming red-figure drinking cup from the classical Greek period.

—M. Lynn Rose

See also Folk Belief.

Further Readings

Garland, Robert. 1995. *The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World.* Ithaca, NY: Cornell University Press.

Websites

Aesop's fables, http://www.aesopfables.com/

AESTHETIC SURGERY

From the close of the nineteenth century to the present, aesthetic surgery has come to be ever more widely practiced. It has also become the focus an ongoing criticism of what limits society and the individual can or should set for control over our own bodies and the bodies of others. These debates are often undertaken in complete ignorance of the history of aesthetic surgery, which is seen as being an American (read: Hollywood), patriarchal form of the oppression that women were (and are) subject to. The reality is that aesthetic surgery is a classic product of the modern world, with all of its advantages and disadvantages including our claim to control our bodies. It is the test case for all of the claims about human autonomy that the Enlightenment defined as "modernity."

The technology of aesthetic surgery, in its modern form, arose out of the anxiety about the visibility of the diseased and damaged body that form its common history with reconstructive surgery. Wounds of war, lesions of diseases from syphilis to smallpox, and congenital malformations all formed the background to the beginning of aesthetic surgery at the close of the nineteenth century. The Berlin surgeon Johann Friedrich Dieffenbach (1792–1847), a central figure in nineteenth-century facial surgery, wrote in 1834 that

> a man without a nose arouses horror and loathing and people are apt to regard the deformity as a just punishment for his sins. This division of diseases, or even more their consequences, into blameworthy and blameless is strange. . . . As if all people with noses were always guiltless! No one ever asks whether the nose was lost because a beam fell on it, or whether it was destroyed by scrofula or syphilis. (Dieffenbach 1829–1834: Vol. 3, p. 39)

Disability was the product of the physical malformation and (equally important) the stigma associated with it. This the surgeon could remedy.

Here there was little question of the nature of the disability associated with the body. For early "reconstructive" surgeons, disability was defined as lack of function coupled with the stigma associated with perceived deformity. With the introduction of the technologies of anesthetics and antisepsis, the potential of a human being, through surgical intervention, to change his or her body became both imaginable and practicable. Yet the idea of a perceived difference from an implicit norm remains central to this new aesthetic surgery. From the first patients in the 1870s and 1880s to the millions (perhaps billions) having aesthetic surgery across the world today, the idea of surgical manipulation of the body has become commonplace. But at its center is the sense of our desire (through the agency of medicine) to give us the bodies that we want rather than those that we have in order to combat the stigma we associate with those aspects of our bodies that we wish to change.

Given the predilections of our desire to control our bodies, the history of aesthetic surgery can be rather neatly divided into the world before the end of the nineteenth century and the world afterwards. It is between 1870 and 1900 that virtually all of the present procedures for the aesthetic alternation of the body are introduced. They build, of course, on earlier developments in surgery. The initial patients, with few exceptions, were men, a fact seemingly lost in the history of aesthetic surgery. But why was there an explosion of both patient interest and surgical innovation at that specific time? Such surgery prior to the nineteenth century, before the introduction of antisepsis (no infection) and anesthesia (no pain), was undertaken only when it was truly a functional necessity. Aesthetic surgery demanded something in addition.

Anesthesia became generally accepted and central to the practice of surgery after the discovery of ether anesthesia by William Thomas Green Morton (1819–1868) in 1846. The further development by the 1880s of local anesthesia, in the form of cocaine for surgery of the eye as well as spinal (subarachnoid) anesthesia and epidural anesthesia, meant that the greater risk of dying under general anesthesia could be avoided. Local anesthesia has played a central part in the development of aesthetic surgery as a widely practiced specialty. It is one of the primary factors in the successful outcome of the patient, who can follow the procedure and, unlike the patient under general anesthesia, does not morbidly fantasize about the opening of the body while unconscious. Under local anesthesia, aesthetic surgery can be experienced as a procedure a patient actively chooses, not a cure to which he or she passively submits under general anesthesia, giving up all control of the self. The patient's perception of autonomy is central to the popularity of aesthetic surgery.

The movement toward antisepsis paralleled the development of anesthesia. In 1867, Joseph Lister (1827–1912) provided a model for antisepsis, which became generally accepted by the end of the century. The potential avoidance of infection meant that patients' anxiety about cutting the skin was lessened. The acceptance of antisepsis for all surgery was relatively slow but was strongly encouraged by aesthetic surgeons. On November 26, 1877, Robert F. Weir (1838–1894), one of the major figures in the creation of American aesthetic surgery, said in a talk before the New York Medical Association that the British and German acceptance of this procedure had outpaced that of the United States. He urged that the smallest detail of the cleansing of patient, surgeon, instruments, and surgical theater be carried out so that the patient not placed at needless risk. Once this was done, the risks attendant on aesthetic surgery decreased sharply because of the reduction in the high incidence of infection.

With pain and infection removed or reduced, aesthetic surgery came into its own. Yet anesthesia and antisepsis were necessary but not sufficient to mark the beginning of the modern history of aesthetic surgery. It was the Enlightenment ideology that each individual could remake himself or herself in the pursuit of happiness that provided the basis for the modern culture of aesthetic surgery. Indeed it is remarkable how often aesthetic surgeons describe "happiness" as the goal of the surgery. "Happiness" for aesthetic surgeons is a utilitarian notion of happiness, such as that espoused by John Stuart Mill (1806–1873), who placed the idea of happiness within the definition of individual autonomy. You can make yourself happy by being able to actively participate in the world. This was mirrored in the rise of modern notions of the citizen as well as the revolutionary potential of the individual.

Autonomy stands as the central principle in the shaping of aesthetic surgery. "'Dare to use your own reason,'" wrote Immanuel Kant (1724–1804), "is the motto of the Enlightenment" (1963:3). And it is the ability to remake one's self that is the heart of the matter. Aesthetic surgery is therefore a truly modern phenomenon that demanded not only a set of specific technical innovations in surgery but also a cultural presupposition that you have the inalienable right to alter, reshape, control, augment, or diminish your body (with, of course, the help of the surgeon). The autonomy that aesthetic surgery represents is truly a modern one: You can act as you desire to become happy, but only with the aid of and comfort provided by the technocrats whose expertise you can employ.

In the course of the nineteenth century and the movement from a functional to a transformative model of aesthetic surgery, the stigma of race had its impact. Some male Jews in Germany wished to vanish into the nonracial world of unracialized men. And in Berlin in the 1890s there was Jacques Joseph (1865–1934). Joseph had been a highly acculturated young German Jewish surgeon practicing in fin-de-siècle Berlin. Born Jakob Joseph, he had altered his too-Jewish name when he studied medicine in Berlin and Leipzig. Joseph was a typical acculturated Jew of the period. He developed the first procedure of reducing the size and shape of the "Jewish" nose at the moment when political anti-Semitism first became a potent force in Germany.

In January 1898, a 28-year-old man came to him, having heard of a successful operation on a child's ears. He complained that

> his nose was the source of considerable annoyance. Wherever he went, everybody stared at him; often, he was the target of remarks or ridiculing gestures. On account of this he became melancholic, withdrew almost completely from social life, and had the earnest desire to be relieved of this deformity. (Joseph 1898 in Aufricht 1970:178)

The psychological symptoms were analogous to those of the young boy whose ears Joseph had repaired.

Joseph took the young man's case and proceeded to perform his first reduction rhinoplasty, cutting through the skin of the nose to reduce its size and alter its shape by chipping away the bone and removing the cartilage. On May 11, 1898, he reported on this operation before the Berlin Medical Society. In that report, Joseph provided a detailed "scientific" rationale for performing a medical procedure on an otherwise completely healthy individual:

> The psychological effect of the operation is of utmost importance. The depressed attitude of the patient subsided completely. He is happy to move around unnoticed. His happiness in life has increased, his wife was glad to report; the patient who formerly avoided social contact now wishes to attend and give parties. In other words, he is happy over the results. (Joseph 1898 in Aufricht 1970:178)

The patient no longer felt himself marked by the form of his nose. He was cured of the "disease" of "nostrility." In his own eyes, he looked less different from the group he desired to join—the non-Jews. Joseph had undertaken a surgical procedure that had cured his patient's psychological disorder. Yet he had left scars, which pointed to the procedure itself, and this became a major concern of Joseph's. He warned his colleagues that "disclosure to the patient on the problem of scarring is very important. Many patients, however, will consider even simple scars too conspicuous." He raised the specter of a court case in which the "unsightly scar might represent a greater degree of disfigurement than the enlarged cartilage of the nose presented previously." More centrally though, surgical scars, unlike scars obtained through socially acceptable and manly activities such as dueling, reveal the inauthencity of the body and the effort to "pass" via medical intervention.

The general claim that the surgery creates some form of happiness remains central to aesthetic surgery. In the nineteenth century, surgeons claimed that they were altering the body to change the psyche. In 1887, John Orlando Roe in Rochester, New York, developed a procedure to alter the shape of the "pug nose." Roe did not only claim to cure the pug nose, he claimed to be also curing his patient's unhappiness. His comprehension of the relationship between mind and body was clear:

> We are able to relieve patients of a condition which would remain a lifelong mark of disfigurement, constantly observed, forming a never ceasing source of embarrassment and mental distress to themselves, amounting, in many cases, to a positive torture, as well as often causing them to be objects of greater or lesser aversion to others. . . . The effect upon the mind of such physical defects is readily seen reflected in the face, which invariably conforms to the mental attitude, and leads after a time to a permanent distortion of the countenance. (quoted in McDowell 1977:114)

The surgeon in curing the deformity makes the patient happy, which in turn alters the physiognomy of sadness.

At the beginning of the twenty-first century, we have a resurgence in the idea that men (too) desire to shape their bodes through surgery to provide them with new, younger bodies. It is not actually much of a change. The bodybuilding culture for men that stressed the muscular, shaped body arose in the 1890s at the same time as the origin of modern aesthetic surgical procedures. Shaping or cutting can reform the male body by the desire of the individual in concert with the professional (either bodybuilder or surgeon).

Today, we have come not much further in the popular understanding of aesthetic surgery. Columnist Anne Duggan in Australia wrote in 2002:

> What man or woman is ever truly happy with every part of their face or body? Even if you are quite comfortable with your appearance, you probably think there is room for improvement. Cosmetic surgery can be a great adjunct to your health and fitness regime, improving those areas that diet and exercise won't. According to cosmetic surgery specialists, having a nip or a tuck is catching on in Australia, as the procedures become more acceptable and accessible for all Australians. Whether you'd like a smaller nose, fewer

> wrinkles or bigger breasts, there is a cosmetic surgery procedure that can help. (p. A7)

Can we truly become happy? And what does that happiness come to mean for us when we achieve it through surgery? Is happiness an appropriate goal for life or does it demand too much?

—Sander L. Gilman

See also Body, Theories of; Deformity; Identity.

Further Readings

Armstrong, Tim. 1998. Pp. 75–183 in *Modernism, Technology and the Body: A Cultural Study.* Cambridge, UK: Cambridge University Press.

Balsamo, Anne. 1996. *Technologies of the Gendered Body: Reading Cyborg Women.* Durham, NC: Duke University Press.

Blum, Virginia L. 2003. *Flesh Wounds: The Culture of Cosmetic Surgery.* Berkeley: University of California Press.

Brieger, Gert H., ed. 1972. Pp. 198–200 in *Medical America in the Nineteenth Century: Readings from the Literature.* Baltimore: Johns Hopkins University Press.

Brunner, Peter Paul. 1996. *Die Entwicklung der Knochenplastik am Unterkiefer im Ersten Weltkrieg*. Zurich: Juris.

Châtelet, Noëlle, 1993. *Trompe-l'oeil: voyage au pays de la chirurgie esthétique*. Paris: Belfond.

Comelli, Albino. 1993. *Da narciso al narcisismo: storia e psicologia del corpo—costume, medicina, estetica*. Trento, Italy: Reverdito.

Davis, Kathy. 1995. *Reshaping the Female Body: The Dilemma of Cosmetic Surgery.* New York: Routledge.

———. 2003. *Dubious Equalities and Embodied Differences: Cultural Studies on Cosmetic Surgery.* Totowa, NJ: Rowman & Littlefield.

Dieffenbach, Johann Friedrich. 1829-1834. *Chirurgische Erfahrungen, besonders über die Wiederherstellung zerstörter Theile des menschlichen Körpers nach neuen Methoden,* 4 vols. in 3 and atlas. Berlin: Enslin.

Duggan, Anne. 2002. "Improve on Nature." *Sunday Mail* (Queensland), April 14, p. A07.

Gifford, Sanford. 1972. "Cosmetic Surgery and Personality Change: A Review and Some Clinical Operations." P. 30 in *The Unfavorable Result in Plastic Surgery: Avoidance and Treatment,* edited by Robert M. Goldwyn. Boston: Little, Brown.

Gilman, Sander L. 1998. *Creating Beauty to Cure the Soul: Race and Psychology in the Shaping of Aesthetic Surgery.* Durham, NC: Duke University Press.

———. 1999. *Making the Body Beautiful: A Cultural History of Aesthetic Surgery.* Princeton, NJ: Princeton University Press; Doubleday Select Bookclubs.

Haiken, Elizabeth. 1997. *Venus Envy: A History of Cosmetic Surgery.* Baltimore: Johns Hopkins University Press.

Hoffmann-Axthelm, Walter et al. 1995. *Die Geschichte der Mund, Kiefer- und Gesichtschirurgie.* Berlin: Quintessenz Verlag.

Joseph, Jacques. 1898. "Über die operative Verkleinerung einer Nase (Rhinomiosis)" (Operative Reduction of the Size of a Nose [Rhinomiosis]). *Berliner klinische Wochenschrift* 40:882–885. Translated in Aufricht, Gustave. 1970. *Plastic and Reconstructive Surgery* 46:178–181. Reproduced in pp. 164–167 of McDowell, Frank, ed. 1977. *The Source Book of Plastic Surgery.* Baltimore: Williams & Wilkins.

———. 1931. *Nasenplastik und sonstige Gesichtsplastik, nebst einem Anhang über Mammaplastik und einige weitere Operationen aus dem Gebiete der äusseren Körperplastik: Ein Atlas und ein Lehrbuch.* Leipzig: C. Kabitzsch. Translated by Milstein, Stanley. 1987. Jacques Joseph, *Rhinoplasty and Facial Plastic Surgery with a Supplement on Mammaplasty and Other Operations in the Field of Plastic Surgery of the Body.* Phoenix, AZ: Columella.

Kant, Immanuel. 1963. "What Is Enlightenment?" *On History,* edited by Lewis White Beck. Indianapolis, IN: Bobbs-Merrill.

McDowell, Frank, ed. 1977. *The Source Book of Plastic Surgery.* Baltimore: Williams & Wilkins.

Reifler, David M., ed. 1994. *The American Society of Ophthalmic Plastic and Reconstructive Surgeons (ASOPRS): The First Twenty-Five Years: 1969–1994; History of Ophthalmic Plastic Surgery: 2500 BC-AD 1994*. Winter Park, FL: American Society of Ophthalmic Plastic and Reconstructive Surgery.

Roe, John O. 1887. "The Deformity Termed 'Pug Nose' and Its Correction, by a Simple Operation." *Medical Record* 31 (June 4): 621–623. Reprinted in McDowell, Frank, ed. 1977. *The Source Book of Plastic Surgery.* Baltimore: Williams & Wilkins.

Romm, Sharon. 1992. *The Changing Face of Beauty.* St. Louis, MO: Mosby Year Book.

AESTHETICS

Disability aesthetics is a critical approach to thinking and making of art through a disability perspective. It is an approach that revises and resists the ways in which mainstream society has marginalized the disabled person as well as disability art. In part, this work has centered on the efforts of arts scholars to critique traditional notions of aesthetics that emphasize an ideal body and simultaneously discount, minimize, or erase disability. Cultural assumptions about disability inform many artistic artifacts and performance, and the analysis of these assumptions helps us to understand how disability has been historically and socially construed as well as how these parameters on disability limit the possibilities for new artistic practices. Consequently, a disability perspective foregrounds the value and power of human variegation, and it challenges the ways in which disability has typically been viewed as a deficit.

It is important to grapple with how art reinscribes and helps maintain traditional societal frames for disability, work that has been undertaken by such scholars as Lennard Davis, David Mitchell and Sharon Snyder, and Rosemarie Garland Thomson. This work helps us understand how disability and its figures have worked as the hidden partners in supporting what are deemed important cultural messages that are disseminated through art. Davis's work on the deafened moment looks at "deafness as a critical modality"—more specifically at the sites and ways in which the emphasis on hearing and sound falls out and there is a reliance on nonverbal signs. There are, as he demonstrates, cultural and artistic practices that emphasize moments of deafness without fully acknowledging the ways in which the practice rests on deafness itself. Mitchell and Snyder show the ways in which disability is used as a narrative prosthesis in literature, how images of disability act to jumpstart engagement with the text through a problem or crisis. It sets in motion the storyline, but by the end of the narrative, the disability most often gives way to some triumph of the able-bodiedness or the normal. Thomson has addressed how freak shows, photographs of the disabled, and other cultural evidence rely on the audience response of staring and thus communicate a set of coded messages about disability and its place in society.

The representation of disability is, of course, not new. Historically, a number of performing artists, as a result of their investment in challenging traditional modes of representation, have incorporated the presence of the disabled in their works. These numerous approaches include disabled characters in plays, sensory frames of reference from a position of "as if" disabled (such as Robert Wilson's early work, *Deafman Glance,* with African American deaf-mute Raymond Andrews), the use of sign language in modern dance works, or an entire aesthetic of modernity based on what could be called a disability perspective, such as the work of Antonin Artaud. In fact modernist (as well as postmodernist) aesthetics has often drawn on the seemingly unstable and often unclassifiable bodies of the disabled to bring new life to art practices. While a number of these examples open up new aesthetic frames, they also have worked to reinscribe the abnormal phenomena back within the regime of normalcy.

All too often the disabled person has fallen out of the picture. This maneuver reflects the larger sociocultural malaise toward dealing with disability—of disappearing or marginalizing the disabled—as well as the ways in which art claims to rest on the position of the ideal body. The disabled person, in these cases, does not play the disabled character. Robert Wilson, for instance, continues his work with its complex visual textures and "deafened" tones without his counterpart, and we still go to see modern dance that uses sign language but does not include deaf dancers.

More recently, disability aesthetics has also begun to account for how disability itself produces art, what those art practices are, and how those endeavors lead to a new aesthetics—revising what we have typically and traditionally considered aesthetics with its emphasis on the beautiful. This account can help us understand how the incidents of the anomalous body in a vast amount of art history are not simply always an effort to discount the lives of the disabled and the ways in which the unusual reinvigorates artistic practice. But, even more significantly, disability art today bypasses traditional modes of representation and demands new practices of engagement.

Artistic practice relies on the manipulation of sensory frames of reference, and these sensory amalgamations carry with them emotional and conceptual implications. Consequently, disability aesthetics as practice provides a rich frame for articulating different ways of existing as persons in the world.

The disabled are privy to all sorts of sensory experience not accessible to the able-bodied. Disability art is one way of providing access to this unfamiliar territory and of creating space for the emergence of new concepts and experiences of artistic creation. This pattern not only challenges traditional representations of the body, but it also unsettles conventional ways of knowing and communicating. And the increasing number of arts organizations, dance companies, and performance companies that generate work giving direct voice to the disabled gives witness to the growing interest in disability arts.

There are a number of challenges regarding the disability perspective. Feminist disability theorist Thomson (1997b) noted: "Disability, perhaps more than other forms of alterity, demands a reckoning with the messiness of bodily variegation, with literal individuation run amok. . . . [D]isability foregrounds embodiment's specificity" (p. 283). The question of "embodiment's specificity" finds particular cogency in disability arts with its emphasis on corporeal particularity and the unpredictable and unfamiliar. In performances of various sorts, disability invites the audience to engage with art and performance in new ways as they provide us with what Petra Kuppers, following dance choreographer Deborah Hay, calls "perceptual challenges." Examples include, but are not limited to, the inclusion of dancers in wheelchairs (Axis and Infinity USA, Candoco Britain), dancers with cerebral palsy and cognitive differences in Restless Dance (Australia), performers with sensory and physical impairments in Graeae Theater (Britain), deaf dancers in Common Ground Sign Dancer Theater (Britain), or the recent inclusion of deaf dancers in Nancy Hauser's Company (United States), as well as a choreographer and dancer who has dystonia, Neil Marcus (United States). This variety not only changes the look of what's staged but also the feel, as these perceptual challenges often create an emergent space of experience and understanding. Consequently, we engage with disability as difference rather than deficit as it bypasses the usual representational circuitry.

Contact improvisation, a dance form where the participants rely on the exchange of energies between a variety of physical contact points and shifts in body weight both individually and shared, has a well-developed history in including disabled performers. Part of the reason for this occurrence is that the form itself does not rely on the typical cultural expectations of upright physicality and presentational qualities; it relies on the feel of the dancing rather than its look.

This radical, liminal space unsettles expected transactions between performer and audience, and it creates an arena of instability. In this arena, previous assumptions and significations become unmoored; new possibilities emerge. Confronted with the material world of disabled performers, the present and palpable bodies of physical difference the audience also faces its own phantasms of disability—questions of illness or weakness, physical appearance, or suffering that are often dismissed or rejected by society at large. This body is unpredictable, unstable. Unleashing ourselves from the proclivity of bracketing the anomalous body helps to generate space not only of visibility for the disabled but also a space for grappling with the inherent hybridity of our physicality—its concomitant sensory and emotional variety.

In the National Theatre of the Deaf, for example, the deaf performers use sign language, which is a visual-kinetic mode of language and often referred to as "silent poetry," but voicing actors also interpret their performances. This work challenges the traditional limits of language, poetry, and the use of voice; deaf individuals speak visually and kinesthetically in ways that the hearing population is not accustomed to hearing. The location of deaf poetry, and by implication deaf poetry as it occurs in theatrical performance, within the larger discussion of the ways in which we have moved from a textually based model of communication to a performance-based model of communication with the emphasis on a visual-spatial field rather than that of sound. Consequently, the use of American Sign Language (ASL) in performance is a valuable site for grappling with an aesthetic that valorizes the position of deafness.

It is important, furthermore, to note that several well-known ASL poets, such as Clayton Valli and Ella Mae Lentz, have chosen not to have their work sound-interpreted as a matter of a political statement to the hearing community. This work invites a consideration of how "think-hearing" is what Michael Davidson has called "a subject of aesthetic critique while utilizing ASL as a powerful discourse to phonocentric models for literature." Davidson has addressed the ways in which the work of Flying Circus, with deaf performer Peter Cook and hearing performer Kenny Lerner, use speech as well as vocalization in their performances to challenge and revise the ways in which the use of speech tends to signal specific meanings for the hearing. Davidson also critiques the work of Deaf performance artist Aaron Williamson and the ways in which he uses the visual channels to render the in-between status and states of a late-deafened adult—the ways in which meaning slides between image, object, body, and voice. For Williamson, Davidson concluded that he critiques the organizing cultural metaphor for meaning as the ear rather than the voice. Work of this sort serves to locate disability artists within the nexus of a broad range of concerns that provides a powerful critique of how the construct of disability operates across a range of questions about human experience.

Street performer Bill Shannon, aka "Crutchmaster," with strong ties to both the hip-hop dance scene and the disability arts scene, has developed an entire dance aesthetic out of his need to use crutches to move around. In his street improvisations, Shannon uses both his crutches and a skateboard to maneuver in and around people passing by on the streets. This approach plays off of and with people's discomfort and confusion about how to deal with someone moving through public space in unfamiliar ways. Consequently, Shannon's prowess in moving invites spectators to revise their expectations about how disabled individuals can navigate public spaces. It also inserts the generation of a new movement aesthetic into the experience of everyday life.

In addition to innovative engagement with how mainstream notions of aesthetics can be changed through the development of new practices for staging the moving body and various sensory frames, the use of storytelling has also helped to further disability aesthetics by investigating new ways to look at narrative. For example, Anne Basting's TimeSlips (U.S. based) is an interactive project on storytelling for Alzheimer's patients. Bastings has developed a process for doing storytelling circles with these patients that centers on telling a story in the present through the impetus of a visual stimulus. The stories that emerge out of these workshops emphasize the power of image rather than the linearity of traditional storytelling. This work has led to the development of an interactive component on the TimeSlips website, installation work, and a TimeSlips play, as well as growing interest in the creative possibilities of dementia.

There are a number of other groups that have used storytelling in innovative ways. Artistic director Ruth Collett's project Stalking Histories (Britain based) explores lost stories from the disability culture, in relationship to such events as the Holocaust in Germany or the impact of Mendel (1822–1884; a botanist and monk who developed the study of genetics) and integrates the use of new technologies and nontraditional sites for the sharing of the stories. As they continue to explore the implications of new technology for disability performance and storytelling, they are making progressive use of their website as a gallery space for the sharing of stories.

Other disability artists exploring how the new technologies makes the production and access to artwork more available for disabled artists include Bilderwerfer's (Austria) web-based collaboration area and Petra Kuppers, director of Olimpias Performance Research Project. She explores the connections between story, mental health system survivors, disability arts, and the new media. The projects take a variety of forms: installations, film, and CD-ROM. Each of these examples develops an alternative venue to the traditional structures of the presentational stage, allowing a more mobile approach to be taken to the making and sharing of art. In addition, cultural expectations about looking at a performance are disrupted or challenged and the audience members must adopt a more participatory and nonlinear approach to experiencing the artwork.

These unfamiliar moments are not easy to analyze or to live through with complete lucidity, yet, as new spaces of exchange open up, new identities and geographies can unfold. Consequently, as we attend to the embodied traces of disabled identity in the mobile landscape of the everyday, performance provides a medium par excellence for mapping new identities. The fixities of personal and social identity, the traumas of history, and the obsessively repeated stories give way to the possibilities of other narratives, new viewpoints. The body shape-shifts, and as it responds to the creative charges and unexpected changes it is suddenly engaged in a new storyline, a different angle in the aesthetic trajectory brought on by the mobilizing of communal energies.

—Kanta Kochhar-Lindgren

See also Body, Theories of; Culture; Dance; Deaf Culture; Drama and Performance; National Theatre of the Deaf; Sign Poetry.

Further Readings

Albright, Ann Cooper. 1997. *Choreographing Difference: The Body and Identity in Contemporary Dance.* Middletown, CT: Wesleyan University Press.

Brueggemann, Brenda Jo. 2002. *Lend Me Your Ear: Rhetorical Constructions of Deafness.* Washington, DC: Gallaudet University Press.

Crutchfield, Susan and Marcy Epstein, eds. 2000. *Points of Contact: Disability, Art and Culture.* Ann Arbor: University of Michigan Press.

Davidson, Michael. 2002. "Hearing Things: The Scandal of Speech in Deaf Performance." In *Disability Studies: Enabling the Humanities,* edited by Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland Thomson. New York: Modern Language Association.

Davis, Lennard. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body.* New York: Verso.

Fahy, Thomas and Kimball King, eds. 2002. *Peering Behind the Curtain: Disability, Illness, and the Extraordinary Body in Contemporary Theater.* New York: Routledge.

Kuppers, Petra. 2003. *Disability and Contemporary Performance: Bodies on Edge.* London and New York: Routledge.

Mitchell, David T. and Sharon L. Snyder. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor: University of Michigan Press.

Thomson, Rosemarie Garland. 1997a. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

———. 1997b. "Feminist Theory, the Body and the Disabled Figure." In *Disability Studies Reader,* edited by Lennard Davis. New York: Routledge.

Websites

National Arts and Disability Center, http://nadc.ucla.edu
National Disability Art Forum, http://www.ndaf.org/
TimeSlips, http://www.timeslips.org/outreach/play.html
World Institute on Disability, http://www.wid.org

AFFIRMATIVE BUSINESSES

Affirmative businesses provide employment opportunities for people with disabilities. They operate as regular businesses, producing goods and services for sale within the broader community. Affirmative businesses have typically emerged from nonprofit organizations and have developed through a collaboration between people with disabilities, vocational rehabilitation professionals, and businesspeople. This collaboration is directed toward the creation of a business organization that is: sensitive to the needs and aspirations of persons with disabilities, constructs a working environment that can meet diverse needs for training and job accommodations, and operates using sound business principles and practices. In this way, affirmative businesses are structured to neutralize the individualism and competition that disadvantage individuals with disabilities in the open labor market.

The exact nature of an affirmative business will depend on the interests and skills of the potential workforce and on the market prospects in the local community. Examples include businesses that have focused on industrial subcontracting, cafés and catering, desktop publishing and video production, car washes, greenhouses, laundry services, and retail convenience and gift outlets. Since they are designed as true businesses, they provide workers with either the opportunity for long-term employment or a place to develop their work capacities before they move on to other jobs in the open labor market.

The effectiveness of the affirmative business is measured by its commercial success. A primary objective is to reduce reliance on funding from government or philanthropic organizations. They are also expected to offer wages that are consistent with standards in the open labor market and opportunities for advancement. Effectiveness is also measured by the extent to which the working environment facilitates participation and ownership by individuals with disabilities.

The affirmative business approach to job development has been applied broadly to people who are disadvantaged with respect to employment. John Durand is widely credited for its application to persons with disabilities in the 1960s. The approach is one of many commercially oriented ventures that attempt to develop business practices that promote a socially responsible and sustainable economy.

Community integration in this employment approach is realized at the level of the business. Employees connect with the broader community in the day-to-day context of offering goods and services to the public, ordering supplies, and participating in local business networks. It is expected that the financial rewards and personal connections made in the context of work will facilitate opportunities for community participation outside of the business.

Critics of the approach have argued that this is segregated employment and is minimized as a credible business model in the open labor market. There are also concerns that these businesses typically provide only entry-level jobs with poor prospects for financial compensation and opportunities for advancement. Finally, it has been argued that the structure of the organization will favor employment of professionals from the human services sectors in key management positions, undermining full ownership by persons with disabilities.

—*Terry Krupa*

See also Consumer-Run Businesses; Employment; Sheltered Workshop.

Further Readings

Coker, Charles C. 1996. "Factors to Consider in Developing an Affirmative Business as a Community-Based Employment Option." Menomonie: University of Wisconsin–Stout, Research and Training Center.

Krupa, Terry, Karen McCourty, Doug Bonner, Barbie Von Briesen, and Robert Scott. 1999. "Voices, Opportunities & Choices Employment Club: Transforming Sheltered Workshops Using an Affirmative Business Approach." *Canadian Journal of Community Mental Health* 18:87–98.

Lunt, Neil and Patricia Thornton. 1994. "Disability and Employment: Towards an Understanding of Discourse and Policy." *Disability & Society* 9:223–238.

Minnesota Diversified Industries. 2003. "MDI: Opportunity to Excel" St. Paul: Minnesota Diversity Industries Corporate Centre. Retrieved October 17, 2003 (http://www.mdi.org/index.php).

Social Venture Network. 2003. *Social Venture Network: Transforming the Way the World Does Business.* San Francisco: Social Venture Network. Retrieved October 17, 2003 (http://www.svn.org).

Strong, Susan. 1998. "Meaningful Work in Supportive Environments: Experiences with the Recovery Process." *American Journal of Occupational Therapy* 52:31–38.

AFRICA

See Deaf Africans, Histories of; Disability in Contemporary Africa; Experience of Disability: Sub-Saharan Africa

AFRICANS, DEAF

See Deaf Africans, Histories of

AGASSIZ, (JEAN) LOUIS (RODOLPHE) (1807–1873)

American (Swiss-born) naturalist

The naturalist Louis Agassiz began his career working on fish fossils and studying under Georges Cuvier (1831). In 1847, he became a professor at Harvard University where he founded and directed the Museum of Comparative Zoology until his death in 1873. Furthering Cuvier's work on geological catastrophism and classification of animals, Agassiz developed the glacial theory of the Ice Age (1840) and a classification of biological life forms (1851–1855). Similar work on biological order led Charles Darwin and Ernst Haeckel to theories of evolution and natural selection. Agassiz rejected these theories, and instead, adhered to natural science as a combination of empirical methodology and natural theology. In 1847, he advocated polygenesis, basing his support on new geological evidence. Polygenesis, the theory that at least some races had separate origins, was also employed as a defense of Christianity and eventually as a social doctrine (1850). He advocated the permanence of different races and worried about the "tenacious influences of physical disability" if races were mixed (1863). While his teaching and early research brought unprecedented national and international recognition for the field of natural science, his antievolution position and support of polygenesis were controversial throughout his life and contributed to his marginalization in subsequent years.

—*Jee Yoon Lee*

See also Race and Ethnicity.

Further Readings

Lurie, Edward. 1988. *Louis Agassiz: A Life in Science.* Baltimore: Johns Hopkins University Press.

AGING

Conceptions and definitions of *old age* and *disability* vary in different cultures. These include chronological age, functional limitations (activities of daily living and instrumental activities of daily living), social performance, or work capacity. One approach is to define aging as an ongoing process that includes age-related changes related to physiological processes occurring at certain stages in life (e.g., puberty and menopause) and age-related conditions that occur as individuals age (e.g., hypertension and coronary artery disease). Criticism of these definitions of aging and disability center on their failure to measure the impact of social, political, economic, and cultural factors on a person's ability to perform or engage in social roles. Common barriers to participating in social roles include architectural barriers and attitudinal barriers that can impede active community participation. The Americans with Disabilities Act of 1990 (ADA) acknowledges that people with impairments (even in the absence of any limitation) may face discrimination due to social forces, such as stigmatization, fears, or myths regarding disability. According to the ADA, a person with a disability is someone who meets at least one of the following criteria: (1) has a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working; (2) has a history or record of such an impairment; or (3) is perceived by others as having such an impairment.

The onset of disability for most people occurs at older ages and the duration is short. These individuals experience disability with aging. Adults who acquire their disability in childhood, before the age of 20 (about 7–9 percent in the United States), experience aging with a disability. The terms *disability with aging* and *aging with a disability* have generated stereotypical views about aging and disability in that the onsets of disability is an issue for older persons and "aging" is an issue for younger adults with permanent disabilities.

GLOBAL AGING AND AGING IN THE UNITED STATES

Human longevity climbed in the twentieth century due to changes in public health policies (e.g., improved sanitation and food and water safety), advances in medical practice (e.g., antibiotics and insulin), and greater emphasis on health promotion and disease preventive. The older population of persons aged 60 years or older is growing faster than the total population in almost every region of the world.

Data from the United Nations Department of Economic and Social Affairs (2002) indicate that over the past 50 years, the number of older persons has tripled from 205 million persons in 1950 to 606 million in 2000 and is projected to triple again by 2050 to approximately 2 billion persons aged 60 or older. People who are 80 years or older are the fastest-growing group of older individuals; this cohort is projected to increase five-fold from 69 million in 2000 to 379 million in 2050.

In the United States, according to the U.S. Bureau of Census (2002), 35.1 million persons are over the age of 65 years (12.4 percent of the total population). Of these, 21 million are women and 14 million are men. The 2003 "American Community Survey (ACS) Data Profile" (U.S. Bureau of the Census 2003) reported that 20 million (12 percent) people 21–64 years old have a disability and 14 million (40 percent) persons age 65 and older have a disability. The likelihood of acquiring a disability increases as people live longer. Age-associated disabilities include impairments in mobility, hearing, vision, cognition, and loss of function due to medical conditions such as congestive heart failure, stroke, and chronic obstructive pulmonary disease. In the United States, the number of people aging with a disability also is increasing. Today, the population over age 60 years includes more than half the persons with disabilities in the United States.

LIFE EXPECTANCY

The average life expectancy in the United States for infant girls is now 79.7 years and 74.1 years for boys. While the life expectancy for persons with disabilities acquired early in life has increased significantly, in general, disabled people have a life expectancy that is 15 to 20 years less than the rest of the population. With advances in medical treatment and living conditions, life expectancy for some people with disabilities (e.g., people with developmental disabilities and spinal cord injury) has risen dramatically and is only slightly lower than that of the general population. Individuals with spinal cord injuries have the highest mortality rate in the first year after injury, and those who have greater neurological deficits tend to die earlier. For people with Down syndrome, cerebral palsy (particularly individuals with lower functional levels), and severe intellectual disabilities, life expectancy is significantly lower than for the general population. In addition, life expectancy for persons with intellectual and developmental disabilities is significantly lower than that of the general population in the presence of the following impairments: severe mobility impairment (requiring a wheelchair and assistance for propulsion), severe manual dexterity impairment (unable to feed and dress without assistance), and severe intellectual disability (IQ < 50).

VIEWS OF AGING AND DISABILITY

Perceptions of aging and disability in any era and culture are influenced by lifespan, economic conditions, social expectations, and images presented in contemporary media, arts, and literature. During the past several centuries in the United States, the religious and secular movements have transformed our views of aging and disability. In the seventeenth century, Puritans revered people who were aged and saw aging as a sacred pilgrimage to God. Similarly, reformers motivated by religious principles worked to help people with disabilities, as they helped children and heathens. During the Victorian age, youth became a symbol of growth and expansion, and people with disabilities, who were increasingly sent to live in mental asylums, state schools, and homes for the feebleminded, had little control over their lives. As the need to provide for a rapidly growing population increased, youthful energy, westward migration, and technological advances made the elderly seem out touch and their traditions seemed cumbersome and a hindrance to progress. In addition, medical advances during the twentieth century promised to eliminate much disability. Though this promise was overstated, people with disabilities were less visible in our communities as many people continued to be placed in institutions or special schools or kept out of sight at home.

In the past 20 years, portrayals of aging have shifted from viewing aged individuals as victims or those to be pitied, shunned, or ridiculed to seeing robust images of aging adults maintaining active lifestyles within their communities. Images of people with disabilities have also transformed from depicting them as broken people who need fixing to people who want the right to live, work, and engage in recreational activities within their communities. Increasingly, we are recognizing and confronting the negative assumptions and values our culture has held about old age and disability.

As more persons are living longer with a disability, whether the disability onset is earlier or later in life, the intersection of the fields of disability and gerontology is greater. Biological, sociological, and psychological theories seek to understand the determinants of mortality, morbidity, and well-being in later life. These determinants include individual biological and lifestyle issues as well as environmental aspects, including support services and the physical environment.

THEORIES OF AGING

Historical Perspectives

The concept of aging represents a phenomenon of populations and individuals. On a *population* level, aging represents the success of a society based on the outcome of human discoveries and developments in hygiene, nutrition, biomedical technology, and sociopsychological and political advancements. Aging also reflects societal challenges, given the costs required of social and health programs in modern societies. On an *individual* level, aging takes into account three main aspects: biomedical, psychological, and social well-being, though throughout the history of the study of aging, the biomedical discipline has predominated, compared with psychology or any of the other social sciences.

Theories related to the universal human phenomenon of aging have been debated since early philosopher-scientists. According to Ebersole, Hess, and Luggen (2004), Aristotle believed that aging was a period of disengagement and interiority, whereas Cicero and Montaigne saw aging as a period of self-discovery, pursuit of gentility, and complexity. Plato viewed aging as the development of wisdom and a metamorphosis of the soul. Leonardo da Vinci saw aging as a time of coping with the reality of physical decline, and Charcot viewed aging as a latency period of diseases that appeared only in old age. While Galen asserted that old age is not a "disease," Rush stressed the importance of heredity and behavior on aging and Cornaro believed that restricted diet and moderation were necessary for a long life. Fothergill linked the effects of mind on body by recommending the benefits of positive attitudes on aging. Villanova thought that moderation and humoral balance were critical to vitality.

Contemporary Theories on Aging

As scientists expanded their knowledge, improved their research methods, and discovered more about aging, they came to view aging as a complex and variable process. During the twentieth century, biologists, sociologists, and psychologists developed theories to explain the phenomenon of aging. These theories fall into several broad categories such as biological (encompassing measures of functional capacities of vital or life-limiting organ systems), sociological (involving the roles and age-graded behaviors of people in response to the society of which they are a part), and psychological (referring to the behavioral capacities of people to adapt to changing environmental demands).

Biological Theories

Although aging and disease are independent processes, aging clearly includes increased vulnerability to disease. Early medical theories focused on the relationship between disease and aging. More recent medical theory focuses on assessing and improving the functional health of aging individuals. Evolving theories addressing not only longevity but also active life expectancy and functional health explain the recent emphasis on health promotion interventions and provide goals for healthy aging.

All organ systems undergo a gradual decrease in reserve capacity, although at different rates. This rate depends on the genetic composition, such as the presence of genetic syndromes or disease resistant genes, and on "wear and tear" brought on by a stressful lifestyle and environmental factors (e.g., smoking, poor diet, alcohol abuse, muscular strain). Diminished immunity increases susceptibility to chronic conditions such as cancer, infections, lupus, and rheumatoid arthritis. When little reserve capacity remains, the likelihood of developing a disease increases. People with disabilities may have less reserve capacity remaining. For example, a person who had polio is unlikely to reach the same peak pulmonary capacity as a nondisabled person. Persons who have been nonambulatory for many years are unlikely to reach the same peak bone density as other persons.

Sociological Theories

Early sociological theories of aging (in the 1960s) focused on the adjustment of older people to losses within the context of their roles in society. Examples of these theories are the disengagement and activity theories. In the 1970s, the perspective broadened to also examine the complex interrelationships between older persons and their physical, political, and socioeconomic environments.

The premise of the disengagement theory proposed by Cumming and Henry is that aging is a time of mutual withdrawal and gradual reduction of roles and responsibilities so that the older person could be replaced. This view depicted the older person as preoccupied with himself or herself and with decreasing emotional involvement with others. Criticism of this theory posits that such disengagement is neither natural nor inevitable and presents a one-sided view of older persons as many persons remain active throughout old age.

Robert Havighurst's activity theory conceptualized aging in terms of the developmental tasks of later life. Using a lifespan perspective, he suggested that these developmental tasks include (1) coping with physical changes; (2) redirecting energy to new roles and activities such as grandparenting, retirement, and widowhood; (3) accepting one's own life; and (4) developing a point of view about death. The premise is that to maintain a positive sense of self, elderly persons must substitute new roles for those lost in old age.

Lawton proposed the concept of the person-environment fit that examines the interrelationship between personal competence and environment; for each level of competence there is an optimal level of environmental demand (environmental press) that is most advantageous to a person's function. Those persons with a low level of competence can tolerate only a low-level press, and those with higher levels of competence can tolerate increased demands. This paradigm is useful in planning suitable interventions for older adults with disabilities who reside in private homes and institutional settings.

Psychological Theories

Psychological theories of aging address old age within the context of a person's life cycle, wherein one moves through stages in certain patterns. Successful aging occurs when people fulfill life tasks that they consider important despite reduced energy in later life.

Erik Erickson's original theory in the 1960s described the last life stages as ego integrity (vs. despair) followed by life review activities that result in wisdom. He believed that mastery in an earlier stage laid the groundwork for success in the next stage. In the 1980s, Paul Baltes distinguished between normal, pathological, and optimal-developmental enhancing and age-friendly environments. He viewed aging as (1) a lifelong process that influences and in turn is influenced by social processes and (2) that is perceived differently by each age cohort. Among individuals, latent reserve capacity is highly variable. Individual and social knowledge can help compensate for age-related decline in fluid intelligence. Aging is a lifelong process of selective optimization with compensation allowing people to age successfully and to engage in life tasks that are important to them.

Successful Aging

For years, gerontology promulgated the "decline and loss" paradigm: that aging encompasses a series of decrements or losses in the individual to which elders and society needed to adapt. Rowe and Kahn's notion of *successful aging* used the concept of physiological reserve to make a distinction between "usual" aging and "successful" aging. People who age *successfully* have a great amount of physiological reserve. Successful aging outcomes include (1) low probability of disease and disease-related disability, (2) high cognitive and physical functioning, and (3) active engagement with life through involvement in close relationships and in meaningful activities (paid or unpaid). It stresses that much of the feared losses with aging are preventable and that many functional losses can be regained. This perspective attributes many of the problems associated with "normal" aging to a high-risk lifestyle. Hence, health promotion activities are seen as a way to lower the risk for disease and disability in later life.

Although this perspective offers a more positive image of aging than do the models focusing on decline and losses, this conceptualization does not take into account early-onset disabilities. People with disabilities can age well. The successful aging model also pays scant attention to (1) aging over the life course; (2) race, class, and gender inequities; (3) implications of losses and gains in later life to older persons with disabilities; (4) stigma associated with disability when viewed as a failure; and (5) limitations of the concept when applied to people with disabilities.

This model fails to adequately address heterogeneity of experiences for people with long-term disabilities whose views of effective functioning may differ from that of other people. People with disabilities may view success as the degree to which the environment changes to accommodate their changing bodies and needs. Hence, stigma is shifted from the old to the disabled, who may be more likely to experience lower adaptive functioning and may be less able to fully participate in community life.

A need exists for a broader environmental approach that stresses environmental accommodations, societal attitudes, and policy changes. People with disabilities have low employment rates (less than one-third in the United States) according to the 1994 "Survey of Income and Program Participation" (McNeil 1994; Yamaki and Fujiura 2002). They are also twice as likely to live alone (19.6 vs. 8.4 percent). Lower income is associated with poorer diet and less exercise. Consequently, people with disabilities need access to programs and policies that promote a higher standard of living, greater participation in society, improved health behaviors, and decreases in inaccessible environments and poverty.

AGING AND AGING WITH A DISABILITY

Age-Related Changes

A common misconception is that age changes indicate illness or disease. Universal changes occur for all people, but the rates of change are different depending on individual circumstances. The gradual wearing down of essential organs and systems is largely related to unmodifiable changes that lead to anatomic and physiological changes. The Baltimore Longitudinal Study (Shock et al. 1984) identified the following normal changes of aging that were not associated with disease:

- Loss of height (1 cm for every 20 years of aging) and weight (peaks in mid-50s for men and mid-60s for women and then declines)
- Reduced cerebral blood flow (20 percent), cardiac reserve (decrease from 4.6 to 3.3 times resting cardiac output), and lung vital capacity (17 percent)
- Decreased muscle mass (30 percent decrease) and bone density
- Diminished smell and taste receptors (smoking, dental problems, medications, or illnesses may contribute to the loss)
- Diminished pain and tactile perception
- Decreased vision (amount of light reaching the retina decreases by 70 percent) and hearing (environmental noise, genetic disease, ototoxic agents contribute to the loss)
- Increased susceptibility to disease

Age-related changes can be categorized as *usual aging* (e.g., combined effects related to the aging process, disease, adverse environmental and lifestyle factors) and *successful aging* (e.g., changes from the aging process uncomplicated by damage from environment, lifestyle, or disease). Individual variations across the lifespan and in every bodily system are tremendous. Moreover, lifelong use and abuse of the body through diet and physical and psychological trauma through accidents and injuries are thought to be related to wear-and-tear changes. Significant changes in structure, function, and biochemistry, along with genetics and lifestyle, are responsible for changes in tissue elasticity, subcutaneous fat, gastrointestinal function and motility, muscle, bone, immunity, and the senses.

Aging with a Disability

A majority of persons aging with a disability will experience a multitude of premature medical, functional, and psychosocial problems as they age. Chronic disability is not stable over the lifespan and an *aging gap* is becoming evident as many persons with disabilities present with functional changes that are customarily not seen in nondisabled persons until much later in life. Recent studies have documented higher rates of morbidity and mortality for adults aging with disabilities in comparison with the general population for a number of health conditions, such as dental disease, gastroesophageal reflux, esophagitis, and constipation. Several chronic conditions seem to be more prevalent among individuals with disabilities than in the general population, including non-atherosclerotic heart disease, hypertension, hypercholesteremia, obesity, heart disease, diabetes, respiratory illness, osteoporosis, and pressure sores. Also, obesity, mobility impairment, thyroid disease, psychotropic drug polypharmacy, and deaths due to pneumonia, gastrointestinal cancer, bowel obstruction, and intestinal perforation have a higher prevalence among groups of people with various disabilities.

Individuals with disabilities have a higher risk of developing chronic health compromises at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated developmental disabilities, access to adequate health care, and lifestyle and environmental issues. Although people aging with early-onset disabilities (including developmental disabilities, spinal cord injury, polio, diabetes, and rheumatoid arthritis) can now expect to live late in life along with their nondisabled peers, many experience major changes in health, function, and psychosocial status at much earlier ages. The new problems reported by people aging with a disability as early as in their 30s and 40s include the onset of age-related chronic health conditions, pain, loss of endurance, changes in employment, discouragement, and worry. These changes, suggestive of *premature aging,* have a major impact on family and friends.

Age-related health problems of women are often overlooked though they have higher rates of osteoporosis (for people with Down syndrome, epilepsy, and cerebral palsy), earlier onset of menopause for women with Down syndrome, and inadequate screening for breast, cervical cancer, and heart disease. People with Down syndrome have an earlier onset of Alzheimer's disease.

People aging with spinal cord injury (SCI) have a greater risk for pressure ulcers, decreased muscular strength, decline in immune system function/increase in incidence of infection, decreased flexibility of soft tissues (e.g., skin, ligaments, tendons, joint capsules), osteoarthritis, osteoporosis (related to immobility), diminished sensation, and spasticity. Individuals with SCI may also experience overuse and degenerative changes in the shoulder and lower extremities due to repetitive use of these joints and nerve entrapment due to repetitive use from wheeling their wheelchairs.

An estimated 25–50 percent of polio survivors are developing post-polio syndrome (PPS), which is a condition affecting polio survivors anywhere from 10 to 40 years after recovery from an initial paralytic attack of the poliomyelitis virus. PPS may affect more than 300,000 polio survivors in the United States according to the National Institute of Neurological Disorders and Stroke (NINDS). While the cause is unknown, new research is starting to clarify the mechanisms of this complex syndrome. With PPD, some of the initial problems that polio survivors had with polio are reappearing. Increasing numbers of polio survivors are reporting the onset of new symptoms including increased muscle weakness, fatigue, swallowing difficulties (dysphagia), breathing difficulty (breathing capacity declines twice as fast compared to their nondisabled peers), and muscle joint pain, after years of stable functioning. Polio survivors are also reporting functional difficulties related to climbing stairs, making transfers, and dressing.

Persons aging with cerebral palsy may experience earlier-onset arthritis related to excessive joint wear and tear, chronic pain, gastroesophageal reflux (heartburn), contractures, and bowel and bladder problems. Women with cerebral palsy are three times more likely to die from breast cancer than nondisabled women. Adults with cerebral palsy are more likely to die from brain cancer, trauma, and diseases of the circulatory and digestive systems than their nondisabled peers. Health care services for these adults are often inadequate in addressing the need for accessible examination tables, increased time for communication, and primary care providers knowledgeable about their health conditions.

Syndrome-specific effects (e.g., Down syndrome, Williams syndrome, autism spectrum disorders, PKU, Smith-Lemli-Opitz syndrome, Prader-Willi syndrome) link to special risk factors. For example, among adults with cerebral palsy later-life morbidity and functional declines seem to be related to the long-standing effect of movement patterns on the musculoskeletal system. Also, recent studies of older persons with autism spectrum disorders suggest that at least some threats to health maintenance and social isolation respond to health promotion approaches.

SUPPORTS TO MAINTAIN COMMUNITY PARTICIPATION

People with long-term disabilities or those who acquire a disability later in life can experience a severe sense of personal loss if they lack adequate family and community resources that allow them to maintain the degree of independence and community participation they desire. Age-related declines in health and functioning and psychosocial losses necessitate accessing an array of potential supportive services. As one ages and has more difficulties with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), it becomes more difficult to maintain a household or employment and there are greater needs for assistive technologies, environmental accommodations, therapeutic and nursing services, and respite and other housing and vocational supports. In addition to care provided by families, a range of public programs can provide these types of support. In comparison with other older adults, older adults with long-term disabilities are more likely to have received some type of housing supports, to have been unemployed or underemployed, and to have lived in poverty most of their lives with little retirement pensions. Some adults with disability, such as those with polio or Down syndrome, may experience earlier age-related physical decline and may experience loss of function, fatigue, and pain, which could result in leaving one's job or current residence, if adequate supports are not in place.

Families

Families have a pivotal role in meeting the increased needs for care by persons with disability as they age. In the United States, up to 80 percent of care, including physical, emotional, psychological, and financial, is provided by family caregivers. Over three-quarters of adults with intellectual and developmental disabilities live with families.

As function changes with age, families are called on even more frequently. With longer life expectancy, parents of persons with a long-term disability have a longer period of responsibility. There is also a greater likelihood of the disabled member outliving his or her parents. These parents are more likely to face dealing with their own aging in addition to the aging of their adult children. Another challenge is planning for future caregiving. Earlier aging of the family member with disabilities has implications for family caregiving. For spouses and parents, the changing roles can be stressful as one of the members develops a disability with aging resulting in increased needs for assistance from family members.

Caregiving can affect the nature of a relationship. For example, a spouse providing personal care can result in a change in the intimate relationship. Caregivers are the main providers of support, including instrumental support (e.g., personal care, transportation, and money) and socioemotional support. Caregivers are mostly women, who often give up, cut back, or lose job opportunities. The consequences can be stressful. The incidence of psychological disturbances among spouses of stroke survivors and of brain injury survivors is high. Cognitive changes (such as in Alzheimer's disease) are particularly difficult for families, who often lack adequate services and experience the loss of shared activities and their own independence.

Public Programs

Strong traditions of public support programs serving for both elderly and disabled persons exist in the United States. In colonial times, almshouses provided care jointly to persons who were elderly, poor, disabled, and mentally impaired. Over time, separate systems of care developed for each of these groups. More recent ongoing efforts seek to build bridges between the aging and disability networks.

The aging and disability programs differ in their philosophical approaches, systems of care, and histories of political lobbying. This divergence can serve as a barrier to merging the two programs. The elderly services focus on retirement and dealing with age-related losses, whereas the disability programs tend to focus on development of skills and rehabilitation. Rather than referring to older persons as *disabled*, they are often described as *frail* or *impaired*. *Caregivers* provide care to elderly persons, while *attendants* provide assistance to people with disabilities. Frequently, elderly persons do not want to associate with disabled and younger adults who do not share many common interests with them.

Aging Programs

Aging programs aim to assist and compensate elderly persons who experience age-related declines in function. Services tend to focus on financial support, disease management, assistance with adaptive functioning, and promoting social well-being. These programs are typically age based rather than need based.

In the United States, Social Security and supplemental security income (1972) provide financial support to elderly, disabled, and poor persons. These programs were also expanded to cover spouses, widows, children of deceased or disabled workers, and parents of children with disabilities. The Older Americans Acts (1965) offers service delivery and support including compensatory services, in-home assistance, and congregate services such as recreation and meals delivered through senior centers. Medicare and Medicaid (established in 1965) provide national health insurance for both elderly (over age 65 years) and disabled persons. It includes hospital, nursing home, and home health care, hence covering both acute and long-term services.

Disability Programs

Disability programs focus on education, job training, and residential services. The emphasis tends to be on rehabilitation and vocational training. In the United States, the Rehabilitation Act (1973) laid the foundation for the disability rights movement. Its Section 504 asserted that people with disabilities had equal rights that prevented discrimination based on their disability. The civil rights of persons with a disability were further protected with the landmark American with Disabilities Act (ADA) (1990). It established equal access for people with disabilities through accommodation in the workplace and in the community. It has helped decrease environmental barriers for both disabled and elderly persons experiencing age-related functional losses. In 1999, the U.S. Supreme Court issued a ruling in the case of *Olmstead v L.C.* that under Title II of the ADA unjustified institutionalization of persons with disabilities is discrimination. This ruling is likely to give momentum to the expansion of community-based care.

BUILDING A COALITION

As more people live longer and potentially develop disabilities and more persons with long-term disabilities live into older age, greater attention is being given to the overlapping needs and constituencies of elderly persons and those with disabilities. Commonalities exist in the needs for long-term care, housing, medical care, and home and attendant care services. Aging is now more likely to adopt the language of the disability rights movement in regard to consumer-directed home- and community-based services. In 1994, the two networks joined together to form the U.S. National Coalition on Aging and Disability in order to hold a series of state conferences in preparation for the White House Conference on Aging in 1995. More recently, policy makers and advocates have begun to see the benefits of some merging of services. Examples of commonalities in needs and services include the Medicaid/Medicare services, assistive technology and environmental accommodations, housing, and health care policies.

Medicaid/Medicare

In the United States as of 2001, more than 40 million people receive health insurance from Medicare and nearly as many receive Medicaid services for their acute and long-term care needs. Over 75 percent of Medicaid expenditures are for institutional care. The trend over the past couple decades has been to reduce institutional spending and to increase community spending. The program has expanded to include the Personal Care (PC) program and the Home and Community-Based Services (HCBS) waiver program in most states. The PC program includes home health care and assistance with personal care, ADLs, IADLs, and housekeeping chores. The HCBS program services include home modification; case management; and habilitation (pre-vocational, educational, and supported employment). Now both of these programs cover not only elderly people but also younger people with intellectual and developmental disabilities. Though this program has grown significantly since the 1990s, states can still limit the number enrolled.

Assistive Technology and Environmental Interventions

As individuals with long-term disabilities and other older adults face declines in health and function, there is a greater need for assistive technology (AT) and environmental interventions (EI) to help them maintain their independence and community participation. With earlier discharge from hospitals and greater emphasis on community living, there is a greater need for AT/EI approaches to help the older adult and the family caregiver.

New and highly personalized devices and technological advances can now aid aging individuals with disabilities in maintaining or increasing their independence, productivity, and quality of life. AT/EI innovations reduce their dependencies on others for assistance, lower their risk of secondary conditions, allow caregivers to provide assistance more easily, and forestall the need for nursing home care. Advances in microelectronics, computer science, communications, bioengineering, and health and rehabilitation sciences have led to the development of a host of physical and cognitive aids. These aids can help older adults function in work, home, recreational, and other community settings as they encounter age-related changes. Examples of the uses of such technologies include the following:

- Helping with planning, execution, attention, and memory (cognitive prosthetics and orthotics)
- Monitoring health and safety (tele-care, tele-health, alert systems)

- Assisting with ADLs and IADLs (robotics, personal digital assistants, adapted eating devices, handrails)
- Controlling the physical environmental in the home (environmental controls, ramps)
- Facilitating greater community participation (navigational systems, recreational aids, communication devices for social interaction)
- Improving mobility (wheelchairs)
- Providing communication and learning aids for educational and employment settings (augmentative communication devices)
- Using information technology (Internet, computers, adapted web browsers)
- Helping to improve vision (glasses) and hearing (hearing aids)

While many older individuals and their caregivers could benefit from such advances, often they are unaware or unable to access or pay for them. This is particularly true for individuals with intellectual disabilities who lag behind other disability groups in their use of technology. Older people and people with disabilities are less likely than other people to own or use computer technology. Barriers to use include lack of proper equipment, poor fit of mobility devices, lack of training in use of equipment, poor communication of needs, and reluctance to accept need for devices.

In the United States, the Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988, and 1994 amendments) provides financial assistance to the states to support programs of technology-related assistance for individuals with disabilities of all ages. These programs provide technical assistance, information, training, and public awareness activities relating to the provision of AT/EI devices and services. They also promote initiatives to increase the availability of funding for, access to, and provision of AT devices and AT/EI services.

Health Promotion and Health Care

Now that people are living longer with a disability whether the disability occurs early or later in life, health promotion and disease prevention increase in importance. Key components of health promotion include adequate health care, diet and nutrition, and physical activities.

Although persons with a disability have a significant need for routine primary care screenings as they age, in general, for them surveillance and early detection of chronic health conditions is poor. Screening activities such as breast, pelvic, and prostrate examinations; blood pressure and cholesterol checks; urinalysis; and bowel analysis can lead to enhanced functioning, prevention of secondary conditions, and an increased quality of life for persons with disabilities. To provide people with disabilities more resources to age well across the lifespan, better diagnostic tools are needed, along with greater understanding of the physiological changes that occur as people age with disabilities.

Adults with disabilities are often disadvantaged when attempting to access social and health services. Much of this is due to several factors: (1) inadequate services capable of addressing their aging-related needs; (2) a need for supportive services, health surveillance and provision, and family assistance; (3) special problems facing women who often find themselves a disadvantaged class; (4) and health practitioners who generally fail to recognize special problems experienced by persons with lifelong disabilities who are aging.

Physical barriers often constitute a problem for many persons with disabilities. Older women with cerebral palsy report difficulties obtaining dental and gynecologic care because of accessibility problems. Health care facilities often are not accessible to individuals with disabilities who may have physical and sensory impairments. In addition, persons with disabilities often experience difficulties with examinations and procedures. For many people, the most important barrier to effective medical care is case complexity. They encounter a variety of medical subspecialists, dentists, mental health providers, and other health care professionals, often without sufficient guidance.

Because of age-related changes, the presence of chronic diseases that are prevalent in the aging population, feeding problems, multiple concurrent medications, cognitive and functional declines, and syndrome-specific morbidity and comorbidities, older persons with disabilities are a nutritionally vulnerable group. Adults with disabilities also have low fitness levels, a high incidence of obesity, and tend to lead sedentary lives. Hence, they are also at a higher risk than the general population of developing secondary conditions and age-related declines at an earlier age.

With the scant attention given to health promotion strategies for people with disabilities, there is a need for prevention strategies that account for their specific impairments and potential risks for developing new conditions for adults living with long-term disability. Specific guidelines pertaining to the types of exercises, nutritional requirements, and use of medications for various types of conditions or syndromes may be necessary. For example, for people with cerebral palsy, exercise prescriptions need to consider the potential for overuse resulting in pain, injury, and fatigue. Adults with Down syndrome are more prone to osteoporosis and are more likely than other people to require calcium and vitamin D supplements as they age. Coordination between various health care providers, patients, and families is critical. Many primary care physicians have little training in disability or geriatrics and even fewer have training that crosses both of these areas. They may lack training in dealing with multiple conditions, interacting medicines, and unique aspects of various disabilities.

To improve the fitness capacity and psychosocial well-being of adults with intellectual or developmental disabilities, Heller and her colleagues (Heller, Hsieh, and Rimmer 2004; Rimmer et al. 2004) developed and demonstrated the effectiveness of an innovative fitness and health education program. Results of this program demonstrated improved physical fitness and psychosocial well-being for participants, including more positive attitudes toward exercise, higher life satisfaction, and less depression. The next challenge is to develop and test methods of delivering health promotion interventions within the individual's natural settings, such as where they live, work, or recreate. This would require developing methods of training staff and setting up on-site health promotion programs as well as using fitness and recreation centers in the community.

FUTURE NEEDS

According to the U.S. National Long-Term Care Survey, the proportion of older adults who report certain activity limitations has decreased. However, the absolute number of older Americans living with disabilities and chronic illness will likely grow particularly as the baby-boom generation enters old age and life expectancy continues to increase. The aging and disability service systems will need to build more capacity to provide services to a growing number of persons with lifelong disabilities who are aging and to other older individuals with disabilities who will increasingly need more services and supports to maintain their health and independence. Communities will need to adapt to this population by designing environments that accommodate elders of diverse abilities and functional limits. This includes developing more accessible transportation, recreational facilities, and businesses. In addition, there is a need for better and more training of health care professionals on age-related changes in disability.

Finally, family caregivers, who provide the greatest amount of care—physically, emotionally, psychologically, and financially—themselves need supportive services.

—Tamar Heller and Beth Marks

See also Aging, International; Alzheimer's Disease; Cerebral Palsy; Down Syndrome; Family; Frailty; Mobility Aids.

Further Readings

Cole, T. R. and B. Thompson. 2001–2002. "Anti-Aging: Are You For It or Against It?" *Generations* 25(4): 6–8.

Davidson, P. W., V. P. Prasher, and M. P. Janicki, eds. 2003. *Mental Health, Intellectual Disabilities and the Aging Process.* London: Blackwell.

Ebersole, P., P. Hess, and A. S. Luggen. 2004. *Toward Healthy Aging: Human Needs & Nursing Response,* 6th ed. St. Louis, MO: C. V. Mosby.

Hammel, J. and S. Nochajski, eds. 2001. *Aging and Developmental Disability: Current Research, Programming, and Practice Implications.* Binghamton, NY: Haworth.

Heller, T., ed. 2004 *American Journal on Mental Retardation* 109(5).

Heller, T., K. Hsieh, and J. Rimmer. 2004. "Attitudinal and Psychological Outcomes of a Fitness and Health Education Program on Adults with Down Syndrome." *American Journal on Mental Retardation* 109(2): 175–185.

Janicki, M. and E. Ansello, eds. 2000. *Community Supports for Aging Adults with Lifelong Disabilities.* Baltimore: Paul H. Brookes.

Janicki, M. P. and A. J. Dalton, eds. 1998. *Dementia and Aging Adults with Intellectual Disabilities: A Handbook.* Philadelphia: Francis and Taylor.

Kemp, B. J. and L. Mosqueda. 2004. *Aging with a Disability: What the Clinician Needs to Know.* Baltimore: Johns Hopkins University Press.

Kennedy, J., ed. 2003. *Journal of Disability Policy Studies,* Special Issue: Disability and Aging, 12(4).

McNeil, J. 1994. "Americans with Disabilities: 1994-95. U.S. Bureau of the Census. 2003. Survey of Income and Program Participation, Current Population Reports P70-61." Washington, DC. (www.census.gov/hhes/www/disable/sipp/disab9495/asc9495.html).

Olmstead v. L. C. (98-536) 527 U.S. 581 (1999).

Rimmer, J. H., T. Heller, E. Wang, and I. Valerio. 2004. "Improvements in Physical Fitness in Adults with Down Syndrome." *American Journal on Mental Retardation* 109(2): 165–174.

Seltzer, M., ed. 2004. *American Journal on Mental Retardation* 109(2).

Shock, N. W., R. C. Greulich, R. A. Andres, D. Arenberg, P. T. Costa Jr., E. W. Lakatta, and J. D. Tobin. 1984. *Normal Human Aging: The Baltimore Longitudinal Study of Aging*. NIH Publication No. 84-2450. Bethesda, MD: National Institutes of Health.

United Nations Department of Economic and Social Affairs (DESA), Population Division. 2002. "World Population Ageing, 1950–2050: Executive Summary." (www.un.org/esa/population/publications/worldageing19502050/index.htm).

U.S. Bureau of the Census. 2002. "Population Projections Program, Population Division." Washington, DC. (www.census.gov/population/www/ projections/popproj.html).

———. 2003. "American Community Survey (ACS) Data Profile." Washington, DC. (www.census.gov/acs/www/Products/Profiles/Single/2003/ACS/Tabular/010/01000US2.html).

Yamaki, K. and G. Fujiura. 2002. "Employment and Income Status of Adults with Developmental Disabilities Living in the Community." *Mental Retardation* 40:132–141.

Websites

Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD), http://www.uic.edu/orgs/rrtcamr/

Rehabilitation Research and Training Center (RRTC) on Aging With a Disability, http://www.usc.edu/dept/gero/RRTCon Aging/

AGING, INTERNATIONAL

The term *aging* is broad and implies various concepts and dimensions including chronological, biological, and mental aging, which are applicable to persons with and without disabilities. The aging process occurs in the context of historical age. Chronological age is the lived time from birth, and administrative age is the age cutoff used by administrators, statisticians, and epidemiologists. Biological aging refers to the physical state of the body in its relation with biological processes of growth, ripening, disease, and decay of organ functioning and body functioning. Social, psychological, cognitive, and social ability also affect aging, and aging may be strongly influenced by legal, ethical, religious, and historical considerations. For instance, under the notion of legal age (categorization based on political considerations), the age category of 55 to 65 years reflects the period when some societies legislate or allow individuals to stop work and become pensioners.

Under the notion of social age, aging may be characterized as a period of changing lifestyle, preretirement, or other social determinants of growing older. As members of the greater society, older adults are more underprivileged when they are long-term disabled. They are often unemployed or underemployed; underprivileged in income and social status; segregated in a special system of work or activity, housing or leisure; and often dependent on the help of others. Scientific data about the impact on social aging of those indicators of low social economic status, segregation, and dependency on health and on the use of health services are very scarce.

Mental or cognitive age refers to intellectual and maturational capabilities. It can be very important in the analysis and interpretation of behavior. When a 2-year-old child repeatedly throws a drinking cup on the floor it is usually interpreted as a sensory-motor game played by that child and his or her parents. The same behavior, exhibited by an older adult, is likely to be viewed as destructive, or even as psychopathological. Cohort effects require the researcher to consider the dimension of historical age in psychological, social, and epidemiological studies. One needs to analyse the impact of cohort effects in all aspects of human life of today's adults who are elderly. To explain today's behavior, adaptations, complaints, functioning, and health problems, one needs to take into account the different opportunity structures and socializing systems available to them when they were young. For example, as a group, young adults with disabilities of today will know much more about their heart, its function, irregularities, and heart failure when they are 60 years old compared to those adults who have already reached this age. In countries such as Germany and Austria, there are very few survivors with severe disabilities of the Nazi regime. Persons from the birth cohorts before the year 1945 are almost nonexistent in the disability statistics of those countries. In all countries, but especially in the developing countries, older adults are healthy survivors from limited opportunity structures in the past. This is the case for persons without lifelong disability, but is especially evident for persons with lifelong disabilities. For example, many of the children with Down syndrome born in the 1950s and 1960s with congenital heart disorder had a very limited life expectancy, whereas those from later birth cohorts were operated on successfully and have joined the ranks of today's adults.

COMMON TERMINOLOGY OF DISABILITY

Within and between countries the term *disability* has very different connotations. The World Health Organization (WHO 2001) has provided one common terminology by developing the International Classification of Impairments, Activities, and Participation (ICIDH-2). The WHO defines impairment as a "loss or abnormality of body structure or of a physiological or psychological function." This (physiological, psychological) impairment can lead to limitations in activities, which in turn can lead to restrictions in participation in society. An individual with an impairment may not experience any disability; alternatively, an individual may have a disability as a direct consequence of an impairment; or a disability may be a psychological response to an impairment.

The original ICIDH was based on a model where impairment, disability, and handicap were causally linked as consequences of diseases or disorders at the levels of the body, person, or society, respectively. The ICIDH-2 uses the human functioning approach. In this approach, there are no assumptions related to causality. The key components are body functions and structures, activities and participation, environmental factors, and personal factors. In this new classification, disability is a negative aspect of body functions and structures as well as activities, while impairment is defined as a negative aspect of body functions and structures only (but not of activities). The term *disability* is also used as a generic term for impairments, activity limitations, and participation restrictions.

NUMBER OF PERSONS WITH DISABILITY IN THE EUROPEAN UNION

In a report of the European Commission (EC) (2001) it is estimated that the number of people in the European Union with a disability varies from 8 to 14 percent. The group consists of disabled people with congenital and acquired impairments, with different degrees of disability, and with mental and physical, permanent and temporary disabilities. Among them are those who are able to work and those who are not; in most countries a significant proportion of people with disabilities report a combination of impairments.

Labor Market Participation and Age

Disability has a reverse effect on labor market participation and on unemployment. Differences in sociodemographic characteristics such as age and education account for the relatively weak labor market position of people with disabilities. The report of the EC (2001) shows that their probability of being in employment is lower for almost all age categories and for all educational levels than for nondisabled persons. These effects reinforce each other. The labor market position of older people with disabilities is worse than the sum of the effects of being old and being disabled. Compared to other people with disabilities, working disabled people are younger and more likely to be male and better educated (EC 2001). However, compared with nondisabled people in employment, the pattern is reversed: Working disabled are older and slightly more likely to be female and less well educated than nondisabled workers. Employment rates vary greatly between types of disability. People with mental illnesses, learning disabilities, or psychological impairments are less likely to be employed than are people with physical impairments

QU: Need a reference for WHO 2001--is it International Classification of Functioning, Disability, and Health ? I added that. If not the correct reference, please substitute the correct WHO 2001 reference in the Further Readings]

(EC 2001). The majority of adults and older adults with intellectual disability in the EU have found employment in sheltered work settings.

AGE AND DISABILITY

There is a strong relationship between age and disability. Disability is much more prevalent among older people: 63 percent of people with disabilities are older than 45 years (EC 2001). For nondisabled people, the corresponding percentage is only 34 percent. Hence, the disabled population is relatively old. This is particularly so in Germany, Greece, Italy, and Spain. This pattern is mainly due to individuals' health conditioning deteriorating with age. Furthermore, many impairments leading to disability are acquired during a person's life. There may, in addition, be a generation factor or cohort effect insofar as younger age groups experience better health, education, and working conditions in their early life and better health care and rehabilitation provision than their predecessors in older generations. Also, the rising life expectancy for people in general and especially for persons with lifelong disabilities affects strongly the number, distribution, and level of participation in society of older adults with disabilities.

LIFE EXPECTANCY AND NUMBER OF OLDER PERSONS

Life expectancy has risen sharply in the past 100 years and is expected to continue to rise, in virtually all populations throughout the world. The number of people reaching old age is therefore increasing. At the end of twentieth century, there were about 580 million people in the world who were aged 60 years or older. This figure is expected to rise to 1,000 million by 2020—a 75 percent increase compared with 50 percent for the population as a whole (WHO 1999). Health is vital to maintain well-being and quality of life in older age, and it is essential if older citizens are to continue making active contributions to society. The vast majority of older people enjoy sound health and lead active lives. Life expectancy has risen and is expected to go on rising in almost every part of the world. It is expected that from the 1,000 million older people in 2020, more than 700 million will live in the developing world. The reason for the increase of life expectancy is the sharp decline in premature mortality from many infections and chronic diseases. Improvements in sanitation, housing, nutrition, and medical innovations including vaccinations and the discovery of antibiotics have all contributed to the steep increase in the number of people reaching older age.

Health Status of Older People

As more people reach a "ripe old age," however, they also enter a period in their lives when they are at a higher risk of developing chronic diseases, which in turn may result in disability. In fact, chronic diseases, including cardiovascular diseases, diabetes, and cancer, are the main contributors to disease in older persons. However, there is mounting evidence from developed countries that people are maintaining better health in later life than ever before. It is estimated that in 1996, there were 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s (WHO 1999). The increase in life expectancy was most spectacular for persons with lifelong disabilities.

Effect of Incidence and Life Expectancy

The high proportion of older adults with lifelong disabilities in the population of countries is a function of incidence and life expectancy. Even when in Western countries the birth rates are declining in more recent years, the overall prevalence is increasing because of longer life expectancies of persons with disabilities born in the large birth cohorts after World War II. In developing countries, the prevalence rates as well as the number of elderly persons with disabilities have been increasing significantly during the past decades by the combined effect of high incidence rates of disability and of a longer life expectancy of affected persons.

DIVERSITY OF DISABILITY AT OLD AGE

"Older people" constitute a very diverse group. Many older people lead active and healthy lives, while some much younger adults are more passive and unhealthy. People age in unique ways, depending on a large variety of environmental and genetic factors.

Environmental Factors

Climate and geographic location can be a significant factor determining the incidence of disability, life expectancy and the process of aging.

Whereas iodine deficiency disorders are a major cause of disability, little is known about the life expectancy and the process of aging of persons with this condition in their community. As a consequence, iodine deficiency disorder can result in intellectual disability, deaf-mutism, spastic-diplegia, and squint. Between 600 and 1,000 million people are at risk of iodine deficiency in various regions of the world, mostly in developing countries. According to Dund and van der Haar (1990) about 710 million persons in Asia, 227 million in Africa, 60 million in Latin America, and 20–30 million in Europe are at risk of developing iodine deficiency disorder. At least 200–300 million of them have goiter or some other demonstrable consequence of iodine deficiency, and at least 6 million suffer from severe consequences of iodine deficiency. The most severe iodine deficiency occurs in inland mountainous areas, far from the sea, such as the Alps, the Andes, or the Himalayas. However, iodine deficiency is not confined to mountainous regions; it has also been associated with areas exposed to frequent flooding. In areas of iodine deficiency, 1 in 10 neonates has intellectual disability caused by the deficiency, and there are small pockets where the figure reaches 1 in 4.

Many young persons, especially those living in developing countries, have vision, hearing, speech, mobility, and/or intellectual functioning impairments. From the start of their life, these are not at all homogeneous groups of disabled persons. These individuals differ widely in genotype and phenotype, severity, and treatability of their impairment. Many of those persons have multiple disabilities, with various and different consequences.

Genetic Factors

For persons with intellectual disabilities, there are over 200 monogenetic causes. An increasing number of specific chromosomal and molecular-generic syndromes are associated with intellectual disability. For example, there are more than 60 chromosome-linked disorders. The interaction of genotype and phenotype is much more complex and shows much more variation between individuals than was expected.

Whereas the aging process is relatively well documented for persons with Down syndrome, there is scarce or nonexistent information about older adults with other causes of intellectual disability such as fragile-X syndrome and fetal alcohol syndrome (FAS). FAS is one of the most common causes of intellectual disability, ranking worldwide ahead of Down syndrome and spina bifida, and is characterized by intellectual disability, abnormalities in the central nervous system, growth retardation, and craniofacial and cardiac abnormalities. Abel and Sokol (1987), basing their estimate on 20 studies from Australia, Europe, and North America, which covered a total of more than 88,000 births, found a rate of 1.9 cases of FAS per 1,000 live births; rates were higher in the United States (2.2 per 1,000) than in Europe (1.8 per 1,000). This European rate will change with the extension of the EU.

AGING IN A LIFESPAN PERSPECTIVE

In his work, Plato (fourth century BC) emphasized the personal and lifespan experience of aging. His concepts have a strong educational and social basis. The feeling of "being old," as an aspect of psychological aging, is very much dependent on the person's view of young and old people. In Plato's view, to age "wisely" and peacefully, it is necessary to live a righteous life. For this reason, youths should be educated to live with a sense of duty in order to enjoy old age. The Platonist view of healthy aging is reflected in the modern conception of geroprophylaxis, **as proposed by Birren and Schroots**, which emphasizes educating people in healthy lifestyles, management of stress, the need for adequate exercise and nutrition, and the prevention of loss of autonomy as well as prevention of disease. This process must begin in young adulthood to be fully effective.

Life Course Development

Genetic components and early disabilities may contribute to how long persons live. However, health and activity in older age are largely an accumulation of the experiences, exposures, and actions of an individual during the whole span of life. The life course

QU: There is no Birren and Schroots reference--should this be Birren and Schaie? If not, please provide reference in Further Readings]

begins before birth. There is evidence that fetuses, undernourished in the womb, grow up to be adults more likely to suffer from a variety of diseases, including coronary heart disease and diabetes; they also seem to age faster than people who receive good nutrition during early life. Although aging begins in the womb, changes attributed to senescence usually begin in the postpubertal years. From age 20 years and older, cognitive functions such as fluid working memory and speed of processing show steady decline with each decade. However, crystallized knowledge does not. In fact, domain-specific knowledge among the intact elderly may exceed that for younger persons. There are differences in rate of decline between some physiological systems. For example, pulmonary function declines more rapidly than physical strength.

Aging is also associated with multiple changes wrought by illness. Some of these changes are gradual (e.g., the onset of osteoarthritis) and others are abrupt (e.g., diagnosis of life-threatening illness). Some have instant disabling consequences for the life of the individual; others will show symptoms in older years. Previous accidents and injuries make chronic and sometimes disabling diseases more likely in adult life. Lifestyle factors in adolescence and adulthood, such as smoking, excessive alcohol consumption, lack of exercise, and inadequate nutrition or obesity, greatly add to disease and disability at any age in adulthood.

Differences in education level, income, and social roles and expectations during all stages of a person's life increase the diversity of aging. Throughout the world, the average education of older people is below that of younger people, and this is especially the case for older adults with lifelong disabilities. Higher levels of education are important, because they are associated with better health and less social handicap. People with higher education levels at all ages tend to adopt and maintain healthier lifestyles and have better access to health care and health information.

Healthy Aging

Since the beginning of **the 1980s, Baltes and colleagues have conducted studies** on the psychological processes of development and aging from a lifespan perspective. Their work resulted in a psychological model, called "selective optimization with compensation." The central focus of this lifespan model is the management of the dynamics between gains and losses (i.e., a general process of adaptation), consisting of three interacting elements: selection, optimization, and compensation. It is expected that the lifelong process of selective optimization with compensation allows people to age successfully (i.e., to engage in life tasks that are important to them despite a reduction in energy). This model does not fit well for persons with lifelong disabilities, because the three major components for healthy aging, low probability of disease or disease-related decline, high cognitive and physical function capacity, and active engagement with life, are valid only for a well-functioning minority. Lifelong disability need not impede healthy or successful aging of persons with lifelong disabilities if there are no significant medical aspects of the disability and if the person has productive coping and compensatory mechanisms during adulthood and has maintained control over his or her life activities.

QU: Please provide a reference for Baltes and colleagues]

AGING, DISABILITY, AND PLANNING OF SERVICES

Person-Centered Planning

Aging is a lifelong process of learning in taking responsibilities and making choices that can be optimized in the concept of person-centered planning. In Western countries, adequate planning of services for the older generation of people with lifelong disabilities is increasingly based on person-centered planning. Person-centered planning values the customer's views and preferences when defining which services to offer, the manner in which they should be offered, and the personnel providing them. To fulfil such requirements, rigorous changes are needed in the planning of services for older persons with disabilities—changes of goals and values as well as changes in the structure of service delivery and the distribution of financial means. With regard to goals and values, today's living situation of older persons with lifelong disabilities can still be characterized in many countries as dependent, segregated, custodial, patient-like, and without dignity.

UN PRINCIPLES FOR OLDER PERSONS

The UN Principles for Older Persons (United Nations 1992) offer a useful opportunity to stimulate alternative and more human goals and values not only in the field of general aging but also in the field of aging with lifelong disabilities. The UN resolution lists in this respect five principles: independence, participation, care, self-fulfilment, and dignity. Two other basic principles are least restrictive environment and self-determination. The independence principle calls for living in environments that are safe and suited to personal preferences and changing capacities. The participation principle requires that older adults remain integrated in society, participating actively in the formulation and implementation of policies that directly affect their well-being.

Under the principle of care, the United Nations urges that older adults should have the benefits and protection of family and community care. The principle of self-fulfilment promotes the ability of older people to pursue opportunities to develop their personhood through access to educational, cultural, spiritual, and recreational resources. The principle of dignity states that older people should be able to live with dignity and security, free of exploitation and physical or mental abuse. The principle of least restrictive alternative stimulates the reduction of unnecessary restriction in the lives of older adults with and without disabilities. The principle of self-determination enhances the wish of growth and autonomy for older adults with disabilities.

Based on these principles, the following structural changes in policy are recommended:

- Build up a developmental-oriented care system with stimulating but safe environments in which all facets of aging from childhood through senescence are addressed.
- Enhance service capacity for older adults with disabilities because of longevity and the demographic bulges due to the high birth rates in the 1950s and 1960s.
- Define an agenda for planning for the needs of an aging population considering demographics, changing ideologies and practicalities, and the changing needs of older adults with disabilities as they age.
- Develop a professional support system that is sensitive and directed toward personal goals, wishes, and choices of older adults with disabilities, a support system that works with realistic yet safe self- determined plans.
- Plan policies and programs for housing and physical infrastructure, health and hygiene, income security, education and training, social welfare, and family support.

It is still an open question whether the model of person-centered planning for older adults with disabilities can be and should be expanded to non-Western countries and cultures. It needs extensive adaptations when applied to countries with low-income economies or to cultures where identity primarily is defined by being member of a family, clan, or community. For successful implementation of a model of person-centered planning, it will be essential that aging and disability be viewed within the context of the local community, its values, priorities, and social and financial resources.

—Meindert Haveman

See also Aging; Family, International; Frailty.

Further Readings

Abel, E. and R. Sokol. 1987. “Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies.” *Drug and Alcohol Dependence* 19:51–70.

Baltes, et al. 19

Birren, J. and K. Schaie, eds. 2001. *Handbook of the Psychology of Aging,* 5th ed. San Diego, CA: Academic Press.

Bosma, H., M. Van Boxtel, R. Ponds, M. Jelicic, P. Houx, J. Metsemakers, and J. Jolles. 2002. “Engaged Lifestyle and Cognitive Function in Middle- and Old-Aged, Non-demented Persons: A Reciprocal Association?” *Zeitschrift für Gerontologie und Geriatrie, Band* 35(6): 575–581.

Dunn, H., and F. van der Haar. 1990. *A Practical Guide to the Correction of Iodine Deficiency.* Adelaide: International Council for Control of Iodine Deficiency Disorders.

European Commission. 2001. *The Employment Situation of People with Disabilities in the European Union.* Brussels: European Communities, Directorate–General for Employment and Social Affairs, Unit EMPL/E.4.

Haveman, M. 2004. “Disease Epidemiology and Aging People with Intellectual Disabilities.” *Journal of Policy and Practice in Intellectual Disabilities* 1:16–23.

Herr, S. and G. Weber, eds. 1998. *Aging, Rights, and Quality of Life.* Baltimore: Paul H. Brookes.

United Nations. 1992. “Proclamations on Ageing.” New York: United Nations Department for Policy Coordination and Sustainable Development.

World Health Organization. 1998. *Primary Prevention of Mental, Neurological and Psychosocial Disorders.* Geneva: World Health Organization.

———. 1999. *Ageing: Exploding the Myths.* No. HSC/AHE/99.1. Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

World Health Organization, www.who.int

AGORAPHOBIA

Agoraphobia is a disabling complication of panic disorder. Although originally conceptualized as separate disorders, research suggests that panic disorder and agoraphobia actually represent a single illness. In fact, agoraphobia in the absence of panic is unusual. The term *agoraphobia* translates literally from Greek as “fear of the marketplace.” Although many patients with agoraphobia are uncomfortable in shops and markets, their true fear is to be separated from their source of security. Agoraphobic patients often fear having a panic attack in a public place and embarrassing themselves or having a panic attack and not being near their physician or medical clinic. They tend to avoid crowded places, such as shops, restaurants, theaters, and churches, because they feel trapped. Many have difficulty driving long distances (because they fear being away from help should a panic attack occur), crossing bridges, and driving through tunnels. Many agoraphobic patients insist on being accompanied to places they might otherwise avoid. At its most severe, agoraphobia leads many patients to become housebound. Common situations that provoke people with agoraphobia are public transport, crowding, and shopping malls. Panic disorder is prevalent among the general population between 1.5 and 3 percent. The prevalence of agoraphobia is slightly higher. Many patients, however, will report that panic attacks began after an illness, an accident, or the breakup of a relationship; developed postpartum; or occurred after taking mind-altering drugs such as lysergic acid diethylamide (LSD) or marijuana.

Panic disorder generally is treated with a combination of specific medication and individual psychotherapy. Cognitive-behavioral therapy (CBT), a form of individual psychotherapy, also appears to be effective in the treatment of panic disorder; its combination with medication may be even more powerful. CBT usually involves distraction and breathing exercises, along with education to help the patient make more appropriate attributions for distressing somatic symptoms. Patients with agoraphobia, with or without panic attacks, should receive behavior therapy. Exposure in vivo is the most effective intervention and in its most basic form may consist of gentle encouragement for patients to enter feared situations, such as shopping in a grocery store.

—Ahmed Okasha

See also Behavior Therapy; Panic Disorder.

Further Readings

Pollard, C. Alec and Elke Zuercher-White. 2003, June. *The Agoraphobia Workbook: A Comprehensive Program to End Your Fear of Symptom Attacks*. Oakland, CA: New Harbinger.

AIDS FOR ACTIVITIES OF DAILY LIVING

Aids for activities of daily living (AADLs) are products, devices, and equipment used within everyday functional activities. They are commonly included as a category of assistive technology. Other common terms for AADLs include adaptive equipment, ADL equipment, self-care equipment/aids, basic assistive technology, rehabilitation equipment or technology, and low technology.

The focus and purpose of these technologies are to adapt the environment, rather than the person, to support identified needs, choice, and control. These products may be used to compensate for impairments and functional limitations or to augment or assist in task performance, such as enabling quicker, safer, or more efficient performance of everyday activities. Products may address vision, hearing, fine and gross motor, sensory, proprioceptive, cognitive, communication, safety, and learning needs.

AADLs include a wide range of devices. Potential categories of equipment may span, but are not limited to, eating and meal preparation, grooming, bathing and showering, dressing, transferring, mobility, writing and basic communication, environmental control, home management, phone use, time management, organization and scheduling, money management, shopping, leisure/recreation/play, community living, and school and work activities. Common examples include tub benches, reachers, large-print or talking devices, and adapted utensils or utensil/tool holders that can be used across many activities.

AADLs are often distinguished from other assistive technologies as low, simple, or basic technology. However, this conceptualization can be misleading in that there is an increasing, rapidly changing pool of products and features from which to choose; many involve electronic components (e.g., phone systems); some involve custom fabrication or fitting to meet the specific person-task-environment demands (e.g., fabrication of a custom orthotic to hold a variety of everyday utensils); and in most cases, AADLs need to be considered as part of an accommodation package involving complex integration and environmental fit issues. For instance, AADLs are often combined with physical and social environment adaptations and strategies. An example is that commonly used ADL equipment in the bathroom includes tub benches/seats, long-handled reachers, raised toilet seats, and extended shower controls. These products are often used in combination with environmental modifications such as grab bars, roll-in or seated shower stall modifications, nonglare lighting, nonslip flooring, and offset temperature controls and sensors, which are then coupled with a set of individually customized strategies to manage and troubleshoot bathroom activities on a routine basis, such as strategies for transferring safely and efficiently.

Previously, AADLs were available only through medical or rehabilitation professionals, most commonly occupational and physical therapists, and required a physician's prescription to obtain and fund them through third-party reimbursement sources such as Medicare, Medicaid, or private insurance. Although rehabilitation remains a primary source for AADLs in the United States, particularly if third-party reimbursement is sought, the market for and availability of this equipment has broadened significantly. Given the functionality of these devices, many are now built into new homes and community environments and are widely available in department stores, consumer product catalogs, and Internet-based vendor sites. With the universal design movement, AADLs are being constantly redesigned and updated to increase their ease of use, efficiency, and ergonomics in response to the growing disability and aging consumer markets. As an example, the line of Good Grip products by OXO International, and other similar product lines on the market, represent a growing line of AADLs that not only support everyday activity but also look and feel good when using them, thus increasing their appeal and lowering their cost given the widespread market base. Thus, many types of AADLs are no longer considered "assistive," but rather are perceived as common tools and are available to the general public.

Research examining the effectiveness of assistive technologies, much of which would be categorized as AADLs, has shown the supportive role this equipment can play in maintaining, increasing, or delaying declines in everyday function for people with disabilities and older adults, particularly as they and significant others in their social world experience age-related issues. AADLs may also support the function and safety of family, personal attendants, and others who may work interdependently with people with disabilities during everyday activities. At the same time, however, research has shown that AADLs are often abandoned at rates from 20 to 50 percent. Reasons for abandonment include that the technology did not do what it was intended to do or did not match the person's needs, the consumer and important others' were not included in the decision-making process, the technology was not accepted due to aesthetics and issues surrounding being labeled as "disabled," a change in needs occurred that was not considered, and the technology was broken or needed to be updated.

These findings point to the critical need for consumer involvement in AADL decisions and to the complexity of factors influencing the fit between the person, the task, the AADL, the physical and social environment in which it will be used, and societal systems and policies involved in obtaining it. Despite the growing need, one of the primary barriers to obtaining needed or wanted AADLs is economic; that is, a large number of people with disabilities cannot afford AADLs and are not able to get reimbursed for them through existing funding systems. As an example, although tub benches have been found to support function and safety, they are typically not funded through third-party reimbursement systems as they are considered "optional," do not qualify as durable medical equipment (DME), and therefore do not meet eligibility criteria.

In response, a number of systems change initiatives have occurred to increase access to AADLs. In the United States, a national network of alternative financing programs offers a consumer-directed program and range of alternative financing strategies to increase access to funding for AADLs and other technologies. Several countries, such as Canada and Sweden, have implemented delivery systems that offer more extensive access to AADLs as part of integrated community living plans across the lifespan. In the United States, several states are using Home and Community-Based Waiver (HCBW) programs to provide needed AADLs as part of an integrated community support package, complying with the 1999 *Olmstead* decision that mandated the right to live in the least restrictive setting with reasonable accommodations.

—Joy Hammel

See also Assistive Technology; Home Modification.

Further Readings

Gitlin, L. 1995. "Why Older People Accept or Reject Assistive Technology." *Generations* (Spring): 41–46.

Gitlin, L. N., M. Corcoran, L. Winter, A. Boyce, and W. W. Hauck. 2001. "Randomized, Controlled Trial of a Home Environmental Intervention: Effect on Efficacy and Upset in Caregivers and on Daily Function of Persons with Dementia." *Gerontologist* 41(1): 4–14.

Hammel, J., J. Lai, and T. Heller. 2002. "The Impact of Assistive Technology and Environmental Interventions on Function and Living Situation Status for People Who Are Aging with Developmental Disabilities." *Disability and Rehabilitation* 24(1–3): 93–105.

Hoenig, H., D. Taylor, and F. Sloan. 2003. "Does Assistive Technology Substitute for Personal Assistance among the Disabled Elderly?" *American Journal of Public Health* 93(2): 330–337.

LaPlante, M. P., G. E. Hendershot, and A. J. Moss. 1997. "The Prevalence of Need for Assistive Technology Devices and Home Accessibility Features." *Technology & Disability* 6(1/2): 17–28.

Mann, W. C., K. J. Ottenbacher, L. Fraas, M. Tomita, and C. V. Granger. 1999. "Effectiveness of Assistive Technology and Environmental Interventions in Maintaining Independence and Reducing Home Care Costs for the Frail Elderly: A Randomized Controlled Trial." *Archives of Family Medicine* 8:210–217.

Olmstead v. L.C. (98–536) 527 U.S. 581 (1999).

Philips, B. and H. Zhao. 1993. "Predictors of Assistive Technology Abandonment." *Assistive Technology* 5:36–45.

Verbrugge, L. and P. Sevak. 2002. "Use, Type, and Efficacy of Assistance for Disability." *Journal of Gerontology Social Sciences* 57B(6): S366–S379.

Websites

Rehabilitation Engineering & Assistive Technology Society of North America, http://www.resna.org

AIDS/HIV

See HIV/AIDS

AIR CARRIER ACCESS

While there is much in common between different countries' approaches in disability antidiscrimination legislation to employment and goods and services, there is considerable variation in approach to air carrier access throughout the world.

In the United States, for example, access is dealt with primarily by means of the Air Carrier Access Act (ACAA; 1986). The act provided for the U.S. Department of Transportation (DOT) to develop new regulations that ensure that disabled people would be treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations (the Air Carrier Access rules) were published in March 1990. The legislation and rules prohibit discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities. People may enforce rights under the ACAA by filing a complaint with the DOT or by bringing a lawsuit in federal court (although recent decisions have cast doubt on the ability of individuals to bring a lawsuit under the ACAA—see *Love v. Delta Air Lines,* 310F 3d. 1347 11th Cir [2002], and the National Disability Council Position Paper on Amending the ACAA to Allow for Private Right of Action, July 8, 2004).

In January 2004, the DOT produced a report on the implementation of the ACAA, in which it detailed some of the ways it had dealt with a failure to comply with the act: "For example, the Enforcement Office has instituted an in-depth investigation of eight major air carriers for violations of the ACAA relating to boarding and wheelchair assistance based on formal and informal complaints. These investigations have resulted in separate consent orders under which a number of airlines were directed to cease and desist from further violations of the ACAA and Department regulations prohibiting discrimination against air travelers with a disability. These investigations also assessed civil penalties to $1.35 million" (*Implementing* 2004:1).

In Australia, the Australian Disability Discrimination Act (1992) makes it unlawful to discriminate in relation to access to premises, including public transportation. In addition—and perhaps as regards transport, more important—specific provision is made in the act for disability standards to be drawn up in relation to the provision of public transportation services and facilities. Failure to comply with these standards is made unlawful. Such standards have now been drawn up, although this has taken 10 years since passage of the ADA. The Disability Standards for Accessible Public Transport (2002) apply to public transport vehicles, conveyances, premises, and infrastructure and set out a timetable for adjustment by public transport operators over 30 years, with fixed milestones every 5 years. They list detailed accessibility requirements including access paths, ramps, boarding devices, allocated spaces, handrails, doorways, controls, signage, information provision, and much more. Given the late passage of the regulations, it is likely to be some time before significant improvements are seen in disability access to air carriers in Australia.

In Canada, provisions relating to accessible air transport are contained primarily in the Canada Transportation Act 1996, which covers, among other methods of transport, air travel. The act created the Canadian Transportation Agency (CTA), which has the power to remove "undue obstacles" from Canada's transportation network. The CTA also attempts to resolve passenger complaints regarding access to air travel. The Air Transportation Regulations make provision for services and information that air carriers are required to provide in relation to disabled people where they are Canadian air carriers operating services within Canada with aircraft of 30 or more passenger seats; while the Regulations on Personnel Training for the Assistance of Persons with Disabilities cover the training of staff—a vital aspect of ensuring accessible transport. There is also the Aircraft Code of Practice, which covers physical accessibility of equipment used in air transportation, although it applies in general only to fixed-wing aircraft with 30 or more passenger seats and only those areas of an aircraft that may be used by the general public.

According to the Council of Canadians with Disabilities, it is generally believed that the CTA has not been successful at tackling systemic issues through either its complaints mechanisms or its other work, although its response to individual complaints has in general been fairly good. Unlike the approach to air carrier access considered above, the European approach to air carrier access has been extremely limited. Very few European countries have antidiscrimination legislation dealing with goods and services at all, and those that do tend not to have addressed air travel. Disabled passengers have had to rely primarily on the International Air Transport Association Resolution 700 (Acceptance and Carriage of Incapacitated Persons) and the Airport Voluntary Commitment on Air Passenger Service—neither of which is based on any rights perspective or indeed has the force of law. However, on February 16, 2005, the European Commission tabled a proposal for a Regulation on the Rights of Passengers with Reduced Mobility When Travelling by Air, which will prohibit discrimination against disabled air passengers. This proposal, once it is adopted by the European Parliament and the Council of the European Union, will apply to all airlines all airports (public and private) and all passengers. The regulation will prohibit refusal of booking or refusal of carriage to disabled persons because of their disability; prohibit charging disabled passengers for assistance needed; ensure provision of assistance for disabled passengers and establish a centralized charging system (the managing body of an airport will provide assistance free of charge to disabled passengers; costs of the centralized system will be covered by airlines, which will pay an amount proportional to the number of passengers they carry [based on all passengers, not just disabled passengers]); and quality standards will be set by the managing body of the airport in conjunction with airport users' committees. The regulation proposal contains mechanisms for complaints, sanctions, and enforcement in the regulation.

In the United Kingdom, which has had disability discrimination legislation since the 1995 Disability Discrimination Act was passed, anything consisting of the use of a means of transport is specifically excluded from the goods and services provisions of the act, although the infrastructure—such as stations and airports—is still covered by the act (and this exemption will be removed by the Disability Discrimination Act 2005 and regulations made under it, although it will not be covering aircraft for the foreseeable future). Although there are regulations governing the accessibility of trains, buses, and coaches, no such provision exists for air travel. There has, however, been a significant legal case involving assistance at an airport for a passenger. In the case of *Ross v. Ryanair and Stansted Airport Ltd.* (EWCA Civ 1751 [2004]), Mr. Ross—a disabled person with a mobility impairment who was not a wheelchair user—brought a claim relating to a charge of £18 that he had to pay for the provision of a wheelchair to get him from the check-in point at Stansted Airport to the departure gate. Mr. Ross succeeded in his case, with the court holding that Ryanair was responsible for providing the assistance and that it should have done so at no charge. It was particularly interesting that the court held that—despite the low cost of Mr. Ross's flights—it was nevertheless reasonable for Ryanair to provide the assistance required at no charge. Ryanair appealed against the decision, on the basis, and the Court of Appeal upheld the appeal purely in relation to who was responsible for providing the free assistance, holding that because of the particular circumstances of the case both Ryanair and the airport were 100 percent liable for ensuring that Mr. Ross and others in his position had access to wheelchair assistance free of charge.

As can be seen from the brief overview above, access to air travel for disabled people, and specifically the legislation and guidance that govern it, is extremely piecemeal. As with antidiscrimination legislation on disability more generally, the United States appears to lead the way in terms of both the comprehensiveness of its legislation and the activity of its enforcement agency—although this is, of course, no guarantee that disabled people as a whole can actually access flights more easily. Such an approach is perhaps a reflection of the reliance in countries such as the United States and Canada, which cover such vast geographic areas, on internal flights to ensure any degree of travel within the country—something that in Europe remains less prominent. Australia, though, has been slow to catch up, with its regulations being promulgated only as recently as 2002. Nevertheless, European countries will have significant ground to make up to ensure that their disabled citizens have the same rights of access as those in the United States, Canada, and Australia.

—Catherine Casserley

See also Disability in Contemporary Australia; Disability Discrimination Act of 1995 (United Kingdom); Disability Law: Canada.

Further Readings

"Code of Practice: Rights of Access to Goods Facilities Services and Premises." 2002. Disability Rights Commission (www.drc-gb.org).

Implementing the Air Carrier Access Act (ACAA): A Status Report from the Department of Transportation. 2004, January. Washington, DC: Department of Transportation.

Kerzner, Lana and David Baker. 1999. *Law Reform: An Analysis*. Winnipeg, MB: Council of Canadians with Disabilities.

"Towards Best Practice in the Provision of Transport Services for People with Disabilities in Ireland." 2004, January. Ireland: National Disability Council.

▣ ALIENATION

Alienation is the act of withdrawing a person's affections from something else. One can alienate another person, a group of persons, an idea or social reality, or even aspects of their own body or behaviors. Alienation often results in an indifference or outright aversion by an individual or group of individuals toward some aspect of life that might otherwise be attractive and significant. Ignoring others or treating them in a way that causes the other person or group discomfort or excludes them from participating in social aspects of life is an example of alienation. Some ethnic minorities in the United States, women, and people with disabilities have a history of being excluded from full participation in social life by others in power, and are examples of how groups in power can alienate those not in power. People can be alienated, or indifferent, to the products they make or promote in their work. Another example of alienation is when an individual withdraws emotional connection from aspects of themselves, such as a part of their body that has an impairment or illness. Often they consider that the impaired body part no longer is a part of them and is indifferently or negatively perceived by the disabled individual.

Alienation is a process that develops in an ongoing relationship between an individual and another person or group of people, or in an individual as he or she negotiates the emotional terrain of dealing with an unwanted aspect of the person's physical or psychological state. It involves an unexpected deterioration in the quality of interactions and outcomes between individual players, and it continues until the alienated individual or aspect of the individual remains spatially or psychologically separate from others or to the whole person. Alienation is the experience of being disconnected with one's self, with others, with one's gods, nature, or a transcendent realm of being. While alienation is not considered to be a mental disorder, it is recognized as an element of a condition called antisocial personality disorder. Often alienation overlaps with other major psychological symptoms such as boredom, depression, and loss of locus of control.

HISTORICAL ORIGINS

In its early intellectual roots in ancient philosophy and medieval theology, the concept of alienation originally contained a fullness of positive, neutral, and negative connotations. The term was first used by Hegel, who stated that human life easily becomes estranged from the natural world unless validated by the divine. It was a force of development, a mode of conciousness used to signify stepping outside oneself; as Hegel put it, "Alienation is the fundamental feature of consciousness throughout its history" and was considered a necessary precondition for man to realize the true self.

Alienation can be applied to different social circumstances. Judeo-Christian texts find the concept of alienation from one's source of transcendant being in both Old and New Testamants: "My God, my God, why hast thou forsaken me?" In its original Marxist sense, alienation referred to the process of labor whereby workers became estranged from the products they produced. Marx understood alienation in terms of social and historical forces that resulted in spritual disillusionment and the physical separation of labor from its products. Marx noted in his famous "alienation of labor" treatise that conditions in a capitalist society make it impossible for workers to live meaningfully in relation to each other, to the products of their labor, or even to themselves. Simone de Beauvoir and other feminist thinkers point out that women in a patriarchal culture undergo additional forms of alienation when they are pervasively treated as the objects of male sexual desire and effectively coerced into submitting to male-biased political, social, and intellectual norms. Goffman (1968) noted that alienation can also occur when people with disabilities feel stigmatized by their surrounding society as a result of their impairment.

PSYCHOLOGICAL PROCESS OF ALIENATION

The psychological component of alienation is a process of self-estrangement and is considered a failure of self-realization. Alienation causes an altered relationship with the self that takes three forms:

1. The "despised" self, a negatively evaluated discrepancy between the person's preferred ideal and the perceived actual self
2. The "disguised" self, a false consciousness that is out of touch with one's feelings
3. The "detached" self, a disjunction between activity and affect (i.e., the individual's engagements in activities that are not rewarding in themselves)

Alienation involves feelings of meaninglessness, powerlessness, being manipulated, social and self-isolation—a major theme in all of these feelings is a person's feeling of lack of power to eliminate the gap between the definition of the role he or she is playing and the one the person feels he or she should be playing in a situation. The intensity of the individual's feelings of powerlessness to achieve the rightful life role he or she has claimed also contributes to the degree of alienation realized. Other feelings of helplessness, loss of community, lack of understanding, and the opposite of commitment can also be present in alienation. Common symptoms of alienation may include the following:

- Loss of a sense of humor
- The conviction that life is without meaning
- Need to withdraw from social and familial circles
- Emotional disconnectivity or numbness
- Belief that one doesn't belong to formerly intimate groups
- Inability to care for others

Alienation is usually thought of in terms of an individual's emotional distance from social groups. However, alienation can also be thought of in terms of an individual's emotional distance from himself or herself—a term called *self-alienation*. This facet is closely associated with an individual's sense of identity. When self-alienation occurs, individuals may be confused about their identity and the role they are "supposed" to play in the context of their life. This disconnectedness serves to depersonalize events, interactions with others, feelings, and interpretations.

ALIENATION AND DISABILITY

In terms of disability, alienation occurs when the state of disability or impairment causes the individual to develop a state of disconnectedness with his or her personal identity, relating to the adaptation to the impairment within the framework of reconciling relations between mind and body expectations and realities. For instance, an athletic person loses his leg in an accident. While the reality is that he is now an amputee, he refuses to go to recommended therapy, stops going to the gym to work out, and drops completely out of his social society. He feels angry that his leg "betrayed him," that it makes him "less of a man," and he eventually considers his impaired leg as something that does not belong to him but is unfortunately attached and therefore must be accommodated. In this example, the man has alienated himself from his community, and he has alienated the impaired part of his body from his personal identity.

While there is research of alienation and how it manifests in the disabled population, it has primarily focused on physical illness or impairment. There is little known about alienation as it relates to individuals with cognitive impairments or mental illness, or whether the concept of alienation operates within impairment categories of this kind.

Individuals may ignore or minimize illness or impairment when they choose not to acknowledge its effects on their lives or their lack of control over those effects; by doing so, they hope to preserve the sense of unity between body and self that they had before disablement. The disabling condition, or impairment, is separated from the primary essence of the individual as it is perceived by the individual to "cause" the events and feelings of disconnect. By placing the disability or impairment "outside" of the individual identity and removing it from their inner essence, it makes the disabling condition something external and foreign to the essential core being of the individual.

—Ann Cameron Williams

See also Depression; Isolation.

Further Readings

Bury, M. 1982. "Chronic Illness as a Biographical Disruption." *Sociology of Health & Illness* 4:167–182.

Goffman, E. 1968. *Stigma.* Harmondsworth, UK: Penguin.

Marx, K. and F. Engels. 1978. *The Marx-Engels Reader*. New York: Norton.

Oliver, M. 1993. "Societal Responses to Long-Term Disability." In *Ageing with Spinal Cord Injury,* edited by Gale G. Whiteneck et al. New York: Demos.

Seeman, M. 1983. "Alienation Motifs in Contemporary Theorizing: The Hidden Continuity of the Classic Themes." *Social Psychology Quarterly* 46:171–184.

ALTERNATIVE MEDICINE

See Complementary and Alternative Medicine

ALZHEIMER'S DISEASE

Alzheimer's disease is considered to be the commonest form of a group of illnesses that predominantly occur in later life and are referred to as "the dementias." These illnesses have in common a progressive loss of brain function leading to the development of impairments in a number of cognitive and functional abilities such as memory, the use and understanding of spoken language, and the ability to undertake complex tasks. As dementia progresses, these impairments become increasingly severe with the eventual loss of everyday living skills, resulting in an inability to care for oneself. Changes in personality and behavior are also apparent. The exact course and characteristics of the dementia in an individual varies depending on the cause for the dementia and also because of individual differences. The majority of the dementias are rare before the age of 60, but the prevalence rates increase steadily in older age groups. The general consensus is that the occurrence of Alzheimer's disease should not be considered inevitable with increasing age, but rather it is an illness that is age related and affects a proportion of people. Summarized below is a compilation of prevalence data published in the Alzheimer's Disease International (1999) "Factsheet 3." These figures are a conservative estimate with some studies suggesting that nearly 50 percent of people over the age of 85 have dementia.

Age group	*Prevalence rates (%)*
65–69	1.4
70–74	2.8
75–79	5.6
80–84	11.1

Alzheimer's disease was named after Alois Alzheimer, who in 1906 described the clinical features and postmortem findings of the brain from an elderly person who had suffered from particular mental experiences prior to her death. On postmortem, she had a significant loss of brain tissue and many microscopic *plaques* and *tangles* in her brain. Later research established that the plaques containing beta amyloid and the neurofibrillary tangles containing aggregations of a modified form of another protein called tau are together the characteristic brain changes of what is now called Alzheimer's disease. It was later established that there was a relationship between the severity of the symptoms of dementia prior to death and the extent to which these plaques and tangles were present in the brain at postmortem. While among Caucasians Alzheimer's disease is considered to be the cause of over half of the cases of dementia, this may not be so across all cultures. Globally, Alzheimer's disease is of increasing concern because the number of people over age 65 years, and therefore at risk of dementia, is increasing. For developed countries, mean life expectancy is now in the late 70s. It has been estimated in the United States that 4.5 million people have Alzheimer's disease at present and, if trends continue, it is estimated that 13.2 million will have Alzheimer's disease by 2050 (see Herbert et al. 2003).

PRESENTATION AND COURSE OF ALZHEIMER'S DISEASE

The clinical presentation and course of Alzheimer's disease reflect the progression of the underlying brain pathology. It has three stages. An early sign is memory loss for recent events. This goes beyond what would be considered normal for that person's age and is a result of the brain pathology starting in an area of the brain called the hippocampus. The person may be unable to remember how to get around, and disorientation becomes a serious problem. In the second stage, involvement of the surfaces (cortex) of the two lateral lobes (cerebral hemispheres) of the brain results in further problems, such as a deterioration in the understanding and use of language, an inability to recognize commonplace objects, and/or an inability to undertake complex tasks (such as brushing one's hair) even though the physical ability to move the necessary parts of the body remains intact. The person's personality may change during the course of the illness and he or she may engaged in inappropriate and difficult behavior or suffer from frightening experiences more characteristic of major mental illnesses, such as experiencing auditory or visual hallucinations or paranoid ideas. In the final, third stage complete care is necessary as the person is unable to feed or care for himself or herself and to undertake the basic necessities of life. The average length of illness from diagnosis to death is between eight and ten years but can be longer.

DIAGNOSIS OF ALZHEIMER'S DISEASE

The diagnosis of dementia, and specifically of Alzheimer's disease, depends on evidence of the progressive development of the above clinical characteristics as set out in established diagnostic guidance, such as the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) or the International Classification of Diseases (ICD-10). Other causes of dementia (e.g., multi-infarct dementia) and also conditions that might mimic dementia (e.g., profound depression, endocrine disorders) are excluded on the basis of the clinical picture and as a result of clinical investigations, such as brain scans and specific blood tests. This process of *differential diagnosis* is crucial as it identifies possible treatable disorders mimicking dementia and guides subsequent interventions. Specific psychological tests are available to enable the systematic assessment of those areas of cognitive ability that are known to decline with dementia, such as memory, orientation, and language. The best known of these is the Mini Mental State Examination developed by Folstein and colleagues. Such established assessments can screen for and monitor the disorder's progression.

CAUSE OF ALZHEIMER'S DISEASE

The cause of Alzheimer's disease remains unknown. Research has focused on investigating the brain changes and also on identifying those factors that might affect the risk of developing the illness or modify its course. One very striking feature is that it is predominantly an illness of later life, increasing age being the most significant risk factor. Both the plaques and the tangles in the brain have been the focus for intensive study. There are those who argue that a protein called amyloid is central to the pathological process. The large amyloid precursor protein (APP) is found across the cell membrane of the brain cells (neurons), with parts inside and outside of these cells. It is a smaller extracellular part of this protein (beta amyloid) that appears to be the basis for the development of the microscopic plaques characteristic of Alzheimer's disease that subsequently accumulate in the brain in the space outside of the neurons. In contrast, there are those who see the formation of the abnormal neurofibrillary tangles (consisting of modified tau protein) inside of the nerve cells as being the crucial pathological event. These two processes must in some way relate to each other leading to the accelerated atrophy of brain tissue and therefore the progressive course of the illness. The main, but not exclusive, brain neurotransmitter system affected is that of acetyl choline, and it is this observation that has been the focus for treatment developments.

In the rare cases of people developing Alzheimer's disease in middle age, genetic factors are important. In these families, subtle changes (mutations) in specific genes (amyloid precursor and presenilin genes) develop. People with Down syndrome also develop the brain changes and the clinical features of Alzheimer's disease relatively early in life. The gene that codes for the APP is located on chromosome 21, the chromosome that is inherited in triplicate rather than in duplicate in those with Down syndrome. Having the abnormal number of three copies of the APP gene and therefore too much of the protein amyloid is the possible process that leads ultimately to plaque and tangle formation in those with Down syndrome. Other genetic risk factors for Alzheimer's disease are not causative but either protect against or increase the risk of developing the disorder with increasing age. One example is the normal variation in the type of ApoE gene inherited by individuals. One variant (number 2) protects against and one (number 4) increases the risk. Lifestyle factors may also have some influence, such as level of past educational achievements and present activity, or the occurrence of previous serious head injuries.

TREATMENT OF ALZHEIMER'S DISEASE

An accurate diagnosis is the starting point for the development of an individualized package of care for the affected person, together with support for carers. The fact that at present there are no treatments that arrest or reverse the progressive brain atrophy can lead to a feeling of hopelessness. However, despite the absence of curative treatments much can be done to maintain the quality of life of the person concerned. Medications developed to date have a temporary modifying effect on the course. Their action is primarily to temporarily restore activity of the neurotransmitter acetyl choline, and by doing so temporarily improve cognitive and functional abilities. Other medication approaches have included the use of antioxidants such as vitamin E, anti-inflammatory medications, and hormone replacement therapy. None of these permanently arrest the course of the illness.

The main approaches to providing support for people with Alzheimer's disease remain maintaining good physical health; trying to ensure a consistent, predictable, and safe environment; and using strategies that help maximize memory and other cognitive functions. Nighttime can be a particular problem with erratic sleep patterns and the increased likelihood of confusion that darkness brings. Thus, changes to lighting and nighttime support are often crucial. Medications may be needed with the development of epilepsy or psychotic phenomena but should be used with care as they can add to a person's disorientation and state of confusion. Guidance from national Alzheimer's disease organizations is available.

—Anthony Holland

See also Aging; Dementia; Down Syndrome.

Further Readings

Alzheimer's Disease International. 1999. "Fact Sheet 3. The Prevalence of Dementia." (www.alz.co.uk).

American Psychiatric Association. 2000. *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed.—text revision. Washington, DC: American Psychiatric Association.

Folstein, M. F., S. E. Folstein, and P. R. McHugh. 1975. "Mini-Mental State, a Practical Method of Grading the Cognitive State of Patients for the Clinician." *Journal of Psychiatric Research* 12:189–198.

Herbert, L. E., P. A. Scherr, J. L. Bienias, D. A. Bennett, and D. A. Evans. 2003. "Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census." *Archives of Neurology* 60(8): 1119–1122.

AMERICAN DISABLED FOR ACCESSIBLE PUBLIC TRANSIT

See ADAPT

AMERICAN DISABLED FOR ATTENDANT PROGRAMS TODAY

See ADAPT

AMERICANS WITH DISABILITIES ACT OF 1990 (UNITED STATES)

The Americans with Disabilities Act of 1990 (ADA) is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States. Passed by the 101st Congress of the United States and signed into law by President George H. W. Bush on July 26, 1990, the statute prohibits disability discrimination by a wide range of private employers, businesses, and state and local government agencies.

ORIGINS AND ENACTMENT OF THE ADA

A shift in focus from asking for charity to demanding civil rights for people with disabilities in the United States in the late 1960s and 1970s prompted calls for federal statutory protection of the civil rights of individuals with disabilities. The Civil Rights Act of 1964, which prohibited discrimination on the basis of race, color, religion, or national origin, was a major inspiration for the concept of similar protection for people with disabilities. Bills to add disability or "handicap" to the grounds of discrimination prohibited by the

1964 act were periodically introduced in Congress, but most of them died in congressional committees. A partial success of such efforts occurred in 1973 with the enactment of Section 504 of the Rehabilitation Act; this provision, patterned on Title VI of the Civil Rights Act of 1964, prohibited discrimination on the basis of "handicap" in programs or activities that receive federal funding.

The first proposal in U.S. legal literature of a more comprehensive federal statute that would prohibit discrimination based on disability, other than by simply adding "handicap" to the Civil Rights Act of 1964, occurred in a 1984 article published in the American Bar Association's *Mental and Physical Disability Law Reporter* (Burgdorf and Bell 1984). The article presented a "statutory blueprint" for such a law, suggesting that it should provide a definition of discrimination on the basis of disability and should explicitly impose obligations to make reasonable accommodations; to remove architectural, transportation, and communication barriers; and to eliminate discriminatory qualification standards. It also advocated broad coverage of such a law, arguing that Congress should prohibit discrimination on the basis of disability in all contexts in which it had prohibited other types of discrimination and should broadly cover all entities whose activities affect interstate commerce.

These theoretical concepts took a major step toward realization when the National Council on the Handicapped, an independent federal agency comprised of 15 presidential appointees, published its 1986 report to the president and Congress, titled *Toward Independence.* Under the leadership of the Council's executive director, Lex Frieden, and informed by the input received in a nationwide series of consumer forums conducted by its vice chair, Justin Dart, the Council advanced 45 legislative recommendations in ten broad topic areas. The first recommendation in the report was that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap." Subsequent recommendations in the report described in detail what should be included in such a statute, and suggested that the law should be called "the Americans with Disabilities Act."

In its 1988 follow-up report, *On the Threshold of Independence* (Farbman 1988), the council took the somewhat unusual step—at the insistent urging of the report's editor, Andrea Farbman—of publishing its own draft ADA bill, written for the council by its attorney staff member Robert L. Burgdorf Jr. With a few changes, the council's draft bill was introduced in the Senate by Senator Lowell Weicker (R-Conn.) on April 28, 1988, and in the House of Representatives by Representative Tony Coelho (D-Cal.) on April 29, 1988. After joint congressional hearings on the bills had been held on September 27, 1988, the 100th Congress expired without either house of Congress taking action on the proposed legislation.

Before reintroducing the ADA legislation in the 101st Congress, congressional supporters revised the proposal in consultation with national disability consumer organizations, adding specificity and some policy compromises. The revised ADA bills were introduced in the new Congress on May 9, 1989, with Senator Tom Harkin (D-Iowa) as the sponsor in the Senate and Representative Coelho in the House of Representatives. On August 2, 1989, the Senate Committee on Labor and Human Resources approved a substitute bill reflecting certain compromises and clarifications arrived at through negotiations between the Bush administration and Senate sponsors of the bill. The Senate passed the bill, with a few floor amendments, by a vote of 76 to 8 on September 7, 1989.

In the House of Representatives, the House Committee on Education and Labor reported out the House's version of the Senate bill, with some additional clarifying language, on November 14, 1989. After approval by the three other House committees to which the legislation was assigned, the full House passed the ADA bill on May 22, 1990, by a vote of 403 to 20. Two separate conference committees were required to work out final differences between the Senate and House versions, after which the House approved the final version of the bill on July 12, 1990, and the Senate followed suit on July 13, 1990.

In his remarks before the more than 3,000 people, predominantly individuals with disabilities, who gathered on the South Lawn of the White House for the signing ceremony, President George H. W. Bush described the act as a "historic new civil rights Act . . . the world's first comprehensive declaration of equality for people with disabilities." The president added that "with today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom" (Bush 1990:1–2). He also noted that other countries, including Sweden, Japan, the Soviet Union, and each of the 12 member nations of the European Economic Community, had announced their desire to enact similar legislation (p. 2).

CONTENT OF THE ADA

The long title of the ADA describes it as "an Act to establish a clear and comprehensive prohibition of discrimination on the basis of disability." The act is divided into five titles: I—Employment; II—Public Services; III—Public Accommodations and Services Operated by Private Entities; IV—Telecommunications Relay Services; and V—Miscellaneous Provisions. The substantive titles are preceded by preliminary sections providing the short title of the act, a table of contents, congressional findings and purposes, and certain definitions.

Title I applies to employers having 15 or more employees, and to employment agencies, labor organizations, and joint labor-management committees. It establishes a "general rule" that "no covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual." This applies broadly to various aspects of applying for, getting, retaining, and benefiting from employment, including compensation, promotion, and "other terms, conditions, and privileges of employment." Title I goes on to specify several forms of discrimination that are contained in the general prohibition, including such things as segregation; using standards, criteria, or methods of administration that have a discriminatory effect or perpetuate discrimination; discriminating against a person because of that individual's relationship to another individual who has a disability; not making "reasonable accommodations" to known limitations of a qualified individual with a disability; and using discriminatory standards, tests, or other selection criteria.

Title II of the ADA, styled "Public Services," prohibits discrimination by any "public entity," a term defined to include states, local governments, or departments, agencies, or instrumentalities of states or local governments; and Amtrak and entities providing commuter transportation services. Title II subjects all the activities, programs, and services of such entities to a prohibition of discrimination on the basis of disability, requiring that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of public entities." Previously, such a nondiscrimination requirement had been applicable pursuant to Section 504 of the Rehabilitation Act only to those activities, programs, and services of such entities that received federal financial assistance. Pursuant to Title II, all state and local government facilities, services, and communications are made subject to accessibility requirements established under Section 504 and to other requirements consistent with other parts of the act, including, specifically, obligations to make "reasonable modifications to rules, policies, or practices"; to achieve "the removal of architectural, communication, or transportation barriers"; and to ensure "the provision of auxiliary aids and services."

Title II also includes detailed provisions applicable to public transportation systems, Amtrak, and commuter transit authorities. These provisions resolved some of the controversial, contentious issues that had arisen from the ambiguity and inconsistency in prior statutes regarding the extent of accessibility obligations for public transportation systems, and had led to considerable litigation. Among other things, these provisions of Title II impose requirements and set standards for accessibility of new or refurbished buses and trains, for bus and train stations, and for paratransit services for people with disabilities unable to use fixed-route bus services.

Title III addresses "public accommodations," defined very broadly to encompass most types of privately owned businesses, including places of lodging, establishments serving food or drink, places of exhibition or entertainment, places of public gathering, sales or rental establishments, service establishments, transportation terminals and stations, places of public display or collection, parks and other places of recreation, schools and other places of education, social service establishments, and places of exercise or recreation. Title III contains a sweeping "general rule" that prohibits discrimination "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." Subsequent provisions identify forms of discrimination encompassed in the general prohibition; these include such things as imposing discriminatory eligibility criteria, failing to make reasonable modifications, failing to provide "auxiliary aids and services" necessary for equal participation of an individual with a disability, not providing opportunities in "the most integrated setting appropriate to the needs of the individual," and denying a person equal treatment because of that individual's relationship with an individual with a disability.

Title III also imposes certain requirements regarding architectural and communication accessibility. One provision requires public accommodations to remove architectural barriers and communication barriers from existing facilities, where doing so is "readily achievable." The act defines "readily achievable" to mean "easily accomplishable and able to be carried out without much difficulty or expense." One of the most far-reaching provisions of Title III is the requirement that newly constructed facilities or altered portions of facilities of "commercial facilities" must be accessible, except where it is "structurally impracticable." The term "commercial facilities" is defined extremely broadly as facilities "intended for nonresidential use . . . whose operations will affect commerce." Title III also prohibits discrimination by private companies that provide transportation services, other than by air, to the general public. In general, public accommodations that offer transportation must provide service to individuals with disabilities equivalent to that available to others. New fixed-route vehicles seating more than 16 passengers must be accessible.

Title IV establishes requirements regarding two types of telecommunications services: telephone transmissions and television public service announcements. Companies offering telephone services to the public must provide telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices throughout the areas that they serve. Any television public service announcement that is produced or funded in whole or in part by any agency or instrumentality of the federal government is required to "include closed captioning of the verbal content of such announcement." "Closed captioning" refers to a system that allows only viewers with a decoder to view the captions.

Title V of the ADA contains various provisions relating to procedural and enforcement issues. Among other matters, it addresses the coverage of Congress and legislative branch agencies by the act; the application of the act to the insurance industry; the availability of attorney's fees under the act; states' liability for being sued under the act; the process for issuing accessibility standards; and liability for acts of retaliation, interference, coercion, or intimidation against a person for exercising rights under the act.

INTERPRETATION AND APPLICATION OF THE ADA

The various titles of the ADA direct that implementing regulations be issued by the federal agencies with enforcement responsibilities under the respective titles. The Equal Employment Opportunity Commission (EEOC) was directed to issue regulations for implementing Title I, the employment provisions of the ADA. As the head of the Department of Justice (DOJ), the attorney general was charged with issuing regulations both for carrying out Title II's requirements regarding state and local government entities and for implementing the requirements Title III places on public accommodations. The secretary of Transportation was made responsible for issuing regulations for the implementation of the ADA's transportation requirements both for state and local government entities under Title II and public accommodations under Title III. The Federal Communications Commission (FCC) was directed to issue and enforce regulations for carrying out Title IV's requirements regarding telephone relay services. These regulations and additional regulatory guidance issued by the federal agencies provide considerable guidance regarding the scope and substance of ADA provisions.

Despite the enforcement activities of the federal agencies and the guidance they have provided, many claims under the ADA have wound up in courts. The passage of the ADA provoked a great deal of litigation. In the lower courts, the results were disproportionately unfavorable (90 percent or higher in some studies) to those filing employment discrimination lawsuits, generally on the grounds that they had not adequately proven that they had a disability under the law.

Eventually, the cases began to make their way to the higher courts. By the end of its summer 2004 term, the Supreme Court of the United States had decided 19 cases interpreting and applying the ADA. It is difficult to draw many firm conclusions from these decisions, but they suggest some general patterns or trends. Examining the results according to which title of the ADA was at issue reveals that the Court decided cases under Title III (public accommodations) in favor of litigants with disabilities, ruled about evenly for and against litigants with disabilities in cases under Title II (activities of state and local governments), and came down against litigants with disabilities in a significant majority of the cases under Title I (employment).

The Supreme Court's decisions can also be classified according to types of legal issues raised. Thus, the decisions addressing the language of the ADA in terms of what things it covers—*Pennsylvania Department of Corrections v. Yeskey* (prisons); *Olmstead v. L.C.* (residential treatment facilities); *PGA Tour, Inc. v. Martin* (PGA Tour golf tournaments); *Clackamas Gastroenterology Associates, P. C. v. Wells* (medical clinic owned by physician director-shareholders); *Tennessee v. Lane* (state courthouse facilities)—have produced results generally favorable to litigants with disabilities. Decisions interpreting the substantive requirements of the ADA—*Olmstead v. L.C.* (prohibiting segregation); *U.S. Airways, Inc. v. Barnett* (reasonable accommodation)—have produced mixed results. The Court's rulings on the scope of defenses available under the act—*Bragdon v. Abbott* (direct threat to health or safety of others); *Albertson's, Inc. v. Kirkingburg* (application of a federal transportation safety regulation); *PGA Tour, Inc. v. Martin* (fundamental alteration); *Chevron U.S.A. Inc. v. Echazabal* (direct threat to the employee's health or safety); *Raytheon Co. v. Hernandez* (non-disability-based misconduct rules)—have also been mixed, although, in numerical terms at least, slightly more adverse than favorable to litigants with disabilities.

The decisions of the Court addressing procedural issues, such as attorney's fees—*Buckhannon Board and Care Home, Inc. v. West Virginia Department of Health and Human Resources.* (applicability of "catalyst theory")—and availability of punitive damages—*Barnes v. Gorman* (under Title II and Section 504)—that disability rights law shares with other civil rights constituencies, have mainly been restrictive of the interests of litigants with disabilities. Decisions addressing the scope of congressional authority to enact the ADA (and other civil rights laws)—*Board of Trustees of University of Alabama v. Garrett* (state liability for monetary damages under Title I); *Tennessee v. Lane* (right of access to state courts under ADA Title II upheld as exercise of congressional authority under Fourteenth Amendment)—have produced mixed results but have not resolved some fundamental questions. Finally, cases addressing who can invoke the ADA's protection have been mixed, but increasingly limiting as time has gone on; some have taken an inclusive view of the definition of disability—*Bragdon v. Abbott* (asymptomatic HIV infection)—and who is "qualified"—*Cleveland v. Policy Management Systems Corp.* (extent of inconsistency between application or receipt of disability benefits and pursuing ADA action)—but some very significant decisions—*Sutton v. United Airlines* (consideration of mitigating measures in determining disability of individuals with severe myopia); *Murphy v. United Parcel Service* (consideration of mitigating measures in determining disability of a person with high blood pressure); *Albertson's, Inc. v. Kirkingburg* (whether monocular vision is automatically a disability); *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams* (whether carpal tunnel syndrome and painful condition of wrists, elbow, and shoulders substantially limited major life activity of performing manual tasks)—have taken a highly restrictive view of what it takes to demonstrate a disability under the ADA.

One of the most influential of the Supreme Court's ADA rulings occurred in the case of *Olmstead v. L.C.,* in which a six-justice plurality agreed that the integration provision of Title II of the ADA requires states to place individuals with mental disabilities in community-based facilities in appropriate circumstances. To the central issue in the case of whether the prohibition of discrimination in the ADA may require placement of persons with mental disabilities in community settings rather than in institutions, the Supreme Court answered with "a qualified yes." The Court concluded that "unjustified isolation," for example, institutionalization when consulting physicians deem community treatment equally beneficial, "is properly regarded as discrimination based on disability." No single opinion in its entirety, however, garnered the votes of a majority.

The effect of this ruling was magnified when President George W. Bush made the ADA's integration requirement a cornerstone of his administration's "New Freedom Initiative." In February 2001, the president formally announced the "New Freedom Initiative" and committed the administration to ensuring the rights and inclusion of persons with disabilities in all aspects of American life. By Executive Order No. 13217, issued on June 18, 2001, the president declared the commitment of the United States to community-based alternatives for individuals with disabilities, and required the attorney general, the secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the commissioner of the Social Security Administration to work cooperatively with the states to ensure that the *Olmstead v. L.C.* decision is implemented in a timely manner, including providing services to individuals with disabilities in community-based settings, whenever appropriate to the needs of the individuals. The executive order directed federal agencies to work together to tear down the barriers to community living. As a result, various federal departments entered into joint efforts with states and others to provide elderly persons and people with disabilities the necessary supports to participate more fully in community life.

A significant issue only partially resolved by the U.S. Supreme Court's ADA decisions through the end of 2004 is that of constitutional limits on congressional authority in relation to the ADA. In *Board of Trustees of University of Alabama v. Garrett* in 2001, the Supreme Court ruled that suits by employees of a state to recover money damages from a state for violations of Title I of the ADA were barred by the Eleventh Amendment to the U.S. Constitution. This followed the Court's decision in 2000 in *Kimel v. Florida Bd. of Regents,* in which the Court had ruled that another federal law, the Age Discrimination in Employment Act, did not validly abrogate states' Eleventh Amendment immunity from suits by private individuals. In *Garrett,* the Court indicated that in evaluating congressional authority to enact ADA provisions as part of its power to enforce the Fourteenth Amendment, the Court would require that legislation reaching beyond the scope of the Fourteenth Amendment's guarantees must exhibit "congruence and proportionality" between the constitutional injury being addressed and the means adopted to address it. Applying such standards to Title I of the ADA as it applies to state employment, the Court found that the evidence Congress assembled of unconstitutional state discrimination in employment was inadequate and that Congress had not imposed a remedy that was congruent and proportional to the targeted constitutional violation.

The scope of the Court's ruling in *Garrett* was relatively narrow; the ruling did not prevent lawsuits against state employers for injunctive relief, did not preclude suits initiated by the federal government for monetary damages, and did not bar suits for money damages against private employers or local governments. And despite the *Garrett* decision, most state workers still retained rights to sue for money damages under Title II of the ADA and under Section 504 of the Rehabilitation Act of 1973. The Court also expressly made clear in its *Garrett* decision that the same analysis might not apply to cases brought under Title II of the ADA. But the Court's ruling in *Garrett* raised substantial fears that the analytical standards applied to Title I would subsequently be applied to bar private suits for monetary damages against states under Title II, and fueled concerns that the *Garrett* decision was but a stepping-stone toward a broader effort by the Court to restrict congressional authority and to expand the rights of states.

Such concerns were allayed to some degree when the Supreme Court issued its decision in the case of *Tennessee v. Lane* in 2004. In the *Lane* ruling, the Court upheld provisions of Title II of the ADA as applied to create a right of access to the courts for individuals with disabilities. The state of Tennessee had raised questions regarding the authority of Congress to place accessibility obligations on states and state entities under Title II and to authorize monetary damages when they fail to comply with these obligations. The Court rejected these challenges and held that Title II of the ADA, as applied to cases implicating the fundamental right of access to the courts, constituted a valid exercise of Congress's enforcement power under the Fourteenth Amendment. The Court found that "Congress enacted Title II against a backdrop of pervasive unequal treatment in the administration of state services and programs, including systematic deprivations of fundamental rights." The Court ruled that the congressional finding in the ADA of persisting discrimination against individuals with disabilities in critical areas, including access to public services, "together with the extensive record of disability discrimination that underlies it, makes clear beyond peradventure that inadequate provision of public services and access to public facilities was an appropriate subject for prophylactic legislation." While recognizing a solid constitutional foundation for the basic thrust of Title II of the ADA, particularly in its application to access to state courts, the *Lane* decision does not fully resolve all questions about the legitimacy of congressional authorization of private lawsuits against states in situations where access to the courts or other "fundamental rights" may not be at issue.

PROBLEMS AND CHALLENGES

The National Council on Disability, which originally proposed the enactment of the ADA, has monitored progress under the law on an ongoing basis. In June 2000, the council issued a report addressing federal compliance, enforcement, technical assistance, and public information activities for Titles I through IV of the ADA. The report, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act,* examined ADA enforcement activities of DOJ, the EEOC, the Department of Transportation (DOT), and the FCC. The National Council on Disability found that, although the executive branch had consistently asserted its strong support for the civil rights of people with disabilities, "the federal agencies charged with enforcement and policy development under the ADA, to varying degrees, had been overly cautious, reactive, and lacking any coherent and unifying national strategy." The report was critical of case-by-case enforcement efforts in lieu of ongoing compliance monitoring and cohesive, proactive enforcement strategies. It also criticized the federal agencies for not having taken leadership roles in clarifying frontier or emergent issues. Underlying causes of enforcement deficiencies were identified as including the "cultures" of particular agencies, their reluctance to expand their views of their missions and to take strong stands on issues, and, critically, chronic underfunding and understaffing of the responsible agencies. Such factors, according to the council, had undermined federal enforcement of the ADA in its first decade, allowing the destructive effects of discrimination to continue without sufficient challenge in some areas and contributing to problematic federal court ADA decisions unnecessarily narrowing the scope of the law's protections. The report included 104 specific recommendations for improvements to the ADA enforcement effort.

In addition to its oversight of federal agency ADA enforcement efforts, the National Council on Disability has monitored ADA cases in the courts. In 2002, the council inaugurated a major initiative to address serious problems created by court decisions interpreting and applying the ADA. Spurred by concerns expressed at a series of meetings with ADA stakeholders, the National Council on Disability had become increasingly troubled by decisions in which the U.S. Supreme Court took restrictive and antagonistic approaches to the ADA, resulting in significant diminishment of the civil rights of people with disabilities. Initially, the council developed a series of policy briefing papers explaining the problematic aspects of the decisions of the Supreme Court and describing their negative implications. Such papers were issued under the title *Policy Brief Series: Righting the ADA Papers,* and were published on the council's website.

On December 1, 2004, the National Council on Disability issued a final summary report, titled *Righting the ADA,* highlighting key material derived from the various specific topic papers and offering legislative proposals for addressing the problematic implications of the Supreme Court's ADA decisions. The report presented legislative proposals in a combined form to produce a draft "ADA Restoration Act of 2004." It explained that such drastic action was necessary to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act (ADA) was supposed to remedy forever": "Like a boat that has been blown off course or has tipped over on its side, the ADA needs to be 'righted' so that it can proceed toward the accomplishment of the lofty and laudable objectives that led Congress to enact it." The ADA Restoration Act was designed to (1) reinstate the scope of protection the act affords, (2) restore certain previously available remedies to successful ADA claimants, and (3) repudiate or curtail certain inappropriate and harmful defenses that have been grafted onto the carefully crafted standards of the ADA.

Despite its concerns about some judicial interpretations and executive agency enforcement of the ADA, the council expressed in both its *Promises to Keep* and *Righting the ADA* reports its belief that the law has had numerous positive effects and has "begun to transform the social fabric of [the] nation":

> It has brought the principle of disability civil rights into the mainstream of public policy. The law, coupled with the disability rights movement that produced a climate where such legislation could be enacted, has impacted fundamentally the way Americans perceive disability. The placement of disability discrimination on a par with race or gender discrimination exposed the common experiences of prejudice and segregation and provided clear rationale for the elimination of disability discrimination in this country. The ADA has become a symbol, internationally, of the promise of human and civil rights, and a blueprint for policy development in other countries. It has changed permanently the architectural and telecommunications landscape of the United States. It has created increased recognition and understanding of the manner in which the physical and social environment can pose discriminatory barriers to people with disabilities. It is a vehicle through which people with disabilities have made their political influence felt, and it continues to be a unifying focus for the disability rights movement. (National Council on Disability 2000:1; 2004b:37–38)

These rosy sentiments are tempered with the observation that "implementation has been far from universal and much still remains to be done."

—Robert L. Burgdorf Jr.

See also ADAPT; Antidiscrimination Law, Judicial Interpretations; Communication: Law and Policy; Family: Law and Policy; Health Care and Disability; Housing: Law and Policy; Rehabilitation Act of 1973 (United States).

Further Readings

Blanck, Peter, Eve Hill, Charles D. Siegal, and Michael Waterstone. 2004. *Disability Civil Rights Law and Policy.* St. Paul, MN: West.

Burgdorf, Robert L., Jr. 1980. *The Legal Rights of Handicapped Persons: Cases, Materials, and Text.* Baltimore: Paul H. Brookes.

———. 1990. "History." Pp. 9–31 in *A Bureau of National Affairs Special Report, The Americans with Disabilities Act: A Practical and Legal Guide to Impact, Enforcement, and Compliance* e Washington, DC: Bureau of National Affairs.

———. 1991a. "The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute." *Harvard Civil Rights–Civil Liberties Law Review* 26:413.

———. 1991b. "Equal Members of the Community": The Public Accommodations Provisions of the Americans with Disabilities Act." *Temple Law Review* 64:551.

———. 1995. *Disability Discrimination in Employment Law.* Washington, DC: Bureau of National Affairs.

———. 1997. "'Substantially Limited' Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability." *Villanova Law Review* 42:409.

Burgdorf, Robert L., Jr. and Christopher Bell. 1984. "Eliminating Discrimination against Physically and Mentally Handicapped Persons: A Statutory Blueprint." *Mental & Physical Disability Law Reporter* 64(8, January/February).

Bush, George H. W. 1990, July 26. "Remarks by the President during Ceremony for the Signing of the Americans with Disabilities Act of 1990." Washington, DC: Office of the White House Press Secretary.

Farbman, Andrea H., ed. 1988. *On the Threshold of Independence*. Washington, DC: National Council on the Handicapped.

Ianacone, Barbara P. 1977. "Note, Historical Overview: From Charity to Rights." *Temple Law Quarterly* 50:953.

Jones, Nancy Lee. 1991. “Overview and Essential Requirements of the Americans with Disabilities Act.” *Temple Law Review* 64:471.

Krieger, Linda Hamilton. 2000. “Foreword—Backlash against the ADA: Interdisciplinary Perspectives and Implications for Social Justice Strategies.” *Berkeley Journal of Employment and Labor Law* 21:9.

LaCheen, Cary. 2000. “Achy Breaky Pelvis, Lumber Lung, and Juggler’s Despair: The Portrayal of the Americans with Disabilities Act on Television and Radio.” *Berkeley Journal of Employment and Labor Law* 21:223.

National Council on Disability. 1997. *Equality of Opportunity: The Making of the Americans with Disabilities Act*. Washington, DC: National Council on Disability.

———. 2000. *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act*. Washington, DC: National Council on Disability.

———. 2002. *Supreme Court Decisions Interpreting the Americans with Disabilities Act* (http://www.ncd.gov/newsroom/publications/supremecourt_ada.html).

———. 2003 *Policy Brief Series: Righting the ADA Papers* (http://www.ncd.gov/newsroom/publications/2003/policybrief.html).

———. 2004a. *National Council on Disability: 20 Years of Independence*. Washington, DC: National Council on Disability.

———. 2004b. *Righting the ADA*. Washington, DC: National Council on Disability.

National Council on the Handicapped. 1986. *Toward Independence*. Washington, DC: National Council on the Handicapped.

Shapiro, Joseph P. 1993. *No Pity: People with Disabilities Forging a New Civil Rights Movement.* New York: Times Books.

Weicker, Lowell P., Jr. 1991. “Historical Background of the Americans with Disabilities Act.” *Temple Law Review* 64:387.

AMOR HEREOS (LOVESICKNESS)

The term *amor hereos,* meaning lovesickness, stems from a twelfth-century Latin medical text by Constantine the African, a translator of Arabic treatises: “Amor qui et eros dicitur morbus est”—” The love, which is called ‘eros,’ is a disease.” Lovesickness, as a concept, dates at least from ancient Greece and later Byzantium continuing in academic medical treatises until the early modern period. Texts on *amor hereos* are found in Greek, Arabic, Latin, French, English, Italian, and many other vulgar languages (languages of the common people). Its life in popular culture continues today.

Amor hereos is a curious cultural condition; it had no social class basis in its early medical descriptions, but by the end of the thirteenth century became an illness of the elite, a transition characterized by modern scholars as one from *amor eros* to *amor heroicus.* This transition occurred in concert with the rise of chivalry; Geoffrey Chaucer refers to it thus in the *Knight’s Tale.* Lovesickness was so important in this courtly context that later texts suggested ways of simulating its symptoms.

In its more classic evocation, the image of the loved one entered through the victim’s eyes, causing a humoral alteration, particularly the two hot humors, blood and black bile. The disabling symptoms of lovesickness were variable, sudden, and chronic (lasting six months or more). Insomnia, pain, anxiety, a jaundiced color, and wasting were some of its symptoms. In one early modern case, a shoemaker fell limp and lost speech for a week, assuming a form of paralysis. Severe melancholy and even death were other potential outcomes.

Some treated the condition with wine, conversations with close friends, walks in nature, music, and observing the faces of beautiful women. Others recommended playing games and doing delightful things, and also fattening and moistening foods, jokes, intercourse with a woman who was not the cause of the condition (often a prostitute), or a purgation of the humors.

Initially, men were the typical victims of lovesickness, though Galen treated at least one woman with the condition in the second century. During the Renaissance, as chivalric culture declined, lovesickness became increasingly a condition of women. With its shifting gender, lovesickness’s pathologic etiology changed from psychological to sexual, while therapy changed to regimenal and dietary interventions.

—Walton O. Schalick III

See also Galen; Hippocrates; Melancholy.

Further Readings

Wack, Mary F. 1990. *Lovesickness in the Middle Ages: The Viaticum and its Commentaries.* Philadelphia: University of Pennsylvania Press.

▣ AMPUTATION

To *amputate* is to cut off (e.g., a limb, arm) by a surgical operation (*American College Dictionary*). The term sometimes is used to refer to a traumatic event such as to have a leg or foot amputated by a land mine where salvage is impossible.

SOME CAUSES OF LIMB AMPUTATION

About 90 percent of lower-limb amputations in Western countries of the world are due to peripheral vascular disease (PVD), which is often connected with diabetes mellitus. Surgical attempts to salvage limbs (e.g., where there is PVD) may later have to go on to amputation. Not uncommonly, salvage failure causes patients and even some surgeons to feel that amputation signifies a failure. However, experienced clinicians look upon necessary amputation positively as a new opportunity for successful rehabilitation if the surgical amputation is handled expertly and if good pre- and postmanagement procedures are followed. Therefore, they believe that special attention should be placed on the techniques associated with amputation and that amputation should be thought of as a high art.

Elective amputation may be necessary following infections of various kinds. Infections frequently occur in the foot when that area has sensory deficits caused by diabetes or other medical conditions. Many amputations due to infections can be avoided if there is good patient compliance with foot management regimens (e.g., proper shoes, foot hygiene, skin care, proper nutrition, and periodic medical observation). Infections such as bacterial meningococcemia are particularly pernicious and may result in loss of multiple limbs or death even in healthy young persons.

Elective amputations can also result from tumors or from failure of limb salvage attempts during tumor removal. Under ordinary conditions, tumor-related amputations are not as common as amputations due to PVD or infection.

The general population probably thinks first of amputation caused by trauma. Leading trauma causes of amputation are farm machinery accidents, car accidents, industrial accidents, burns from high-voltage electrical accidents, frostbite, and military combat.

A small number of children are born with limb deficiencies. Years ago, before the fetus could be viewed in utero by ultrasonic methods, the birth of a child with a limb deficiency was often a shock to parents. This shock can now be ameliorated with counseling and preparations before the child's birth.

DEVELOPMENT OF AMPUTATION SURGERY AND ARTIFICIAL LIMBS

Amputation of body parts and their artificial replacements can be traced to antiquity. Ambroise Paré, a French Army surgeon of the sixteenth century, is often regarded as the father of amputation surgery, partly because of his development of the ligature, his selection of sites for amputations, and his interest in prostheses and outcomes. Development of the ligature and later the tourniquet, aseptic techniques, and anesthesia have been keys to successful amputation surgery. With these techniques, amputation procedures developed rapidly during and following World War I, particularly by German surgeons exemplified by Krukenberg and Sauerbruch. In a number of countries the end of World War II in 1945 ushered in the first organized research and development efforts in the field of amputation and prosthetics. Scientists, engineers, and prosthetists were brought together with surgeons to advance the field of amputation and prosthetics, as admonished by Sauerbruch around 1916.

This interdisciplinary approach has been productive and significant advances are being made, but adequate replacement of human limbs remains a daunting task. It seems clear that technology is not enough. Surgeons need to be important members of research teams in this field, not only to perform amputations but also sometimes to reorganize body tissues in ways that make it possible to design and build completely new kinds of limb replacements that may be superior to what has been known previously.

PEOPLE WITH AMPUTATIONS

People who have had amputations, like many other persons with disabilities, are not sick. Whether famous or infamous, many people who have had amputations have been achievers throughout history. The Netherlands'

Peter Stuyvesant wore a wooden leg and was governor of New York. England's Admiral Horatio Nelson was a right-arm amputee. Blind in his right eye, Nelson ended his naval career—and life—with a spinal cord injury from a sniper's shot in 1805. Look carefully at Nelson's statue on the tall column in Trafalgar Square in London and you will be able to see that his right sleeve is empty. Confederate General Thomas J. "Stonewall" Jackson was accidentally shot in the left arm by his own troops as evening fell at Chancellorsville. When he died from blood poisoning a few days after amputation of his arm, General Robert E. Lee, leader of the Confederate forces in the American Civil War said, "Jackson has lost his left arm, and I have lost my right arm."

French actress Sarah Bernhardt, "the Divine Sarah," had a leg amputation. John Wesley Powell was an intrepid explorer of the Colorado River without a right arm. Bernhard Schmidt was not inhibited by amputation of his arm when he was 15 years old. Known in Germany as "the optician," his famous telescope design and his ability to make mirrors and lenses to high accuracy is legendary. "Peg Leg" Bates was a dancer in New York City, even though he had lost part of his left leg in an auger accident. He became a star tap dancer using an artificial leg. Harold Russell, who lost both hands in a military training accident, received two Academy Awards—one for Best Supporting Actor and a second, honorary, award for "bringing hope and courage to his fellow veterans"—for his acting role in the 1946 movie *The Best Years of Our Lives*. That event led him to become an important American advocate for persons with a disability.

Two unlikely amputations occurred in 2003. A young woman, Bethany Hamilton, lost her left arm in a shark attack while surfing. A hiker/climber, Aron Ralston, 27, had to amputate his own arm below the elbow using his pocketknife to escape death when he became caught by a boulder in a remote area of Utah.

The previous paragraphs illustrate how the lives of some widely known people have been altered by amputation of limbs. Their stories are compelling but really no more compelling than the stories of many others with amputations who are just less well known.

—Dudley Childress

See also Accidents; Biomechanics; Burns; Diabetes; Phantom Limb Pain; Harold Russell; Surgery; Veterans.

Further Readings

Childress, Dudley S. 2002. "Development of Rehabilitation Engineering over the Years: As I See It." *Journal of Rehabilitation Research and Development* 39(6, November/December, Suppl.): 1-10. (http://www.vard.org/jour/02/39/6/sup/childress.html).

Kuiken, T. A., G. A. Dumanian, R. D. Lipschutz, L. A. Miller, and K. A. Stubblefield. "Targeted Muscle Reinnervation for Improved Myoelectric Prosthesis Control." Rehabilitation Institute of Chicago Neural Engineering Center for Artificial Limbs, Chicago, and Northwestern University Feinberg School of Medicine. Accepted, IEEE International EMBS Conference on Neural Engineering, Washington, DC, March 16-19. (example of reorganization of body tissues)

Literary Digest, August 26, 1916. [Sauerbruch's admonishment].

Smith, Douglas G., John W. Michael, and John H. Bowker, eds. 2004. *Atlas of Amputations and Limb Deficiencies: Surgical, Prosthetic, and Rehabilitation Principles*, 3d ed. Rosemont, IL: American Academy of Orthopaedic Surgeons.

▣ AMPUTEES AT PERSEPOLIS

As Alexander the Great advanced to take Persepolis in southwestern Persia in January 330 BCE, he met a large, desperate group of released Greek prisoners whose hands, feet, ears, or noses had been cut off by their captors. In one account, there were 800 men who had been trained in various skills or crafts, "then their other extremities had been amputated and they were left only those which were vital to their profession." In another version, nearly 4,000 men had had parts amputated and then were "branded with letters from the Persian alphabet" to amuse their captors: "They looked more like outlandish phantoms than men."

The group begged Alexander to save them from their tormentors. Shaken by the spectacle, Alexander promised help. The men withdrew to discuss what to ask. The key issue was whether to return to Greece and disperse to their villages, facing an uncertain reception because of their appearance, or to remain as a mutually supportive group in the Persian lands conquered by Alexander. The debate is framed in the mouths of two orators. One states that public and private reactions back home will be adverse, and they know this because they themselves would find each other's appearance intolerable if they were not all in the same boat. They should stay in Persia, keeping their misfortune hidden from those who had known

[QU: Source for the two quotes: "then their other extremities . . ." and "They looked more like outlandish phantoms than men."]

them earlier. The second speaker suggests that decent people do not think like this, and the group should certainly return to breathe the sweet air of their homeland and enjoy their freedom, their own gods and culture.

A few of the men wanted to return to Greece, but the great majority voted to ask for land and benefits in Persia. When their delegates met Alexander again, he had already decided that they would opt to go home, and he had made arrangements for transport and cash in hand. When the men explained what they really wanted, Alexander changed his plan, granting them land, livestock, clothing, food, and money.

The incident has undergone much skeptical review by classical scholars, as many curious myths and legends are attached to Alexander's life. The earliest extant manuscript record of the story dates from about 1,200 years later. It may have been rooted in contemporary records, but it could have been fabricated centuries later. However, no evidence actually disproves the story. The mutilations, the anticipated public reactions, and other details are consistent with other data from Persia in that period. It appears as the world's earliest record of a recognisable debate among a large group of people with significant disabilities, and also the first record of such a group advocating their case with a ruler and causing him to change his plan for their welfare.

—Kumur B. Selim

See also History of Disability: Ancient West.

Further Readings

Diodorus of Sicily, chapter XVIII: 69.2 to 69.9; translated by C. B. Welles, 1983, London: Heinemann. VIII: 315, 317.

Miles, M. 2003. "Segregated We Stand? The Mutilated Greeks' Debate at Persepolis, 330 BC." *Disability & Society* 18(7): 865–879.

Rufus, Quintus Curtius. 1984. Pp. 103 in *The History of Alexander*, Vol. V: 5.5 to 5.24; translated by J Yardley. London: Penguin.

ANTHROPOLOGY

Cultural anthropology is an especially well-suited disciplinary perspective to use in considerations of impairment and disability. This is partly evident in the number of nonanthropologists who have applied anthropology's methods and core concept of culture in their research. The central concern of cultural anthropology has always been the understanding of difference: how various forms of difference are defined, constructed, and managed in different times and places. This preoccupation with difference and the discrimination that is often attached to devalued differences reveal why anthropology can be of vital importance to the study of disability.

Particular dimensions of this work have produced questions that are especially salient for impairment. Some examples illustrate the connections: In what ways are the negative cultural constructions of subgroups based on their differences contributing to and rationalizing their marginalization and oppression? Parallel issues faced by many indigenous peoples are elaborated in ethnographic research. How do questions of power, resistance, voice, representation, and self-determination get worked out for cultural subgroups? We look at how both these processes also hold the potential for positive group identity and emancipation. Anthropologists interrogate medicalized, individualizing responses to what are fundamentally sociopolitical or economic justice problems in a way that echoes concerns in disability studies. Beyond its conceptual concerns, anthropological research methods and critical reflection on them offer potentially fruitful avenues for research in this field. This is especially true for new areas that require an exploratory approach because not enough is known to undertake standard survey research.

Although for various reasons anthropologists have been slow to engage more deeply in disability studies, original and controversial research in the past decade suggests that the tide is turning. Anthropology offers salient insights and practical tools for sharpening core disability studies debates, partly because it has already been over isomorphic terrain in relation to issues faced by indigenous people and minority groups around power, voice, intra-movement fragmentation, insider-outsider (emic/etic) debates, and how to stake claims for recognition and accommodation with a dominant group that uses different measures of value. Anthropological experience with cross-cultural comparison and its conundrums will also be instructive.

Anthropology would grow from greater attention to advances in critical disability studies where the aforementioned issues combine with sensitive cultural norms and ethical/medical taboos to reveal the limits of some theories' usefulness. For excellent examinations of how anthropology and disability are linked, see especially Kasnitz and Shuttleworth (1999), Linton (1998), and Stiker (1992).

DEFINITION OF TERMS

This entry uses the Union of the Physically Impaired against Segregation (UPIAS) definition of *impairment* as a physical or cognitive lack or abnormality a person has and *disability* as a restriction or disadvantage accruing to the person due to physical and social environments not being designed to support that impairment. The term *developmental disability* will be used to encompass intellectual disability (mental retardation) as well as autistic spectrum disorder, cerebral palsy, and other conditions that can result in substantial restriction of cognitive function or the expression thereof.

Anthropology and *culture* have no single, agreed-on definitions. This reflects both their breadth of subjects and theories and the discipline's tradition of self-critique. Minimally, anthropology is the study of human cultures that comprise human beliefs and behaviors. Culture, then, is what we think and feel, how we make sense of the world, and what that can lead us to do (action) and produce (artifacts). Anthropologists do not *create* meaning, but rather use their analytical writing (ethnography) to evoke and render intelligible (to others) a way of life that is already meaningful to those living it, as Clifford Geertz put it. While the audience used to be those "outside" the culture under study, increasingly, ethnographies are written with inside audiences in mind, through new articulations and analyses of their experiences.

For instance, Pamela Cushing's (2002) ethnographic research of L'Arche, a residential support organization for people with developmental disabilities, sought to elucidate how that subculture worked against stigma to promote mutuality in caregiving relations. Her research aimed to inform and influence state policy makers and other providers who are currently struggling with how to improve relations and social inclusion in the mainstream. Esther Ignani's research (2005) with youths with disabilities seeks to work against misinformed but common notions of what life with impairment is like, as they co-create autobiographical films. This is part of what Cushing calls reshaping the public's moral imagination regarding disability, and what anthropologists Rayna Rapp and Faye Ginsburg (2001) call rewriting disability narratives.

Although anthropologists study all aspects of culture, current research focuses more on everyday life than grand, ritual events. Second, its methodological core is the grounded, long-term research of participant observation, which includes extended periods of sharing and participating in everyday life with those you are studying as well as in-depth qualitative methods such as individual and group interviews, or narrative analysis. Combined, these make anthropology well suited to identify gaps between stated beliefs and actual lived behavior. Rather than judge such gaps from their own worldview, anthropologists use the gaps as a starting point to begin asking critical questions about the culture: What purposes or whose interests might such a gap serve? What tensions or uses of power does it reveal? This perspective could help to explore the gap between the positive hopes of disability rights and the daily forms of exclusion faced by many individuals and families living with developmental disability.

Culture is often defined through its traits. Culture is not inherited but learned both consciously and inadvertently, and shared among a group. Although shared differential access to cultural knowledge is inevitable, subgroups develop specialized cultural norms and knowledge, or, alternatively, status differences can restrict one's access. For example, within disability culture, subgroups such as wheelchair users or Deaf people have their own nuances, jokes, and language based on shared experience. An understanding of culture as dynamic (changing), heterogeneous (having different, even disparate elements), and syncretic (many influences) has replaced the previous view of culture as static (unchanging), homogeneous, and bounded (closed). Since many disability scholars use culture as a core concept, the definition is important: The term is often diluted or misused outside the discipline. The idea of a "disability culture," for example, has been widely debated with little reference to anthropological theory, as discussed below.

Another important development in cultural theory is the recognition of how power is at work in cultures and a need for greater critical examination of those processes. Feminist and postmodern scholars have shown that since cultures have multiple subject positions within them, cultural knowledge is always partial, positioned, and embedded in such power relationships. This does not mean that all perspectives are invalid or solipsistic, but rather that multiple views need to be gathered and consulted to establish an empirical sense of the whole. In terms of disability studies, such theories indicate that better evocation of the worldviews of people with anomalous bodies and minds will contribute to widening the scope of human understanding.

Finally, anthropologists have also identified common pitfalls in how the concept of culture is applied that are relevant to disability. Wikan (1992) argued that the very notion of "a culture" lures people to overemphasize differences, especially exotic ones, that tend to separate us as humans, over the commonalities that could bring us together. Roeher (1996) and Trent (1994) have shown how detrimental a fixation on (devalued) difference has been for people with impairments whose identity becomes conflated with the impairment.

Others argue that the culture concept tends toward generalizations that gloss or flatten intragroup differences. For instance, the idea of promoting a coherent front for the disability movement or culture is a form of strategic essentialism and can be effective for rhetorical and activist purposes. The pan-impairment solutions that get proposed, however, do not necessarily meet the particular needs of all members. This has arguably been the case for people with developmental disabilities within the broader disability movement. They remain burdened with significant stigmas; ongoing resistance to their inclusion in schools and workplaces and rising rates of selective abortion of fetuses with impairments are two cultural indicators of this attitude.

HISTORICAL CONTRIBUTIONS

Anthropologists studying impairment such as Stiker ([1982] 1999), Kasnitz and Shuttleworth (1999), and Rapp and Ginsburg (2001) have variously lamented that no adequate anthropology of disability had yet emerged. Just 15 years ago, Oliver (1990) noted that most anthropologists still considered disability (unlike gender or race) to be an unproblematic category, and like many writers, consigned nontypical or so-called deviant people to footnotes. Anthropologists' lack of engagement can be traced to manifold factors. Goffman's (1963) "courtesy stigma" (avoidance of deviance) could play some role in our field site choices, and perhaps disability was not as visible a "social issue" the mainly preindustrialized peoples we have classically worked with. It is not true however, that impairment was absent in past ethnography because disabled people did not survive in tribal societies (Linton 1998).

Two theoretical explanations for our absence are also plausible. For many years, the ethnographic optic was predominantly *across* cultural groups; an interest in *intra*cultural heterogeneity or theorizing exceptionality (such as impairment) is only of recent interest. Marxist and feminist approaches have since added much-needed correction to this interpretive bias. Furthermore, prior to the 1970s, ethnographies aimed for a "snapshot" of a coherent, homogeneous tribe or cultural group, which did not leave much room for inclusion of anomalous characters or unusual scenarios. Corrective research has emerged such as those that explicitly consider exceptional circumstances of families with a child with an impairment.

Interestingly, Oliver noted that the analyses of certain anthropologists who did venture into disability contained prescient insight akin to the future social model. Benedict (1934) made an impressively early attempt to argue for conceptualizing epilepsy and other abnormalities as cultural constructs. Farber (1968) wrote that disability is a "social imposition" not a personal limitation and that the negative effects of labeling were equal to those due to actual "incompetence." Based on Mexican research, Gwaltney (1970) perceptively concluded that the meaning of blindness is variable and thus must be culturally contextualized. These insights hint at an idea of the *social* status of handicap historically and cross-culturally.

When Edgerton did his now famous longitudinal ethnographic study (1967) of deinstitutionalization of the "mentally handicapped," however, he chose to use Goffman's concepts of stigma and institutional effect, as well as labeling and symbolic interactionism. Edgerton's portrayal was evocative and was widely read across the social sciences, helping identify significant transition challenges. He described how people tried to pass (as normal) in society through coping tactics, relationships, and harmless ruses. Klotz (2004) argued that Edgerton's conceptual framework biased the course of ethnography toward concepts implying deficit or lack, and away from cultural construction or direct subject/worldview elaboration. Still, such vintage ethnographies offer useful perspectives on cultural norms of the period, and they drew much-needed attention to deinstitutionalization as a social concern.

CONTEMPORARY RESEARCH

Disability studies as a critical field of study based in human and social sciences (outside medical, rehabilitation, and education) has grown rapidly since the mid-1970s with the founding of the Society for Disability Studies (United States) in the early 1980s. While the use of anthropological theory and methods by other scholars has been an important part of that growth, engaged anthropologists remain few and, as Kasnitz and Shuttleworth (1999) noted, they often write for anthropological audiences without sufficient reference to disability studies developments, although this is changing.

Categories of Anthropological Research

Grouping the existing ethnographic research in impairment/disability helps to highlight the relevance of anthropology to impairment and disability studies, whether undertaken by anthropologists or not. There is no set typology for this formative area of research. The categories below reflect recent anthropological activity. See the final section of this entry for areas of strong potential. Cultural constructionism, cross-cultural comparison, and cultural research methods and perspectives are the three categories and the risks of disability studies interdisciplinarity are also addressed.

The most effective of these works take disability seriously as an analytic category within the culture, rather than beginning from a traditional biological, individual perspective. While the latter is also useful, it can hide or distort other important cultural processes and beliefs at work. Groce's (1988) ethnography of Martha's Vineyard, an island off the New England coastline, is notable in this vein. She shows how the meaning of deafness, an impairment that was generally perceived in American culture to be a deficit and a "personal tragedy," was socioculturally contingent. Since hereditary patterns made deafness pervasive on the island, most locals learned to sign, thereby greatly reducing the stigma and "disabling effects" of the environment.

Another example of taking disability seriously as an analytic category comes from emerging attention to impairment in medical anthropology. Rapp and Ginsburg (2001) explore how parents' experience of having and raising a child with an impairment is interwoven with cultural expectations and taboos regarding perfection and health in individuals and families. Along with Gail Landsman (1998), they examine how the private narratives and experiences of American parents expecting or raising an anomalous baby interact with the mainly negative public narratives of disability. Their work builds from literature, such as Kenazburo Oe's (1995) biography and novels about his family's transformation through the birth of their son.

Cultural Construction and History

A common approach to impairment/disability among anthropologists and others is to show how it is a socially and culturally constructed category, contingent on values and ideology as much as physical/mental conditions. Acknowledging this contingency helps to provide the analytical framework for understanding the powerful negative effects that labeling, segregating, and devaluing have had. Those effects are largely ascribed to the negative assumptions of the biomedical and functional models of impairment (although these should not be seen as separate from the moral fabric of the society that produces them). This critical cultural history approach examines the shifting meanings that disability has had over time in a culture.

It works from the postmodern assumptions that truth is partial, contingent, and interested. Four examples of this approach demonstrate its power and breadth.

Trent (1994) used archival research and document analysis of early- to mid-twentieth-century U.S. institutional records, correspondence, and government policy shifts. He teased out a set of cultural meta-narratives that successively guided policy, welfare support, IQ testing, rehabilitation, and institutional life for "the mentally retarded." He shows how these conceptual changes had less to do with scientific advances than with broader sociocultural or economic changes. For example, he noted the impact on people with intellectual disabilities of changes in social organization due to industrialization; in notions of contagion due to rise of germ theory and in systems of moral and social control that arose with eugenics. Trent outlined the public and professional shift from narratives of compassion and protection *of* "the handicapped" to that of suspicion and protecting society *from* them. Anthropologists have long examined how such meta-narratives interweave cultures, effectively permeating public perspectives about a subgroup such as indigenous peoples.

Stiker ([1982] 1999) also situates impairment/disability in its cultural and historical context using cultural symbolism. He examined the emergence of state governance of the "invalid body" in France, as many war veterans acquired physical impairments. Stiker critiqued disability scholars for too smugly accepting the medical and social models as theoretical end points. Like Foucault's studies of madness and institutions, Stiker used enduring cultural problematics such as limits and boundaries (here, normal and abnormal) as his optic for exploring such social changes.

An anthropological perspective should, he argues, alter the reductive emphasis of considering disability simply in terms of oppression (rights, minority group politics) and economic systems (exclusion/poverty). That disabilities operate as powerful emotional triggers suggests deeper social conflicts than just material oppression in a particular social structure (Western, capitalist, medical). Disability discrimination also originates in our abiding collective cultural fantasies about perfect bodies, health, and minds, and the converse fears of infirmity, deformity, and unreason.

Indeed Stiker suggested that the specificity and fundamental symbolic significance of disability can be clouded or drowned by those other emphases. For example, he applauded Murphy's use of cultural liminality as a heuristic with specific symbolic meanings for impairment related to modernist, social order. Research into broader symbolic and cultural meanings could offer more thorough understanding of the bases for exclusion that would feed more creative ways of imagining impairment back into the social fabric.

Two anthropologists use this symbolic approach. Desjardins (2002) conducted research into the emic (insider) perspective of people with developmental disabilities on their experience of daily social life in relation to the mainstream, which he described as simulacra or parallel worlds. He uses his findings to undermine mainstream assumptions about what kind of inclusion people want and to explore what the symbolic meaning and function of the inaccurate assumptions were. He points to modern society's intolerance of real difference, but also to the potential richness of life on the margins. Michalko (2002) begins from personal experience of blindness and usefully generalized to cross-impairment issues with a range of theoretical perspectives. He insisted that disability is a difference that matters symbolically and practically and should not be elided with other differences.

Cross-Cultural Comparison

Anthropology's locus classicus has been preindustrial, non-Western societies and thematic cross-cultural comparisons using those findings. Some anthropologists, and other scholars using ethnography, are beginning to answer the call for greater ethnographic description and theorizing of anomalous bodies and minds in those settings. This work has helped substantiate further that impairment and disability as conceived in the West, are culturally located notions, but still needs improvement. The disability specialists Kasnitz, Shuttleworth, and Linton argue that more cross-cultural studies are needed. Specifically, they call for studies designed for this purpose, not ones that mine old data for signs of (Western-defined) impairment, that makes for thin data and risks layering etic interpretations on local perceptions. Phenomenological studies are needed that do not begin from Western categories and that assess local understanding and management of perceived challenging, anomalous conditions.

Devlieger's (1995) ethnography of the African Songye people's worldview is a good model. His goal is to understand whether the concepts of impairment or disability hold any meaning in the Songye symbolic systems. He found that they have three categories of "abnormal" kids, none of which is equivalent to the U.S. term *disability*. He showed that Songye are more concerned with the existential and familial (the social meaning of anomalous children) than the technical (rehabilitation, cure, medicine). This leads them to think more about causes, especially social ones, and how to rebalance those social wrongs, rather than how to "fix" the child directly. This notion curiously echoes earlier Christian notions of disability as punishment, which may have been imported via missionaries. Furthermore, social consequences of impairment are variable.

Ingstad and Whyte's (1995) widely read collection of cross-cultural research introduced useful new perspectives, and the critiques of it are also instructive. Kasnitz and Shuttleworth (1999) noted inconsistent use of the terms disability and impairment across contributors, and various authors begin from an etic/outsider understanding of an impairment (e.g., blindness). Finally, these and other cross-cultural researchers often neglect to acknowledge, use, or challenge existing disability studies theory hence omitting key disciplinary concerns. Still, this and other cross-cultural texts are necessary first steps.

Oliver (1990) noted that the paucity of existing material and its tendency toward a medical or individual model makes it difficult to develop either an empirical or theoretical account of disability cross-culturally. More research is needed both on specific impairments and on pan-impairment conceptions, and both need to draw on and evoke the emic point of view more extensively. While Devlieger cautioned that greater state involvement does not necessarily signal better quality of life, there is also an unhelpful tendency for some authors to romanticize the non-Western societies' approaches, assuming that the *lack* of an elaborate medical labeling system indicates de facto greater support or acceptance. For example, the lack of state or medical support for people with developmental disabilities in Ukraine reflects rejection and lack of political will or resources, not acceptance. Greater anthropological attention to these concerns should aid in creating a basis for cross-cultural comparison even without common terms. Oliver reviewed research that begins to name common factors that effect perception and treatment.

Insider's Perspective and Methods

Disability studies scholars continue to call for greater inclusion of the active voices of people with disabilities in research and less emphasis on the perspectives of nondisabled peoples' *response to* disability. Insider (emic) writing has expanded in the past two decades. These tend to be by or about people with physical impairments, often late-onset or acquired ones. They are mainly autobiographical and only occasionally analytical (e.g., Murphy 1990). People with developmental disabilities often need special supports to tell their story or alternative media forms. College and university access centers and disability studies programs are beginning to develop creative solutions for increasing disabled students' access to social science education.

The qualitative, intimate research methods of anthropologists and some sociologists have begun to yield more representative accounts. Qualitative research can be especially fruitful when exploring new areas or emic worldviews such as the views of people with intellectual impairment. Klotz (2004) discusses anthropologists who have used participant observation and naturalistic phenomenology for this purpose to good effect. This research emphasized the centrality of interactions and relationships to understanding what a person with profound intellectual impairments is experiencing, and the meaning of certain behaviors. Such research can expand anthropological paradigms and contribute to better social care policy.

The anthropologist Gelya Frank (2000) undertook long-term collaboration with a social sciences student who had complex physical impairments. Both wrote about the student's life story, one as an autobiography, and one as a reflexive ethnobiography that critically explored what could be learned about the student's cultural environment from events, themes, and structures in her life story and how she narrates them. Narrative theory continues to flourish in the field.

The anthropologist Murphy (1990) wrote a combination ethnography and autobiography, which "anthropologized" his personal experience of acquiring a degenerative disability. This widely read book attempts to situate processes such as stigma in specific cultural values and personal interactions. He also explored, with some disdain, the direct relationship between his physical and mental decline and the quality or willingness of others to interact with him. He theorized his experience that when a person with impairments cannot fully "recover normalcy," he or she is socially positioned in what anthropologists term a "liminal" or "in-between" state: not ill but not well, neither sidelined fully nor integrated, and perceived somehow as at fault for being a disturbance to modernist order.

Challenges for Interdisciplinarity

Murphy's (1990) insightful book was critically acclaimed and widely read by anthropologists and activists, but it has also been critiqued in ways that illustrate the challenges of doing research in an interdisciplinary field. It is difficult to keep abreast of developments in theory across all the fields whilst also maintaining depth in one's own discipline.

Murphy chose to write within anthropological and sociological frameworks rather than within the emergent disability studies sociocultural model. While some, such as Stiker, praised his innovative application of those frameworks, others critiqued his insensitivity to disability studies theory. For instance, Arthur Frank identified common themes in acquired disability narratives such as restitution (cure/getting well again), chaos (confusion), and quest (illness as route to transformation). Kasnitz and Shuttleworth contended that Murphy sustained a restitution narrative through much of the book emphasizing only negative aspects of his impairment: loss, depression, and exclusion. Furthermore, his story often conflates identity and impairment in contrast to the disability studies theorists' attempt to show that impairment is neither deterministic nor universalizing. Many anthropologists and other authors have similarly either ignored disability studies and even accused it of analytical omissions that it did not have, presumably due to inadequate knowledge of that literature.

Anthropologists must better situate their research both in anthropology and emergent disability studies theory to avoid a merely add-on treatment of disability. This theory is increasingly sophisticated and offers insights around difference, power, and exclusion, which will also refine anthropological theory. For instance, classic ethnographic categories such as kinship and reproduction are problematized and enriched by considerations of the exceptional family, while still avoiding exotification or overemphasis on role of difference. Disability studies theorists must also become more familiar with fundamental advances in relevant anthropological theorizing such as cultural analysis and change, difference, positionality, representation, voice, narrative, and interpretivism.

FUTURE RESEARCH DIRECTIONS

Anthropological theory and approaches are especially well suited for illuminating disability as a social, cultural, and symbolic process. Greater attention to questions raised by impairment-disability will also sharpen and inform that theory. What follows are a few suggestions for future research directions for anthropology and impairment-disability.

Symbolism and Cultural Analysis

Anthropological theories of voice, power, difference, and representation can illuminate underlying cultural tropes and values that impairment and disability trigger. Theorizing exceptionality, anomaly, and marginality may provide one fruitful avenue. More nuanced studies of disability symbolism in Western and other cultural stories, idioms, and events are needed. Further examination of the role of religion and spirituality as symbolic systems of meaning in relation to impairment fits well into this category.

Medical Anthropology

Medical anthropology involves reflexive analysis of the construction of knowledge of health, illness idioms, and social injustice. It can reintroduce disability studies to questions of embodiment, the role of medical technologies in people with disabilities' lives, and issues with health care systems. Anthropologists have recently turned greater attention toward the sensory, somatic, and biological aspects of life, after years of neglect. Sterilization, euthanasia, reproduction, caregiving, and abuse are all potential disability studies topics. One question is, how does neo-eugenics come to make cultural sense amid the inclusive discourses of disability rights? What are the roots of the countervailing discourses of perfection and mastery?

Disability Culture Debate

The scholarly and popular disability communities continue to debate whether or not there is a disability culture, its politics and cohesiveness, and boundaries (who is in or out of it). Anthropologically informed voices could help articulate the characteristics and evolution of the social movement and support it to consider its options, for example, to sound a caution about how strategic essentialism (pan-disability arguments) is used for rhetorical/activist purposes, since it can leave people out, render inadequately considered solutions, and ultimately fragment the group.

Policy: Social Inclusion

Social inclusion and exclusion policy provide a good starting point for bringing cultural and disability questions together (Cushing 2003). The challenge is, what alternatives are we giving people with disabilities? Social inclusion is not either/or; it is an ongoing process involving many important cultural variables alongside the economics. Anthropology could provide subtle insight around the negative or fearful attitudes toward disability in our culture that act as barriers to greater social acceptance along with the physical integration. It can also illuminate the diverse, culturally contingent meanings of inclusion from an emic (disability) standpoint. Considerations of quality of life, belonging, and spirituality are all salient.

Methodology

Participant observation and creative forms of personal interviews hold the possibility of greater phenomenological understanding of insiders' everyday life experience of impairment-disability, and of generating more positive narratives of this experience as grist for the social mill. The long-term nature of fieldwork lends itself well to studies of impairment and the life course, adult-onset changes, and shifts in self-understanding. Participatory action research offers a route to include the voice and agency of more people with disabilities; however, such work must carefully balance activist aims with research standards of empiricism.

—Pamela Cushing

See also Autobiography; Citizenship and Civil Rights; Cultural Context of Disability; Deafness, on Martha's Vineyard; Developmental Disabilities; Disability in Contemporary Africa; Inclusion and Exclusion; Sociology.

Further Readings

Ablon, J. 1984. *Little People in America: The Social Dimensions of Dwarfism.* New York: Praeger.

Benedict, Ruth. 1934. "Anthropology and the Abnormal." *Journal General Psychiatry* 10:59–80.

Clifford, James and G. Marcus, eds. 1986. *Writing Culture: The Poetics and Politics of Ethnography.* Berkeley: University of California Press.

Cushing, Pamela. 2002. "Shaping the Moral Imagination of Caregivers: Difference, Disability and Inequality at L'Arche." Doctoral thesis in cultural anthropology, McMaster University, Hamilton, ON.

———. 2003. *Report on Social Inclusion and Exclusion Policies*. Toronto: L'Institute Roeher Institute.

Davis, Lennard J., ed. 1997. *The Disability Studies Reader.* New York: Routledge.

Desjardins, M. 2002. *Le Jardins d'Ombres: La poetique et la politique de la reeducation sociale*. Montreal: University of Montreal Press.

Devlieger, Patrick. 1995. "Why Disabled? The Cultural Understanding of Physical Disability in an African Society." Pp. 94–106 in *Disability and Culture*, edited by B. Ingstad and S. W. Whyte. Berkeley: University of California Press.

Edgerton, R. [1967] 1993. *The Cloak of Competence,* revised and updated. Berkeley: University of California Press.

Farber, B. 1968. *Mental Retardation: Its Social Context and Social Consequences.* Boston: Houghton Mifflin.

Frank, Gelya. 2000. *Venus on Wheels: Two Decades of Dialogue on Disability, Biography and Being Female in America.* Berkeley: University of California Press.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity.* Englewood Cliffs, NJ: Prentice Hall.

Groce, Nora E. 1988. *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard.* Cambridge, MA: Harvard University Press.

Gwaltney, J. 1970. *The Thrice Shy: Cultural Accommodation to Blindness and Other Disasters in a Mexican Community.* New York: Columbia University Press

Holzer, Brigitte, A. Vreede, and G. Weigt, eds. 1999. *Disability in Different Cultures: Reflections on Local Concepts.* Bielefeld, Germany: Transcript Verlag, Roswitha Gost, Sigrid Noke.

Ignani, E. 2005. "The Poster Child Shoots Back: A Media Ethnography of Disabled Youth's Experience of Home and Community Care." Doctoral thesis in progress for Social Science and Health Program, Faculty of Medicine, University of Toronto.

Ingstad, B. and S. R. Whyte, eds. 1995. *Disability and Culture.* Berkeley: University of California Press.

Kasnitz, Devva and Russell Shuttleworth. 1999. "Engaging Anthropology in Disability Studies." *Disability Policy Studies* 1(1) (World Institute on Disability, Oakland, CA).

Klotz, Jani. 2004. "Sociocultural Study of Intellectual Disability: Moving beyond Labeling and Social Constructionist Perspectives." *British Journal of Learning Disabilities* 32:93–104.

Landsman, Gail. 1998. "Reconstructing Motherhood in the Age of 'Perfect' Babies: Mothers of Infants and Toddlers with Disabilities." *Signs* 24(1): 66–99.

Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity.* New York: New York University Press.

Michalko, R. 2002. *The Difference That Disability Makes*. Philadelphia: Temple University Press.

Murphy, Robert. 1990. *The Body Silent.* New York: W. W. Norton.

Oe, Kenzaburo. 1995. *A Healing Family: A Candid Account of Life with a Handicapped Son*. New York: Kodansha America.

Oliver, Michael. 1990. *The Politics of Disablement.* London: Macmillan.

Rapp, Rayna and Faye Ginsburg. 2001. "Enabling Disability: Rewriting Kinship, Reimagining Citizenship." *Public Culture* 13(3): 533–556.

Roeher Institute. 1996. *Disability, Community and Society: Exploring the Links*. Toronto, Canada (www.roeher.ca).

Stiker, Henri-Jacques. [1982, in French] 1999. *A History of Disability.* Translated by W. Sayers. Ann Arbor: University of Michigan Press.

Trent, James W., Jr. 1994. *Inventing the Feeble Mind: A History of Mental Retardation in the United States.* Berkeley: University of California Press.

Wikan, Unni 1992. "Beyond the Words: The Power of Resonance." *American Ethnologist* 19(3): 460–482.

Websites

Anthropological resources list from the American Anthropology Association, http://www.aaanet.org/resinet.htm

Differences between the terms *impairment, disability*, and *handicap,* http://www.pediatrics.emory.edu/NEONATOLOGY/DPC/Impairment%20MX.htm

Disability Research Digest, http://www.smd-services.com/information/disability_research_digest.html

Disability Studies Quarterly, various social science perspectives on impairment-disability including medical anthropology sources, www.dsq-sds.org

General sociology anthropology sources, http://www.socscire-search.com/r7.html

L'Arche, www.larchecanada.org

UK disability-related literature archive, http://www.leeds.ac.uk/disability-studies/archiveuk/

ANTIDISCRIMINATION LAW, JUDICIAL INTERPRETATIONS

The U.S. Congress took a comprehensive approach to disability discrimination in the Americans with Disabilities Act of 1990 (ADA), defining the covered class broadly, providing flexible, individualized requirements, and authorizing various remedies. Congress's approach reflected a civil rights approach to disability. Under this model, people with disabilities are recognized as a minority that traditionally has been unnecessarily excluded from full participation in society. This modern approach to disability contrasts with traditional models that saw disability as an automatic and necessary basis for exempting people from both the benefits and responsibilities of full community participation. The traditional model addressed disability as either a medical issue to be cured or a justification for charity and segregations. While Congress intentionally used the civil rights model in drafting the ADA, the courts, and most notably, the U.S. Supreme Court, often have continued to rely on the traditional models in interpreting the law. This has led to severe, and sometimes inconsistent, restrictions on disability law.

LIMITATIONS ON WHO IS PROTECTED

Mitigating Measures

The ADA defines a disability as a physical or mental impairment that substantially limits a major life activity. Congress took a broad view of disability when enacting the ADA. The U.S. Supreme Court, in its first case analyzing that definition, appeared to adhere to that definition. The Supreme Court in *Bragdon v. Abbott* took up the issue of when an impairment's limiting effect is substantial. The divided Court found that Ms. Abbott's asymptomatic HIV substantially limited the major life activity of reproduction. The Court concluded that the risk of transmitting the disease to a fetus or sexual partner constitutes a limitation on the ability to reproduce.

Thus, the *Bragdon* Court indicated that limitations external to the disabled individual may be taken into consideration. The Court also made clear that the impairment need not completely prevent the major life activity. In this case, the 8–25 percent risk of HIV transmission to a fetus was substantial enough.

The Court considered whether the "substantial" inquiry should take into consideration personal choices as well as objective limitations. Because of the divisions within the majority, the Court did not provide a clear answer. The Court noted that Ms. Abbott had testified that the risk of transmission controlled her decision not to have a child, thus implying that the decision might have turned out differently if she had made the decision for other reasons or if she had chosen to ignore the risk and have a child. However, the majority drew back from giving dispositive weight to the personal choice factor, stating that "in the end, the disability definition does not turn on personal choice."

However, in a subsequent series of cases interpreting the definition of disability, the U.S. Supreme Court has severely restricted the scope of the statute's protection. The Supreme Court imposed significant restrictions in *Sutton v. United Air Lines, Inc.* and its companion cases, *Albertson's Inc. v. Kirkingburg,* and *Murphy v. United Parcel Service, Inc.*

In *Sutton,* twin sisters had vision worse than 20/200 in both eyes, but corrective lenses gave them 20/20 vision. United rejected them for positions as pilots based on a company requirement that pilots must have uncorrected vision of at least 20/100. In *Albertson's,* Mr. Kirkingburg was a truck driver who was blind in one eye. When the company discovered that he did not meet a federal vision guideline, it fired him without exploring the possibility of a waiver of the federal guideline. In *Murphy,* the plaintiff was a mechanic with high blood pressure that was near normal when he took medication. His job required him to drive commercial vehicles, and he was fired because the employer believed his high blood pressure would not meet a federal requirement.

Together, this trilogy of cases raised the issue of whether mitigating measures should be taken into consideration when assessing whether a person's impairment is substantially limiting. Mitigating measures are measures, such as medication, equipment, or internal coping mechanisms, that reduce the effects of an impairment. The Supreme Court made clear that, when judging whether an individual is substantially limited for purposes of ADA protection, the individual's mitigating measures must be considered.

Thus, the Sutton sisters are not covered by the ADA because their eyeglasses improve their vision to 20/20. Mr. Murphy is not protected because, when medicated, his high blood pressure does not prevent him from functioning normally. Mr. Kirkingburg may not be protected, despite having vision in only one eye, because his brain has developed subconscious adjustments to compensate for reduced depth perception. The Court made clear that the side effects of medications and other mitigating measures should also be taken into account and could weigh in favor of finding a substantial limitation.

The Court relied on three parts of the statute to support its conclusion: (1) the fact that the statute is written in the present indicative verb tense ("limits"), thus "requiring that a person be presently—not potentially or hypothetically—substantially limited"; (2) the requirement of an individualized inquiry focusing on the actual effects on the particular individual, rather than general or speculative effects; and (3) the statute's findings stating that there were approximately 43 million people with disabilities in the United States and the Court's belief that covering everyone who wears glasses would far exceed that number. The Court's conclusion rejected the opposite analysis adopted by the U.S. Department of Justice and the Equal Employment Opportunity Commission and supported by the ADA's legislative history.

The Court's approach in the *Sutton* trilogy demonstrates a particular view of disability and discrimination protections. The Court views people with disabilities as fundamentally different from the general population, rather than as part of the spectrum of ability levels within society. The Court treats disability rights protections not as a check on unfairness, justified by a history of prejudice, but as a type of affirmative action or charity intended only for a small group of individuals whose disabilities set them apart from the Court's view of the general population.

The Court's analysis will prevent individuals with minor impairments from receiving accommodations, such as equipment or policy changes, in the workplace. It will allow a defendant to refuse to hire an individual solely because of his or her impairment, such as diabetes, but escape liability by arguing that the impairment does not arise to the level of a disability because the individual takes medication. It creates a gap in which individuals are considered (quite possibly unfairly) too impaired to work but not impaired enough to be protected from discrimination.

As a result of the analysis in the *Sutton* trilogy, courts are frequently called on to analyze whether a plaintiff's impairment significantly restricts him or her from engaging in a major life activity. Because the plaintiff bears the burden of proof on this issue, impairments that respond to medication, such as diabetes, depression, and epilepsy, are difficult to establish as disabilities, often being ruled out on summary judgment without reaching the merits of the case. However, mitigated impairments still may be "regarded as" disabilities, and entitled to coverage under another prong of the ADA definition of disability.

Major Life Activity

To be covered under the ADA, a person's impairment must substantially limit one or more major life activities. Major life activities include "functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." The Supreme Court in *Bragdon v. Abbott* provided that major life activities are not restricted to those that have "a public, economic, or daily character." Thus, purely personal activities, such as reproduction, can be major life activities. However, the activity must be of "comparative importance." In *Toyota Motor Mfg., Kentucky, Inc. v. Williams,* the Supreme Court emphasized the need to assess work-related and non-work-related activities in determining whether a limitation is substantial.

In *Toyota,* the plaintiff, Ms. Williams, had carpal tunnel syndrome, which prevented her from lifting more than 20 pounds, working with her arms raised, and doing repetitive wrist or elbow movements. She worked doing paint inspection and assembly inspection at a Toyota factory. Toyota added body auditing and surface repair to Williams's job. To do these tasks, Williams had to hold her arms at shoulder height for several hours at a time. Because her carpal tunnel syndrome bothered her, she requested to be reassigned to do only paint inspection and assembly inspection. Toyota refused. Williams was, therefore, placed under a no-work restriction and fired.

In that case, the Court addressed the boundaries of the major life activity of performing manual tasks. A unanimous Court found that major life activities are those "activities that are of central importance to most people's daily life." The Court went on to decide that performing manual tasks could be a major life activity only if the tasks included were centrally important to most people's daily lives. The Court recognized that "the manual tasks unique to any particular job are not necessarily important parts of most people's lives." Instead, "household chores, bathing, and brushing one's teeth are among the types of manual tasks of central importance to people's daily lives."

The *Toyota* Court, therefore, required a weighing of the objectively important manual tasks Ms. Williams could and could not do. No special weight or emphasis is to be placed on whether the impairment actually affects the job from which the plaintiff is being excluded. While the *Toyota* decision is arguably limited to the major activity of performing manual tasks, some courts that have addressed the issue have applied the requirement of "central importance to most people's daily lives" to other types of major life activities as well.

Direct Threat to Self

The U.S. Supreme Court has narrowed the protection of the ADA by excluding from coverage anyone whose disability would be aggravated by the job or activity in which they seek to participate. Thus, in

Chevron v. Echazabal, Mr. Echazabal was denied employment by Chevron because Chevron believed the job would exacerbate his hepatitis. Although the statute only allows employers to exclude disabled employees who pose a direct threat to the health or safety of others, the Court ruled that Title I, as interpreted by the Equal Employment Opportunity Commission, allows employers to exclude qualified people with disabilities from the workplace because they pose a direct threat of harm solely to themselves. Therefore, people whose disabilities do not prevent them from doing the job and do not pose any risk to other employees or customers may be excluded from jobs because the job might aggravate their disabilities. Disability advocates oppose this approach as allowing paternalistic attitudes of employers to override their own choices.

LIMITATIONS ON RIGHTS CONFERRED

The Supreme Court has not only narrowly interpreted the size of the class of individuals protected by the ADA, it also has interpreted the scope of the rights conferred by the act narrowly. In general, Title I does not require an employer to violate legitimate seniority provisions to accommodate an employee with a disability. The Supreme Court, in *U.S. Airways v. Barnett,* held such an accommodation to be presumed unreasonable where the seniority policy or collective bargaining agreement contains bona fide seniority provisions. The Court held that reassignment to another job in direct violation of a company seniority system is unreasonable as a matter of law, absent a special showing by plaintiff to the contrary.

A showing that reassignment would violate the rules of a seniority system therefore typically warrants summary judgment for the employer, "unless there is more." According to the Court, the plaintiff bears the burden of showing that special circumstances demonstrate the assignment is reasonable. Once the plaintiff has made this showing, the employer then must show evidence of case-specific circumstances that demonstrate undue hardship.

In *Hernandez v. Hughes Missile Systems Co.,* the plaintiff worked as a technician for Hughes. During his employment, he was addicted to drugs and alcohol, and he eventually tested positive for cocaine. The plaintiff was given the option to resign in lieu of termination, which he chose to do. Two years later, the plaintiff applied to be rehired with Hughes, attaching a letter from his counselor to his application. His counselor indicated that Hernandez had been attending Alcoholics Anonymous and staying sober. Hughes declined to rehire the plaintiff based on an unwritten policy of not rehiring former employees whose employment had ended due to termination or resignation in lieu of termination.

The Ninth Circuit Court of Appeals had found this facially neutral policy could be discriminatory if Hughes regarded the plaintiff as being disabled—by virtue of being a previous drug and alcohol user—at the time it failed to rehire him. The appeals court applied a disparate impact analysis to the plaintiff's claim, finding that the facially neutral no-rehire policy violated the ADA because it excluded former drug addicts based on their disabilities. The Supreme Court used this case as an opportunity to focus on a distinction between disparate treatment and disparate impact theories of disability discrimination, a distinction that had not played a large role in previous disability rights case law. A disparate impact claim challenges a facially neutral rule that has an undue effect on a protected population. A disparate treatment claim challenges a rule that treats people with disabilities differently from nondisabled people. The Supreme Court found that Hernandez's argument that Hughes' policy was discriminatory toward former drug addicts was a claim of "disparate impact," rather than a claim of disparate treatment. However, because Mr. Hernandez had not specified such a claim in his complaint, he was precluded from relying on disparate impact as a basis for liability. This approach requires courts and claimants to be specific about the bases for ADA claims, at the risk of losing them.

LIMITATIONS ON ENTITIES COVERED BY THE LAW

In *Board of Trustees of the University of Alabama v. Garrett,* the Supreme Court held that an individual state is immune, pursuant to the Eleventh Amendment to the U.S. Constitution, to suits for money damages under the employment provisions of the ADA. The

Court's reasoning in *Garrett* can be summarized as follows: To abrogate the states' Eleventh Amendment sovereign immunity pursuant to Section 5 of the Fourteenth Amendment, Congress needed to find sufficient proof of a pattern of unconstitutional discrimination against people with disabilities in the area of state employment. The unconstitutionality of this state behavior must be judged by a rational basis standard, because people with disabilities do not receive heightened scrutiny under the Equal Protection Clause. The Court held that Congress failed to meet the requisite standard of proof and that the means it employed to remedy ADA violations were not a congruent and proportional remedy to the harms it did find.

In *Tennessee v. Lane*, the Court faced the issue of whether states are immune from suits for money damages under Title II of the ADA. The plaintiff in *Lane* sued the state of Tennessee for failure to make a state courthouse accessible. The Court held that because access to courts is a "fundamental" constitutional right under the Due Process Clause, Congress validly abrogated states' sovereign immunity insofar as Title II applies to this category of claims. The Court's decision was a narrow one, and left unclear whether states can be sued for damages for ADA violations of other fundamental rights or in cases that do not involve fundamental rights.

There has been a separate question regarding the application of ADA Title III to foreign-flagged cruise ships that enter U.S. waters. The courts of appeals have split on the issue. In *Stevens v. Premier Cruises, Inc.*, the Eleventh Circuit Court of Appeals held that Title III applies to those aspects of cruise ships that qualify as public accommodations in themselves (e.g., lodging, restaurants, shops, and spas), at least while the ships are in domestic waters. The Eleventh Circuit found that foreign-flagged ships were not, in themselves, extraterritorial when they were in U.S. waters. The Fifth Circuit Court of Appeals disagreed, and in *Spector v. Norwegian Cruise Line Ltd.* applied a presumption against extraterritoriality absent a clear expression of intent by Congress. The Fifth Circuit believed that Title III enforcement in U.S. waters would necessarily result in extraterritoriality, because the architectural changes would be permanent and would be carried into foreign waters by the ships. The Fifth Circuit relied on *EEOC v. Arabian American Oil Co.*, in which the Supreme Court held that Title VII of the Civil Rights Act does not apply to American employees of American companies abroad. The Supreme Court granted *certiorari* to review the question, and a decision is expected in mid-2005.

—Eve Hill, Charles Siegal, Michael Waterstone, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States).

Further Readings

Albertson's Inc. v. Kirkingburg, 527 U.S. 555 (1999).

Bd. of Trustees of the Univ. of Alabama v. Garrett, 531 U.S. 356, 374 (2001).

Blanck, Peter, Eve Hill, Charles Siegal, and Michael Waterstone. 2003. *Disability Civil Rights Law and Policy*. St. Paul, MN: West.

Bragdon v. Abbott, 524 U.S. 624 (1998).

Chevron U.S.A. v. Echazabal, 536 U.S. 73 (2002).

EEOC v. Arabian American Oil Co., 499 U.S. 244 (1991).

Hernandez v. Hughes Missile Systems Co., 298 F.3d 1030 (9th Cir. 2002).

Murphy v. United Parcel Service, Inc., 527 U.S. 516 (1999).

Spector v. Norwegian Cruise Line Ltd., 356 F.3d 641 (5th Cir. 2004).

Spector v. Norwegian Cruise Line Ltd., 125 S.Ct. 26, 159 L.Ed.2d 856 (U.S. Sep 28, 2004).

Stevens v. Premier Cruises, Inc., 215 F.3d 1237 (11th Cir. 2000).

Sutton v. United Airlines, 527 U.S. 471 (1999).

Tennessee v. Lane, 124 S.Ct. 1978 (2004).

Toyota Motor Mfg., Ky., Inc. v. Williams, 534 U.S. 184 (2002).

29 C.F.R. § 1630.2(i) (2003); 28 C.F.R. § 35.104 (defining "disability") (2003).

U.S. Airways, Inc. v. Barnett, 535 U.S. 391, 394 (2002).

ANTIPSYCHIATRY MOVEMENT

The antipsychiatry movement is lacking a clear definition and the name itself was not totally accepted by its supporters. Nonetheless, one could say that it is characterized by its diversity, both theoretical and geographic. The effort to offer a synthetic, global image risks reducing this important dimension. Developed in Great Britain, it spread to several European countries, including Italy, and also had proponents in the United States. The movement was built up around forceful personalities from the psychiatric profession, who elaborated an important critique both of the ideas at the heart both of theories of the mind and of associated practices. Its exponents have drawn on contributions from the outside the profession, in particular from philosophy, and social criticism, the latter deriving in part from the context of the political and social confrontations of the 1960s. Their philosophical inspiration is based as much on existentialism as on phenomenology, Marxism, and certain libertarian currents.

The physicians D. Cooper, R. Laing, F. Basaglia, and J. Foudraine have by and large challenged the validity, even the necessity, of existing institutions for treatment of psychiatric disorders. They fault these institutions for their violence against patients, for example, through the use of electroshock treatments. They also blame them for being the more-or-less voluntary instruments of social repression, in which the sick person is the exemplary victim. Psychiatrists of the antipsychiatry movement react against the excesses of the old hereditary determinism and the nosography that had become a finality rather than a stage in the understanding of the patient's suffering. The various exponents of the movement have not limited their criticism to the notions and concepts at the heart of psychiatric reasoning; they have been equally active in the sphere of praxis. Kingsley Hall in Great Britain, Trieste with the Italian Basaglia, and the Bonneuil Center in France represent some of the efforts to create real alternatives to the psychiatric hospital and have quickly become sites of pilgrimage for caregivers and intellectuals, who have placed a great deal of hope in the realization of these alternatives.

But the critical spirit of antipsychiatry practitioners and the hope that it raised have not been widely diffused. The antipsychiatry movement has remained a collection of individuals rather than a true school of treatment. Its probable legacy is, then, difficult to assess. On the one hand, the radical nature of its critique has engendered lively resistance. Without necessarily associating antipsychiatry with the left-leaning political and intellectual movements of the 1960s and 1970s, it must be stated that the psychiatric community has, on the whole, not been favorably disposed toward antipsychiatry. It has interpreted the antipsychiatry project as a denial of mental illness, which is a considerable exaggeration. On the other hand, antipsychiatry has renewed the critique of a medical discipline that, by the admission of its own representatives, cannot meet its own costs. Nonetheless, such criticisms have necessarily been generated from a common base: the utility and necessity of a science of the human psyche that produces facts and norms. The most fruitful lesson of antipsychiatry is doubtless to have reminded us that psychiatric knowledge is a tributary in the link between the production of medical facts and social norms. From this perspective, the Italian law on mental health inspired by Basaglia and passed in 1978 bears witness to the way in which a society can renew its relationship with exclusion and alterity. This is what antipsychiatry, however awkwardly but sincerely, wished to point out.

—Jean-Christophe Coffin

See also Mental Illness; Psychiatry.

Further Readings

Basaglia, F. 1968. *L'istituzione negata.* Turin, Italy: Einaudi.

Cooper, D. 1967. *Psychiatry and Antipsychiatry.* London: Tavistock.

Critique. October 1968.

Crozier, Michel. 1979. "Les angoisses existentielles des intellectuels français: Réflexions sur vingt années de révolution culturelle." *Commentaire* 6.

Ey, H. 1978. *Défense et illustration de la psychiatrie.* Paris: Masson.

Laing, R. 1961. *The Divided Self.* London, Tavistock.

Scheper-Hughes, Nancy and Anne M. Lovell, eds. 1987. *Psychiatry Inside Out: Selected Writings of Franco Basaglia.* Translated from the Italian by Anne M. Lovell and Teresa Shtob. New York: Columbia University Press.

Szasz, T. 1961. *The Myth of Mental Illness.* New York: Harper and Row.

ANTISOCIAL PERSONALITY DISORDER

Antisocial personality disorder (APD) is characterized by a pervasive pattern of disregard for the feelings of others often accompanied by violation of the rights of others through negligence or overt actions. This disorder is believed to occur in 3 percent of adult males and 1 percent of women. In the past, this disorder was often called "psychopathic" or "sociopathic," though these terms are misleading as in the past they have become identified too closely with serial killers and other extreme and violent forms of this disorder. While it has a lifelong course, many patients with this disorder "burn out" in later life and become less problematic.

These behaviors usually begin in childhood and are often marked by early problems with the law. The most common childhood diagnosis is conduct disorder. People with APD usually lack empathy and often do not have the capacity to engage in close relationships. They may experience odd beliefs and behaviors as well as distorted and paranoid thinking. Such individuals have great difficulty conforming to social norms and rules making it very difficult for them to maintain employment and function within a family. Although individuals with APD are most commonly seen as a problem to society, they are also disabled. Many individuals with APD engage in high-risk, novelty-seeking behavior often associated with substance use. Because of these behaviors, they are much more likely to die prematurely or have morbidity associated with disease, vehicular accidents, and homicide or suicide attempts.

—Joseph Flaherty

See also Psychiatric Disorders.

Further Readings

American Psychiatric Association. 1994. *Diagnostic and Statistical Manual of Mental Disorders,* 4th ed. Washington, DC: American Psychiatric Association.

Johnstone, L. and D. J. Cooke. 2004. "Psychopathic-like Traits in Childhood: Conceptual and Measurement Concerns." *Behavioral Science and Law* 22(1): 103–125.

Paris, J. 2004. "Gender Differences in Personality Traits and Disorders." *Current Psychiatry Reports* 6(1): 71–74 (Review).

Websites

Antisocial personality disorder, Internet Mental Health, http://www.mentalhealth.com/dis/p20-pe04.html

Antisocial personality disorder, MedLine Plus, http://www.nlm.nih.gov/medlineplus/ency/article/000921.htm/

ANXIETY DISORDERS

Anxiety is an innate emotion and an adaptive mechanism that signals a potentially harmful internal or external change and enables us to avoid harm. When anxiety occurs for seemingly no reason, or in an exaggerated manner, to relatively innocuous stimuli and disrupts a person's life, an anxiety disorder (AD) is diagnosed. ADs are the most common psychiatric disorders in the world. Despite effective treatments, most ADs are not diagnosed or treated adequately. ADs are often chronic and disabling conditions associated with enormous emotional and monetary costs. Surprisingly, very little research has been done on the quality of life, functional impairment, and disability associated with ADs.

DISABILITY ASSOCIATED WITH ANXIETY DISORDERS

People with ADs experience significant emotional distress due to anxiety symptoms associated with an abnormally increased expectation of harm and overestimation of danger. This leads to a pattern of progressive avoidance of situations that may trigger symptoms, which, over time, envelops all aspects of life. They have an increased risk of developing depression, substance abuse, suicidal thoughts, and an excessive use of medical services. Anxiety also complicates the manifestation and treatment of other illnesses such as schizophrenia, depression, and heart disease. Severe ADs can be as disabling as other disorders associated with increased disability such as heart disease and depression. The seriousness and public health relevance of ADs is highlighted by a U.S. study that estimated the annual cost (for 1990) associated with ADs, to be $42 billion, accounting for almost a third of costs due to all mental disorders. More than 50 percent of those costs resulted from repeated use of nonpsychiatric health services.

Specific Anxiety Disorders

Panic Disorder

Panic disorder (PD) is characterized by sudden, sometimes spontaneous attacks of terrifying anxiety accompanied by mental and bodily symptoms such as the experience of terror, heart palpitations, and sweating. Fear of the attacks themselves generates a pattern of avoidance that can severely constrict the person's life. During attacks, fear that the symptoms may signal a heart attack, stroke, or other medical problem leads to repeated emergency room visits and expensive workups. People with PD report poor emotional and physical health and significant impairment of family life, and they have increased work absenteeism and decreased productivity. They are more likely to be financially dependent, attempt suicide, and have extremely high rates of using medical care compared to people without PD. PD patients are equally or more impaired on ratings of mental health and role functioning as people with depression or diabetes. They have higher rates of other ADs and depression, the presence of which increases the severity of the disability.

Social Anxiety Disorder and Specific Phobias

Social anxiety disorder (SAD) typically develops in adolescence, is more common in women, and usually runs a chronic course. SAD and phobias involve an exaggerated, irrational fear of usually nonthreatening objects or situations. Symptoms of anticipatory anxiety, distress when in the presence of the feared object or situation, and active avoidance of triggering situations are characteristic. SAD is often accompanied by depression and a higher risk of alcohol abuse. Persons with SAD are more likely to rate themselves as low functioning, to be impaired in their social relationships, and have a specifically increased risk of dropping out of school and college. They are more likely to have lower incomes, greater rates of unemployment, and financial dependency compared to those without SAD. Persons with SAD report significant subjective distress comparable to other ADs (such as PD). Even subthreshold SAD symptoms have been shown to be associated with significant disability, which increases with concurrent depression.

Generalized Anxiety Disorder

People with generalized anxiety disorder (GAD) have persistent worry and anxiety symptoms for at least a six-month period. GAD affects women more than men. Prevalence rates are higher in midlife, and it tends to run a chronic course. GAD is often accompanied by other disorders such as depression, PD, SAD, and substance abuse. Indices of disability in GAD such as impairment in social and role functioning and reduced work productivity have been reported to be comparable in severity with those for major depressive disorder. GAD is more prevalent in primary care patients compared to the general population and possibly the most common AD in this group. GAD patients in primary care have worse emotional and physical health perceptions than those with other ADs, increased unexplained physical symptoms, and high rates of use of medical care. People with GAD have also been shown to have significantly more impairment in social and role function compared to medical disorders such as diabetes and congestive heart failure, despite less physical impairment. The presence of depression (which is common), and other conditions, increases the burden of disability as well as economic costs (due to absenteeism, increased health care use, and hospitalizations).

Posttraumatic Stress Disorder

Persons exposed to a life-threatening trauma (sexual abuse, combat, natural disasters) may, as a sequel, have troubling symptoms including recurrent intrusive thoughts and dreams of the trauma, abnormally increased alertness and anxiety, and emotional numbing, as well as avoidance of situations that remind them of their trauma. Posttraumatic stress disorder (PTSD) is highly prevalent, tends to run a chronic course, and is often associated with other anxiety disorders, depression, and substance abuse. Patients have significant problems with anger and trust, leading to difficulty in interpersonal relationships. Follow-up studies of PTSD in war veterans reveal significantly diminished subjective well-being as well as increased physical limitations, unemployment, and increased work absenteeism and early medical retirement in firefighters. Veterans with war-related PTSD have high rates of health complaints, medical conditions, and health care use. Similar impairments of subjective distress, poor physical and emotional health, and impaired social and role functioning are also experienced by nonveteran PTSD patients (e.g., rape victims). PTSD often co-occurs with chronic pain and other medical conditions (such as HIV) and is associated with intensified pain, greater disability, and worse medical outcomes. PTSD is associated with the higher rates of suicide attempts compared to other ADs and the general population.

Obsessive-Compulsive Disorder

Obsessive-compulsive disorder (OCD) is characterized by the presence of repetitive, highly intrusive, anxiety-provoking thoughts and images known as obsessions, leading to mental and motor compulsions (repetitive ritualized thoughts or acts) to reduce the anxiety. People with OCD often spend several hours a day engaged in compulsions, to the exclusion of normal life activities. OCD usually manifests in children or young adults, tends to run a chronic waxing-and-waning course, and is associated with significant disability in many life areas. Many OCD patients report low self-esteem, tend to seek help very late, have an increased chance of being unmarried, and have high rates of major depression during their lifetime. People with severe OCD have seriously impaired independent living skills and social functioning, and they tend to be financially dependent, similar to people with schizophrenia. OCD is one of the most disabling (10th) of all medical illnesses in the world according to a World Health Organization study. Family members of the patient are often caught up in the compulsions, which reduce quality of life for the entire family and is a significant obstacle to treatment success.

ASSESSMENT, ADVOCACY, AND LEGISLATION

ADs are clearly and severely disabling, but surprisingly, assessment of functional disability in persons with anxiety and depression in primary care and specialty clinics is still not routine practice. Specifically targeting functional gains rather than just symptom reduction with treatments could greatly improve functional outcomes. Routine use of simple validated rating scales can objectively document functional impairment, aid in evaluating the true efficacy of treatments, and assist patients in their application for disability benefits or appropriate workplace accommodations. This is extremely relevant to persons with ADs, who often experience shame, ridicule, and stigmatization. The Americans with Disabilities Act (ADA) prohibits discrimination against an individual with a mental or physical disability in employment and other life areas and is of great potential value in efforts to improve functional capacities and reduce stigma of those with ADs. However, actual application of this legislation to patients with ADs is far from optimal. Though participation in family support groups has not been systematically studied, clinical observations suggest that such groups could provide useful information and support to people with ADs and their families.

THE EFFECTS OF TREATMENT

Several options for treating people with ADs exist, including cognitive-behavioral therapy and medications. Obstacles to treatment include frequent failure of the health system to detect disorders and the shame, fear, and stigma that often accompany diagnoses. Even when treated, many patients are left with residual symptoms and disability. However, there is also clear evidence that both effective psychotherapeutic and medical treatment can improve personal and occupational functioning, raise quality of life, and reduce unnecessary medical use costs in most ADs.

—Brian Martis

See also Behavior Therapy; Obsessive-Compulsive Disorder; Panic Disorder; Posttraumatic Stress Disorder; Psychiatric Disorders.

Further Readings

Anxiety Disorder Association of America. 2004. “Anxiety in the Workplace.” Retrieved January 31, 2004 (http://www.adaa.org/AnxietyDisorderInfor/workplace.cfm#q1).

Calhoun, P. S., H. B. Bosworth, S. C. Grambow, T. K. Dudley, and J. C. Beckham. 2002. “Medical Service Utilization by Veterans Seeking Help for Posttraumatic Stress Disorder.” *American Journal of Psychiatry* 159(12): 2081–2086.

Mogotsi, M., D. Kaminer, and D. J. Stein. 2000. “Quality of Life in the Anxiety Disorders.” *Harvard Review of Psychiatry* 8(6): 273–282.

National Institute of Mental Health. 2004. “Anxiety Disorders.” Retrieved January 31, 2004 (http://www.nimh.nih.gov/anxiety/anxietymenu.cfm).

Roy-Byrne, P. P., M. B. Stein, J. Russo, E. Mercier, R. Thomas, J. McQuaid, W. J. Katon, M. G. Craske, A. Bystritsky, and C. D. Sherbourne. 1999. “Panic Disorder in the Primary Care Setting: Comorbidity, Disability, Service Utilization, and Treatment.” *Journal of Clinical Psychiatry* 60(7): 492–499.

Stein, M. B. and Y. M. Kean. 2000. “Disability and Quality of Life in Social Phobia: Epidemiologic Findings.” *American Journal of Psychiatry* 157(10): 1606–1613.

Steketee, G. 1997. "Disability and Family Burden in Obsessive-Compulsive Disorder." *Canadian Journal of Psychiatry* 42(9): 919–928.

Wittchen, H. U., R. M. Carter, H. Pfister, S. A. Montgomery, and R. C. Kessler. 2000. "Disabilities and Quality of Life in Pure and Comorbid Generalized Anxiety Disorder and Major Depression in a National Survey. *International Clinical Psychopharmacology* 15(6): 319–328.

APHASIA

Aphasia is an acquired disorder of linguistic processing that disturbs translating thoughts into language. Aphasia does not arise from loss of memory for words as associated with dementia, or loss of organs of speech production as occurs after laryngectomy or muscles weakened by motor neuron diseases (e.g., ALS). All patients with aphasia suffer from the inability to precisely name objects on confrontation. Aphasia disturbs the syntax of language, the rules of organizing language, lexicon, and the meaning of the sounds.

Aphasia can be caused by stroke, head trauma, and primary or secondary brain tumors that destroy or disconnect portions of the speech-related centers of persons that are located in the left hemisphere of almost 90 percent of all humans. Two-thirds of left-handed persons have speech facility localized to their left cerebral hemisphere.

Nonfluent aphasia causes decreased rate of word production. Broca's aphasia causes mispronunciation, decreased fluency, loss of grammatical structure, and inability to repeat verbatim phrases that contain conjunctive, or conditional, words. These patients retain understanding and appropriate speech content and are angered by inability to communicate. The lesions of Broca's aphasia involves Brodman's areas 44, 45, and 46, but also areas 8, 9, 10. (See an illustration of Brodman's areas online at http://spot.colorado.edu/~dubin/talks/brodmann/brodmann.html.) Transcortical nonfluent aphasia is diagnosed when patients can repeat, but have impaired ability to name and to speak fluently. The lesion for this disorder lies in the frontal lobe of the speech-dominant hemisphere anterior to the locus for Broca's aphasia.

The fluent aphasias include Wernicke's and transcortical fluent aphasia. Persons speaking fluently but displaying faulty repetition and loss of meaningful content, who are unable to understand written or spoken words and unaware of meaningless utterances, are diagnosed with Wernicke's aphasia. Damage to posterior portions of left auditory association cortex (Brodman's area 22) and Brodman's areas 37, 39, and 40 produces Wernicke's aphasia. Persons repeating accurately but speaking or reading out loud with paraphrastic words, due to erroneous substitution of a letter or a concept, are diagnosed with transcortical fluent (sensory) aphasia.

Conduction aphasia (CA) is distinguished from other aphasias by inability to repeat accurately, intrusion of paraphrastic words, and normal fluency and understanding. CA is caused by damage to area 40, the supramarginal gyrus and the left auditory cortices (areas 41 and 42).

Global aphasia patients manifest nearly complete loss of ability to comprehend language and formulate speech, with right hemiparesis. Damage to the terminal branches of the left middle cerebral artery produces this disorder, or multifocal infarctions from emboli can damage Wernicke's and Broca's areas, sparing intervening basal ganglia and internal capsule. Speech output is greatly reduced due to damage to the head of the caudate nucleus and subjacent internal capsule. Loss of speech function cannot be attributed solely to an isolated area of the brain, but rather disconnection of working units within the brain.

Recovery from global aphasia depends on permanence of hemiparesis. If there is damage to Broca's and Wernicke's areas and sparing of the intervening tissue, recovery from global aphasia can occur. Treatment directed at the physiological defect will hasten recovery. Melodic intonation therapy ameliorates patients with loss of word production; visual communication therapy improves global and Wernicke aphasia.

—Edward J. Fine

See also Apraxia; Paul Broca; Speech and Language; Traumatic Brain Injury.

Further Readings

Damasio, Antonio R. 1992. "Aphasia." *New England Journal of Medicine* 326:531–539.

Damasio, Hannah and Antonio R Damasio. 1989. "The Lesion Method in Humans." Pp 38–82 in *Lesion Analysis in Neuropsychology.* New York: Oxford University Press.

Geschwind, Norman. 1965. "Disconnexion Syndromes in Animal and Man." *Brain* 88:237–294.

Websites

"Brodmann Areas in the Human Brain with an Emphasis on Vision and Language," Mark Dubin, University of Colorado, http://spot.colorado.edu/~dubin/talks/brodmann/brodmann.html

APRAXIA

Apraxia has been defined as a disorder of voluntary actions that can neither be referred to as elementary motor disorders, such as paresis or tremor, nor general cognitive problems, such as dementia or aphasia. Symptoms can be observed in a variety of settings, from traumatic brain injuries to cerebral infections to congenital disorders. Notions about apraxia have been important in our developing understanding of the workings of the human brain.

The concept of apraxia arose from the debate over cerebral localization of function in the late nineteenth century. In particular, it was linked to another condition, aphasia, a complete or incomplete inability to comprehend or use language (often because of brain injury, infection, or stroke). A central issue of this debate was whether language is an isolated function of the human mind, the neural substrate of which can be localized within the brain. Opponents of this compartmentalization of the human mind into localizable functions emphasized that aphasia is regularly accompanied by disturbances of nonverbal intellectual capacities. The German psychiatrist Carl Maria Finkelnburg observed that communicative gestures of aphasic patients are frequently clumsy and incomprehensible. In a very influential paper published in 1870, he posited that they suffer from a general "asymbolia" preventing the use and comprehension of any communicative signs. Ten years later, the linguist Heymann Steinthal used the term *apraxia* to denote the faulty use of everyday life objects, such as a fork and knife or a penholder, by patients with aphasia. He considered their errors an "augmentation" of aphasia.

Modern theories of apraxia have been shaped in the early twentieth century by the German psychiatrist Hugo Karl Liepmann. By systematic group studies, he confirmed the frequent occurrence of disturbed communicative gestures and aberrant use of tools and objects in patients with left-hemisphere brain damage and aphasia. To this confirmation, he added the new observation that these patients commit errors also when imitating gestures, an observation central to his conception of apraxia. He reasoned that in imitation the model of the intended movement is unequivocally provided by the demonstration and that errors thus testify to insufficient motor execution. He concluded that apraxia is a disorder of motor control that frequently accompanies aphasia but is itself a distinct and localizable symptom of circumscribed brain damage rather than indicating the augmentation of aphasia to general mental deterioration. For explaining the frequent co-occurrence of aphasia and apraxia after left-hemisphere brain damage, Liepmann speculated that the left hemisphere has a dominance for motor control beyond and perhaps above its dominance for speech.

The dependence of apraxia on left-hemisphere damage has since then been largely, although not completely, confirmed. Whereas the production of communicative gestures on command seems to be very tightly bound to left-hemisphere integrity, imitation of gestures and the use of tools and objects may be sensitive to right-hemisphere brain damage too depending on the exact nature of the task used to assess them. Liepmann's proposal that apraxia is a disorder of motor control fares less well in the light of contemporary research. His idea that faulty imitation implies deficient motor execution of a correctly conceived gesture was challenged by studies showing that patients who cannot imitate gestures have similar difficulties when asked to replicate them on a manikin or to select them from an array of pictures, and by reports of single patients in whom severely defective imitation of gestures contrasted with flawless execution of communicative gestures on command.

After more than 100 years of research, the existence of apraxia in many patients with left-hemisphere brain damage is firmly established, but its nature and its relationship to aphasia and to hemisphere dominance remain subject to debate and inquiry.

—Georg Goldenberg

See also Aphasia; Speech and Language; Traumatic Brain Injury.

Further Readings

De Renzi, E. 1990. "Apraxia." Pp. 245–263 in *Handbook of Clinical Neuropsychology,* edited by F. Boller and J. Grafman. Amsterdam, New York, and Oxford, UK: Elsevier.

Goldenberg, G. 2003a. "Apraxia and Beyond—Life and Works of Hugo Karl Liepmann." *Cortex* 39:509–525.

———. 2003b. "The Neuropsychological Assessment and Treatment of Disorders of Voluntary Movement." Pp. 340–352 in *Handbook of Clinical Neuropsychology,* edited by P. Halligan, U. Kischka, and J. C. Marshall. Oxford, UK, and New York: Oxford University Press.

▣ ARATA

See Australian Rehabilitation and Assistive Technology Association

▣ ARCHAEOLOGY

The consideration of disability in archaeology is a recent development. It has emerged in response to challenges to the discipline, particularly to those critiques that question archaeology's relevance in the contemporary world. Archaeological reactions to these concerns have included the development of both public archaeologies and community-based archaeologies. These ways of doing archaeology represent some archaeologists' attempts to frame archaeology outside its traditional niche as a private, professional, and academic pursuit. This is accomplished through collaborative projects formulated through the cooperation of archaeologists and communities from outside the discipline. Through these community-based methods, archaeologists hope to increase diverse communities' engagement with the past.

Public and community-based strategies ultimately allow archaeologists to forge connections with audiences and participants traditionally alienated from professional and academic circles. One such group of audiences and participants includes persons with disabilities. To create relationships with new audiences and participants, including persons with disabilities, archaeologists must address research questions related to the experiences and interests of these individuals. This has been enacted in two distinct ways.

First, archaeologists strive to understand disability in past human populations by placing disability at the center of their research questions. In so doing, they attempt to develop knowledge that is relevant to individuals concerned with experiences of disability across both time and place. To interpret disability in the context of past peoples, archaeologists make interpretations based on the consideration of various types of data. These data include, but are not limited to, the remains of structures, material objects, and human remains.

Archaeologists have traditionally based their interpretations of disability on medical models. Owing to the influence of larger sociopolitical movements, such as the disability movement, social models are becoming more common in archaeological interpretations related to disability. This trend builds on the use of social models to interpret and understand how humans have both constructed and experienced ideologies of gender, sexuality, age, and race across time and place.

Second, archaeologists have begun to recognize how ideas about ability, disability, and the body are connected with the practice of archaeology. This has occurred as a result of sociopolitical movements that have raised awareness about disability across communities and experiences. Media institutions present archaeology as a very physical pursuit. Moreover, these institutions portray archaeologists as nondisabled individuals. For instance, images of archaeologists with disabilities rarely grace the covers of glossy science magazines or show up on prime-time television specials. As a result of observations such as these, archaeologists have begun to develop research that looks at the ways in which ideas about ability and disability affect the accessibility of archaeology and archaeological programming. Some current research addresses these issues by focusing on the involvement or lack of involvement of people with disabilities in archaeology. In addition, following work that explores the theoretical issues connected to these relationships, more and more archaeologists are attempting to create practical, grounded solutions by archaeological programming that is accessible to a diverse range of embodiments and experiences.

—Meredith A. Fraser

See also History of Disability: Pleistocene Period.

Further Readings

Cross, Morag. 1999. "Accessing the Inaccessible: Disability and Archaeology." *Archaeological Review from Cambridge* 15(2): 7–30.

Hubert, Jane, ed. 2000. *Madness, Disability and Social Exclusion: The Archaeology and Anthropology of "Difference."* One World Archaeology No. 40. London: Routledge.

Resource: The Council for Museums, Archives and Libraries. 2003. "The Resource Disability Portfolio Guides." London: Resource: The Council for Museums, Archives and Libraries. Retrieved December 2, 2003 (http://www.resource.gov.uk/action/learnacc/00access_03.asp).

White, Esther C. 1993. "Do You See What I'm Saying? Teaching Deaf Students Archaeology at Mount Vernon." *Journal of Middle Atlantic Archaeology* 9:29–33.

ARISTOTLE (384–322 BCE)

Greek philosopher and scientist

Student of Plato, tutor to Alexander the Great, Aristotle is one of the most influential ancient figures in Western thought. A scientist and philosopher, Aristotle was interested in categorizing and systematizing all phenomena. Aristotle is important to disability studies for several reasons. His writings rest on careful observation; some observations are strikingly modern; others, such as his speculations in *Generation of Animals* that a female is technically a deformed male or that children sometimes inherit from their parents such characteristics as scars and brands, seem quaint at best. Aristotle considers the ideal state and proposes several highly regulated components of human organization in the *Politics*. These regulations, within a detailed caste system, include his recommendation for the elimination of deformed infants. "As to exposing or rearing the children born, let there be a law that no deformed child shall be reared" (1335b). Ironically, according to later biographers, Aristotle's own physical characteristics were far from perfect. In addition to being bald and having thin legs, he lisped. Paul Cartledge (2000:199–200) provided a succinct overview of Aristotle's life in *The Greeks: Crucible of Civilization*.

—M. Lynn Rose

See also Euthanasia.

Further Readings

Aristotle. 1932/1977. *Politics.* Translated by H. Rackman. Loeb Classical Library. Vol. 21 of 23 vols. Cambridge, MA: Harvard University Press.

Cartledge, Paul. 2000. *The Greeks: Crucible of Civilization.* New York: TV Books.

Huys, Marc. 1996. "The Spartan Practice of Selective Infanticide and Its Parallels in Ancient Utopian Tradition." *Ancient Society* 27:47–74.

ARNOLD, IVAN KARLOVICH (1805–1891)

Russian school administrator

Ivan Karlovich Arnold, who was deaf, was the founder of the first Moscow school for the deaf (1860). The school was later named after him—Arnoldo-Tretyakov School. He was educated in the St. Petersburg School for the Deaf and then in Berlin, Germany. He graduated from the Art Academy in Dresden, Germany. Arnold was the director of the Moscow School for the Deaf from 1860 to 1866.

—Anna Komarova and Victor Palenny

See also Deaf, History of the.

ART THERAPY

Art therapies allow individuals to express themselves through creative means. Often the process of making art is the core of the process of art therapy: Through the work, individuals can experience themselves as empowered, valued, able to achieve, and able to deal with a task. Art can articulate deep feelings and can bring unconscious issues to the fore. Group art therapy approaches can also foster sociality, and find forms of being with others not usually sanctioned by everyday life.

Dance, music, drama, drawing, photography, sculpture, creative writing—most art practices have specialized art therapy approaches associated with them. One significant difference between "mainstream" art practices and art therapy is the status of the final product: Concepts such as mastery, control, and commercial value are either not important or much less important than self-expression. Also, public consumption is not necessarily an aim of art therapy. Public display can have therapeutic effects on individuals, in particular, people who have seen themselves as being devalued, invalid, for a long time, but the processes and products of art therapy are also private, and often remain so.

Against both mainstream practice and art therapy approaches stands community or participatory art practice. Here, training is also often unimportant, and process is often stressed over product as a value in its own right. Different from art therapy, though, community and participatory practices often stress the community as the focus of the work practices. Doing something together and finding ways of expressing a shared vision become important concepts in this art practice, and public display is often seen as effective in community transformations.

Within disability culture, art therapies have a dual standing. On the one hand, art therapy approaches can be useful in allowing people to work through the social stigma or personal problems associated with impairment and disability issues. Art therapy is also often the first place where institutionalized people encounter the alternative expressive means of art, enabling them to find new perspectives on their life experiences.

On the other hand, the potential emphasis of art therapies on the individual as the locus of intervention can be seen to hinder political processes. For many disability activists, the "problem" of disability is not the individual and his or her acceptance or adjustment, but the wider social world and its exclusionary practices. The "medical" framing of art therapy, and the professional status of art therapists, many of whom are licensed or part of professional bodies that control training, can here be seen as extensions of the oppressive regime of normalization. For this reason, many disability activists resist the wider connotations of "therapy" and instead investigate other forms of art making, both inside and outside the mainstream.

—Petra Kuppers

See also Dance; Drama and Performance; Music; Poetry.

Further Readings

American Journal of Art Therapy. 1969–present.

American Journal of Dance Therapy. 1977–present.

Malchiodi, Cathy, ed. 1999. *Medical Art Therapies with Adults.* London: Jessica Kingsley.

ARTHRITIS AND CARTILAGE DISEASES AND INJURIES

Musculoskeletal diseases are the most prevalent causes of chronic medical disability, due to painful and/or restricted mobility of any joints, weakness, and potentially, associated predisposition to visceral impairments. Of the diseases that have been separated from "rheumatism," this entry briefly describes osteoarthritis (OA), gout, rheumatoid arthritis (RA), ankylosing spondylitis, and juvenile polyarthritis.

OA is by far the most common arthropathy. Its actual prevalence in relation to disability has been difficult to establish because surveys have usually based the diagnosis on radiographic findings and, except in advanced cases, the correlation between the radiographic findings and symptoms of pain and/or restricted motion is poor. OA primarily is a disease of articular cartilage, but not necessarily a consequence of aging. It is not a sufficiently specific diagnosis since cartilage may deteriorate for a variety of reasons. The disease may be an isolated result of injury to the affected joint or adjacent bone, or be due to asymmetric weight bearing, as results from unequal leg length. It can be attributed to a heritable predisposition affecting only the finger joints, or be the end result of cartilage damage from RA or gout. It may be multi-articular and resemble RA. Joint infection, mainly due to tuberculosis or gonorrhea, once was an important cause, but this has become rare since the advent of effective antibiotic therapy.

Treatment of OA has continued to depend mainly on analgesics with some anti-inflammatory potency. These numerous nonsteroidal anti-inflammatory drugs (NSAIDs) have largely replaced aspirin. The principal potentially serious side effect from the older "COX-1" medications is gastrointestinal bleeding, and from the "COX-2" medications cardiovascular injuries.

Advanced disease in individual joints is treated orthopedically. Joint replacements were first performed in the hips and now in many joints. These procedures are performed more frequently in cases of OA than RA. All require postoperative physical therapy to maximize range of motion and/or improve the strength of adjacent muscles.

Gout, which had frequently been a synonym for rheumatism, in the mid-nineteenth century, was the first to be differentiated by the new science of biochemistry. While it remained uncertain how an excess of uric acid in the blood causes gout, this substance became accepted as etiologically critical. As the diagnosis became dependent on the detection of uric acid, gout became recognized less frequently, and again increased as the sensitivity of uric acid determinations improved, achieving its present level in the 1960s. Gout also was the only musculoskeletal disease for which a fairly specific and effective medication became available in the nineteenth century. While colchicine can abort acute joint inflammation, it has no effect on the production or elimination of uric acid. Thus, the development of chronic disability due to the accumulation of tophi (uric acid nodules) was not diminished. Subcutaneous tophi may be disfiguring, but usually are not disabling. However, accumulation of urate in joints causes destruction of articular cartilage as well as bone, resulting in loss of motion, contractures, and cutaneous ulcers from which urate extrudes and chronic pain. These manifestations were first ameliorated by the discovery of drugs that stimulate increased elimination of uric acid by the kidneys (probenecid in 1952 first), and a drug that inhibits the synthesis of uric acid (allopurinol in 1963).

Numerous terms were coined for both rheumatoid arthritis (RA) and osteoarthritis (OA) and, indeed, RA was called OA at one time. *Rheumatoid arthritis* was proposed in 1859 because it did not imply "any necessary relation between it and either gout or rheumatism [i.e., rheumatic fever]" (Garrod 1859:542). The first objective differentiation was made radiologically, based on excess bone formation adjacent to joints (hypertrophy) in OA and loss of bone (atrophy) in RA. This soon was followed by description of a fundamental pathologic difference: OA begins with deterioration of articular cartilage and RA begins with inflammation of the synovial tissue that lines joints and only secondarily affects the cartilage.

The discovery of *rheumatoid factor* in the blood of patients with RA in the 1950s was hoped to overcome diagnostic uncertainties. However, it has proven to develop in no more than three-fourths of cases of RA and often only develops after clinical findings have made the diagnosis likely; furthermore, positive tests are not limited to RA. Overdependence on this test has led to many misdiagnoses. It, however, has prognostic value. The presence of rheumatoid factor tends to be associated with the eventual development of extra-articular manifestations and a more aggressive course of RA than is typical of cases that remain rheumatoid factor-negative.

The simplest of numerous sets of criteria to classify the severity of RA and response to treatment is the Steinbrocker Functional Classification:

I. Unrestricted in all activities

II. Normal activities can be performed, but with discomfort and/or some limitation of joint motions

III. Activities are limited mainly to self-care

IV. Incapacitated with little or no self-care capability

Salicylates, and soon thereafter synthetic analgesic drugs, became available about 1880, aspirin in 1898. Aspirin became accepted as the drug of choice for rheumatic fever, but pessimism prevailed for any drug therapy for RA. Physical therapy, mainly hydrotherapy and massage, was recommended with guarded hopes until the 1930s, when aspirin in larger doses became the choice for analgesia and gold salt injections to retard disease progression. The introduction of corticosteroid drugs, beginning with cortisone in 1950, because of their potent anti-inflammatory effect was for some years believed to be the solution to the treatment of RA. However, the recognition of serious side effects with chronic use dashed this hope after a decade. These drugs are still employed in small doses in combination with other agents. The breakthrough for advanced disease began in the 1950s with orthopedic surgery: osteotomies (realignment of a joint) and insertion of prosthetic joints. In the 1980s, immunologically based therapy that endeavors to interrupt the inflammatory process before joints are seriously damaged began and is now the forefront of research.

Two-thirds of patients with RA are women, and nine-tenths of patients with pain and stiffness usually progressing from the pelvis up the vertebral column are men. Nevertheless, whether the latter is a variant of RA, rheumatoid spondylitis, or a separate disease, ankylosing spondylitis, was not resolved until the 1970s. This resulted from the discovery of a class of antigens inherited from both parents (HLA) and that specific immunologic types of these could be distinguished. The presence of some of these types appeared to predispose to the development of or resistance to certain diseases. The presence of HLA-B27 was found to be present about 12 times as frequently in cases of ankylosing spondylitis than in the general Caucasian population, but no more frequent in cases of RA. The same technique demonstrated that most cases of polyarthritis in children are not RA.

The primary therapy of ankylosing spondylitis, contrary to other arthropathies, from the 1920s to 1950s was roentgen irradiation. For unknown reasons, this had a significant analgesic effect on the inflammation of the spinal column, but not on peripheral joints. It was discontinued not because a more effective drug had been found, but because of evidence that it may induce myelogenous leukemia. Courses of physical therapy are more important in this disease than in other arthropathies. There still is no therapy to prevent adjacent vertebrae to fuse and a strong tendency for anteflexion to develop. Therefore, the goal of the physiatrist is for erect posture to be maintained. A severely flexed back, even with unaffected extremity joints, can be totally disabling.

Juvenile polyarthritides occur less than 5 percent as frequently as RA. The eponym of Still's disease resulted from a description in 1897, which distinguished it from the then common disease of rheumatic fever. It remains uncertain how many diseases are included within childhood arthritis. The syndrome described by Still is the most acute, with fever and potentially multiorgan involvement, but the least common. Cases with few affected joints (*pauci-articular*) are the most frequent and most likely to undergo cessation of symptoms but most prone to ocular inflammation and permanent impairment of vision. In the third category (*oligo-articular*), many joints are affected without visceral involvement. These cases most closely resemble adult RA, but they differ in their HLA type. No doubt, a few children do develop adult RA or ankylosing spondylitis and some adults develop juvenile chronic polyarthritis. Skeletal disability depends greatly on the age of onset. The earlier the disease begins the more growth centers are likely to be affected. This may result, for example, in arrested growth of the jaw or, most often, small stature. The principal modes of treatment have until recently been physical and aspirin or NSAID because of apprehension of untoward effects from the more potent immunosuppressive agents.

—Thomas Benedek

See also Orthopedics; Pain; Physical Therapy.

Further Readings

Dieppe, Paul, Frank A Wollheim, and H. Ralph Schumacher. 2002. *Classic Papers in Rheumatology.* London: M. Dunitz.

Garrod, A. B. 1859. The Nature and Treatment of Gout and Rheumatic Gout. London: Walton & Maberly.

Koopman, William J., ed. 2001. *Arthritis and Allied Conditions,* 14th ed. Philadelphia: Lippincott Williams & Wilkins.

Lawrence, Reva C., Charles G. Helmick, Frank C. Arnett, et al. 1998. "Estimates of the Prevalence of Arthritis and Selected Musculoskeletal Disorders in the United States." *Arthritis & Rheumatism* 41:778–799.

Porter, Roy and G. S. Rousseau. 1998. *Gout: The Patrician Malady.* New Haven, CT: Yale University Press.

Websites

American College of Rheumatology, http://www.rheumatology.org
Arthritis Foundation, http://www.arthritis.org/

ASPERGER SYNDROME

HISTORY

Asperger syndrome is an eponymous neurodevelopmental disorder on the autistic spectrum, named after the Viennese pediatrician Hans Asperger (1906–1980). In 1944, he described a group of children with difficulties in affective contact, a lack of "practical intelligence," academic failure, motor clumsiness, and less frequently, obsessions or stereotypies, using the term *autistic psychopathy* (*Die Autistischen Psychopathen im Kindesalter*). The publication was largely ignored by contemporaries, appearing first in translation in 1991. In 74 of Asperger's case records, 68 percent fulfilled current criteria for Asperger syndrome while 25 percent fulfilled criteria for autism. Asperger's original descriptions were similar to those of childhood autism published in English by Leo Kanner in 1943.

EARLY LITERATURE

A number of early case descriptions have been provided for individuals who may have had Asperger syndrome, most notably in the Scottish case of Hugh Blair of Borgue. Many famous individuals may have been affected. These include L. S. Lowry, Ludwig Wittgenstein, Sir Keith Joseph, Eric Satie, Albert Einstein, and Isaac Newton.

DIAGNOSTIC CRITERIA

Asperger syndrome first appears as a clinical disorder in both the World Health Organization's International Classification of Disease (ICD-10) in 1993 and in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) in 1994.

On both the ICD and *DSM* systems, the core features of Asperger syndrome are as follows:

Impairment in social interaction

Restricted, repetitive behavior and interests

No "clinically significant" delay in language

No "clinically significant" cognitive impairment;

Does not meet criteria for other problems such as schizophrenia

Current nomenclature in the area of autism, including Asperger syndrome, is in a state of flux. Much of the published literature has used varied criteria not matching those in the current diagnostic systems. Less restrictive criteria have often been used, sometimes including those with communication problems, learning difficulties, and comorbid schizophrenia.

Physical Correlates

There are no consistently reported physical features. There are reports of excessive joint flexibility, dermatological abnormalities, and muscular dystrophy. Metabolic abnormalities, particularly of prefrontal cortical function, and of mitochondrial dysfunction are reported. No data have been collected indicating the extent of such associations.

Differential Diagnosis

DSM or ICD criteria do not clearly distinguish between Asperger syndrome and "high functioning autism." The distinction is supposedly on exclusion of clinically significant communication problems, learning delay, or schizophrenia. Autism can be diagnosed in individuals without such problems. Any difference would, therefore, need to be on the basis of factors additional to the current diagnostic criteria. Some reviews and research studies conclude there is no basis on which to differentiate.

Neuropsychological Differentiation

The neuropsychological profile in Asperger syndrome may discriminate the condition from other autistic spectrum disorders on the basis of a nonverbal learning disability (NVLD) profile. Similar differences have been reported in several studies analyzing Asperger cases. Others, however, have failed to replicate the findings across reported groups or consistently within the reported population. A subgroup of individuals with a diagnosis of Asperger syndrome shows an NVLD profile; a further subgroup does not.

—Kenneth J. Aitken

See also Autism.

Further Readings

Frith, U., ed. 1991. *Autism and Asperger Syndrome.* Cambridge, UK: Cambridge University Press.

Klin, A., F. R. Volkmar, and S. S. Sparrow, eds. 2000. *Asperger Syndrome.* New York: Guilford.

Prior, M., ed. 2003. *Learning and Behaviour Problems in Asperger Syndrome.* New York: Guilford.

Websites

Online Asperger Syndrome Information & Support (OASIS), http://www.udel.edu/bkirby/asperger/

▣ ASSISTIVE TECHNOLOGY

The Technology-Related Assistance for Individuals with Disabilities Act of 1988 defined *assistive* *technology* (AT) as "any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities." Conceptually, this definition encompasses not only the device but also the applied nature of how the device is used and who uses the device. Fundamental to this definition is the concept that assistive technologies enhance the ability of a person with a disability to participate in major life activities, actions, and tasks that would be difficult or impossible to perform without technologies that are used as a consequence of the individual's impairment-related limitations. This principle of enhanced ability includes an increased level of independent action, a reduction of time spent in activities of daily living, more choices of activities, and greater satisfaction in participating in activities. In short, the technology included under the rubric of assistive technology has to assist the user to participate in activities.

The other essential inclusion criterion for defining AT is setting the rules for who is or is not included as disabled. Who is considered disabled varies by the type and severity of impairment (mild arthritis to near total paralysis), functional capacity (reduced vision or hearing to deaf or blind), or type of activity (work tasks or personal care). Well over 50 definitions of disability are in use in the United State alone. Most of these definitions are based on the idea that the inability to do an activity is caused by the person's physical or cognitive impairment. Recent models and classifications of disability portray disability as the outcome of interactions of people and their environments. The expression of disability changes with nature of the environment. AT devices are a part of the environment that can reduce the expression of disability. AT is used to improve building accessibility, augment communication, afford computer access, allow environmental control over electronic devices, modify homes for access, assist with personal care activities and family activities, enhance mobility, stabilize seating, and modify workplaces and schools. The impact AT has on individuals' ability to interact effectively and independently in their environment has been established, and millions of people with disabilities rely on numerous AT devices daily.

The International Classification of Functioning, Disability, and Health (ICF) uses *disability* as a term that covers problems in organ structures and functioning, activity limitations, and restriction in participation. Improvement in any of these three components reduces disability and improves function. This new ICF classification framework allows for AT to be applied to reducing an individual's impairments, improving tasks performance in activities, and promoting full participation in major life activities. This framework is important because devices that improve structure and their functions (e.g., prosthetic legs, cochlear implants, implanted electronic control of bladder); devices that improve activity performance (e.g., voice entry, stair-climbing wheelchairs, communication boards); and environmental modifications (e.g., automatic door openers, level entrances, accessible bathroom) that reduce or eliminate restriction to participation can all fit the definition of AT.

AT SERVICES

A model for assessing the component interactions of the service delivery system has been developed to provide a framework for understanding how AT and the services often needed for acquiring AT can change performance of people with disabilities. This model, the human activity assistive technology model (HAAT), postulates four components: human, activity, assistive technology, and context. All components must be considered when selecting an AT device.

For simple, inexpensive AT, consumers require little if any help in acquiring devices. However, when the AT device is complex, costly, or paid for by a third party, the process of obtaining the device can require the help of individuals trained in providing AT services. The services needed may include evaluations for the types of AT that are needed to enhance physical, sensory, and cognitive functions; improve performance in activities; and increase participation in major life activities. The evaluation may involve an interdisciplinary team of people who have training in engineering, therapy, medicine, and device use. The introduction of AT into the life of a person with a disability requires an analysis of the existing capacities of the consumer, the settings where the AT will be used, the features included in the AT device, and the goals of the consumer and his or her family, employer, and educator.

After the AT device is selected that best fits the consumer's situation, the device is purchased. If the device is inexpensive or the consumer has the necessary funds, the acquisition is relatively straightforward. However, if other organizations provide the funds for the AT purchase (third-party payers), then the consumer may find the process difficult, lengthy, and frustrating. For example, when the AT is paid for by health insurance, the rules for what may be purchased and the forms required for reimbursement are very complex. This part of AT services requires that competent, experienced individuals assist the AT consumer in providing the information required by the reimbursement entity. For AT deemed to be medically necessary, a physician must sign and send in a letter that describes the individual's diagnosis, prognosis, and the functions that will be improved or maintained by the requested device. If the first request for reimbursement is denied, then a lengthy process of appeals ensues.

Once a device is acquired, services may be needed to fit, customize, maintain, or repair the AT device. These services are provided at durable medical equipment companies, rehabilitation facilities, or volunteer organizations. An additional important but often neglected service is the training or technical assistance provided to the consumer and his or her family in the use of the AT. For example, communication boards that allow individuals with no or poorly understood speech to make their needs and views known take a significant amount of time to learn. To offer this full array of services, people need to be trained in the wide variety of skills required to match the individual's needs and capabilities with the features of the AT.

AT CLASSIFICATION AND CHARACTERIZATION

Well over 20,000 AT devices are listed in computer databases (http://www.abledata.com/) and in sales catalogs. A device can be located using any of several strategies including product name, company, or key word, which helps when searching for a device. In the United States, the following categories are used to provide a structure for organizing AT: architectural elements, sensory elements, computers, controls, independent living, mobility, orthotics/prosthetics, recreation/leisure/sports, and modified furniture/furnishings. Each general category has a numeric codes as do the subdivisions of the categories. In Europe, AT devices used by individuals with disabilities are classified by the 2002 ISO 9999 "Technical aids for persons with disabilities—Classification and terminology." The classification uses a three-tiered hierarchical organization with the highest level describing a broad set of functions such as devices for housekeeping. The second level, subclass, includes a great degree of specificity in the use of the device (e.g., AT for meal preparation). The specific devices are classified at the third, or division, level, which could include devices such as special knives and cutting boards. These classifications allow for rapid information retrieval, tracking product inventories, and matching devices to impairment, activities, and participation.

AT devices that help people do activities can be characterized in many ways. Some devices are technologically complex, involving sophisticated materials and requiring precise operations and are referred to as *high tech*. Examples include prosthetic limbs that have joints that can move in several planes, powered mobility devices that balance on two wheels, communication devices that are programmed to output speech, and computer screen readers for graphic displays. Simple, inexpensive, and easy-to-obtain devices are commonly referred to as *low tech*. Finger extenders, large-handled eating utensils, canes, and large-print reading materials are examples of low-tech devices.

Another distinguishing characteristic is *hard technologies* and *soft technologies.* Hard technologies are tangible components that can be purchased and assembled into AT systems. This includes everything from simple mouth sticks to computers and software. Soft technologies are much harder to obtain because they are the human areas of decision making, strategy development, training, and concept formation. They may be available in one of three forms: (1) people (e.g., a teacher or therapist, effective strategies), (2) written (e.g., an instruction manual), and (3) computer (e.g., help screens). Hard technologies cannot be successful without the corresponding soft technologies, which are difficult to acquire because they are depend so much on human knowledge that is obtained slowly through formal training, experience, and textbooks.

Another distinction is between commercially available devices, those that are mass produced for the general population or for individuals with disabilities, and those that are custom made for an individual person. Often commercial products are designed according to the principles of universal design so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

Some AT devices are used in many different applications across a wide range of applications (general purpose) and others are intended for a specific application (special purpose). The first type includes (1) positioning systems for body support, (2) control interfaces (e.g., keyboards, switches, and joysticks), and (3) computers. Specific applications include devices for communication, manual and powered wheelchairs, feeding devices, hearing aids, and mobility aids for persons with visual impairments. Due to the unique needs of people with disabilities in each of these areas, the assistive devices must be specifically designed to meet those needs.

An assistive device may function as an appliance or a tool. The distinction is based on whether skill is required to operate the device. If there is skill required, the device is referred to as a tool and soft technologies become important. If no skill is required, then the device functions as an appliance. Examples of appliances are eyeglasses, splints, a wheelchair seating system designed for support, and a keyguard for a computer keyboard. Since a powered wheelchair requires skill to maneuver it and success depends on the skill of the user, the wheelchair is classified as a tool. Other examples are augmentative communication devices, electronic aids to daily living (EADLs), and reading devices for individuals who are blind.

AT USERS

In 1990, more than 13.1 million Americans, about 5 percent of the population, were using AT devices to accommodate physical impairments, and 7.1 million persons, nearly 3 percent of the population, were living in homes specially adapted to accommodate impairments. The majority of persons who use AT are elderly. They primarily use low-tech devices for maintaining their capacity to do their personal care (e.g., grab bars in the bathroom, special kitchen utensils, brighter lighting, canes, and walkers). Children and young adults use a significant proportion of the devices, such as foot braces, artificial arms or hands, adapted typewriters or computers, and leg braces. By 2000, approximately 10 percent of the U.S. population (25 million people) used AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

Several studies have reported that the most frequently used AT is mobility devices, 60 to 70 percent of all devices reported. Hearing devices, personal care devices, information technologies, and anatomical devices were reported by less than 10 percent of the people in these U.S. national surveys. The sources for payment of these devices included personal pay, health insurance, Medicare, Medicaid, vocational rehabilitation, employers, Department of Veterans Affairs, charitable organizations, and several others. The consumer most often pays for mobility devices (canes, crutches, walkers, specialized recreational wheelchairs), hearing devices, and home modifications. To offset those who pay for their own AT, deductions from earned income are allowed for most medically necessary devices, businesses that make their buildings accessible, and some modifications to vehicles. Many charitable organizations raise funds that are used to provide AT for children whose families cannot afford to pay for the devices the child needs.

High-tech devices for mobility (electric powered wheelchairs), voice recognition systems, and prosthetic limbs were most often paid for by third-party payers (e.g., private insurance, Medicare, Department of Veterans Affairs, schools, and vocational rehabilitation). Medicare and Medicaid (Centers for Medicare and Medicaid, CMS) uses a list (*Coverage Issues Manual*) of devices (termed *durable medical equipment*), to guide the purchase of about $7.7 billion of medically necessarily equipment. However, third-party payers such as private insurance companies, Medicare, Medicaid, and the vocational rehabilitation system have no consistent or compatible payment formulas across geographic regions, by types of impairment or disability, or by eligibility criteria.

BENEFITS OF AT USE

With the introduction of AT, some people with disabilities can to do activities without the help of family members or paid assistants, participate in parenting, improve their work productivity, avoid being institutionalized, and join in active recreational activities. Although many people with disabilities report that the use of AT greatly improves their quality of the life, measurement of the change in their choice, satisfaction, self-esteem, adaptability, safety, and competence have been little studied. Several new assessments are beginning to be used to assess how individuals feel about their devices, how they use their devices, and the quality of their participation in major life activities.

The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) is a measure of satisfaction with device features and service provision. The QUEST includes a broad range of variables reflecting that user satisfaction is a multidimensional phenomenon involving three types of variables: those involving the environment, pertinent features of the person's personality, and the characteristics of the AT itself. The QUEST allows the user to determine the relative importance of the satisfaction variable. The Psychosocial Impact of Assistive Devices Scale (PIADS) is a self-report measure that provides a measure of the psychological response to using AT devices. Three components of the PIADS are adaptability, competence, and self-esteem. The PIADS has been applied to measurement of outcomes with a variety of AT devices from eyeglass and contact lens wearers to users of EADLs. The PIADS and QUEST are reliable and valid measures of the consumer perspective in conjunction with assessments of functional status.

AT USE AND DISUSE

Most of the literature on AT is focused around the issues of design; consumer preferences; use, disuse, and abandonment; and costs and policy. Phillips and Zhao (1993) surveyed more than 200 users of AT devices and identified four factors that were significantly related to the abandonment of AT devices: (1) failure of providers to take consumer opinions into account, (2) easy device procurement, (3) poor device performance, and (4) changes in consumer needs or priorities. Consumers may abandon devices when their opinion is not considered. An essential component of the assistive device delivery system is an effective process that ensures that the needs and goals of the individual are accurately identified. Easy device procurement refers to the situation in which a consumer obtains a device from a supplier without an evaluation by a professional provider. This most often occurs with simple devices such as crutches, canes, or reachers. Poor device performance may be the result of inaccurate or inappropriate expectations on the part of the user, a mismatch between consumer skills and device characteristics, or actual device failure.

AT LEGISLATION

In addition to defining AT and AT services, U.S. federal legislation influences many aspects of AT from basic research to mandating provision to providing funds for purchase. The Rehabilitation Act of 1973 (P.L. 93–112), as amended, requires that programs receiving federal funds to provide reasonable accommodations (Section 504), make electronic equipment accessible to people with disabilities (Section 508), and include AT in vocational rehabilitation plans. The Individuals with Disabilities Education Act (IDEA) of 1990 (P.L. 101–476) and 1997 (P.L. 105–17) states that a child's need for AT must be determined on a case-by-case basis, made part of the individualized education plan (IEP), and paid for by the public school system. The Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Technology Act) and the Assistive Technology Act of 1998 (AT Act) provide funds for state programs to support increased AT services, advocacy for AT, information on AT, and alternative financing for AT. The Americans with Disabilities Act of 1990 (ADA) (P.L. 101–336) prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications. The impact of the ADA on AT and AT service provision has been enormous because nearly all building have had to make accessible entrances, bathrooms, program areas, and parking spaces. In addition, the provision of interpreters for the deaf, Braille, and large-print materials for the blind are required for effective communication. The Telecommunications Act of 1996 (P.L. 104–104) requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning.

FUTURE DIRECTIONS

Advancements in AT will occur in the technology itself, the services associated with the technology, and in the government policies and programs relative to AT. There will more widespread use of universal design, with less special-purpose AT required. People who have disabilities must continue to have access to the Internet to participate in the knowledge-based economy. This is a challenge since the Internet is becoming more and more dependent on multimedia representations involving complex graphics, animation, and audible sources of information; people who have disabilities have greater challenges in the retrieval of information. This creates barriers for those who are blind or deaf. Complicated websites that may include flashing pictures, complicated charts, and large amounts of audio and video data will be difficult for people who have learning disabilities and dyslexia to use.

AT needs to take advantage of advances in handheld, portable, and satellite-based communication and computing technologies to allow greater capability for persons with disabilities. Control interfaces that directly sense signals from the brain or nerves need to be further developed to allow greater control of devices by people with severe physical disabilities. Intelligent interfaces are required to adapt to the needs of persons with disabilities to allow greater participation in work, recreation, and self-care. Devices that can transmit messages from the brain to activate target muscles (e.g., finger, arms, feet, legs) without having to pass through the spinal cord need to move from basic research laboratories to clinical trials. Devices based on direct stimulation of the brain for those with visual and hearing loss need further development. Technology advances will also occur in materials (lighter, stronger, and more durable) used to make devices such as wheelchairs and the cases for portable electronic devices.

In the area of service delivery, community centers are needed where people with impairments can try different types of AT without first having to purchase a device. To avoid device abandonment, consumers of AT devices need a greater say in what is recommended for and provided to them and greater control over the resources to purchase AT.

In the area of government policy and programs, longitudinal studies are needed to assess the effects of AT interventions on the lives of consumers. Tax reforms are needed to reduce the cost of purchase for the individual and to encourage investment in new AT. Justification for government programs and health insurance purchase of AT needs to expand beyond medical necessity and in-home use to include activities that are important for community participation by people with impairments including employment, recreation, education, volunteer services, and many others.

—David B. Gray and Albert M. Cook

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Communication; Computer Technology; Educational Assistive Technology; Individuals with Disabilities Education Act of 1990 (United States); Information Technology; Mobility Aids; Rehabilitation Act of 1973 (United States).

Further Readings

Americans with Disabilities Act, P.L. 101–336, 104 Stat. (1990), pp. 327–378.

Batavia, A. and G. Hammer. 1990. "Toward the Development of Consumer-Based Criteria for the Evaluation of Assistive Devices." *Journal of Rehabilitation Research* 27(4): 425–436.

Centers for Medicare & Medicaid Services. 2002. *Coverage Issues Manual.* (http://www.cms.hhs.gov/manuals/pub06pdf/pub06pdf.asp).

Cook, A. M. and S. M. Hussey. 1995. *Assistive Technologies: Principles and Practice.* St. Louis, MO: Mosby Year Book.

Day, H. and J. Jutai. 1996. "Measuring the Psychosocial Impact of Assistive Devices: The PIADS." *Canadian Journal of Rehabilitation* 9:159–168.

Demers, L., R. Weiss-Lambrou, et al. 1996. "Development of the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST)." *Assistive Technology* 8:3–13.

Gitlin, L. N., M. Corcoran, and S. Leinmiller-Eckhart. 1995. "Understanding the Family Perspective: An Ethnographic

Framework for Providing Occupational Therapy in the Home." *American Journal of Occupational Therapy* 49(8): 802–809.

Individuals with Disabilities Education Act, P.L. 101–476, and 1997, P.L. 105–17 (1990).

Individuals with Disability Education Act Amendments, P. L. 105–17 (1997).

"ISO 9999:2000 Technical Aids for Persons with Disabilities—Classification and Terminology." 2003. International Standard for Organization (http://www.iso.org/iso/en/CombinedQueryResult.CombinedQueryResult?queryString=ISO+9999).

LaPlante, M. P., G. E. Hendershot, and A. J. Moss. 1992. *Assistive Technology Devices and Home Accessibility Features: Prevalence, Payment, Need and Trends*. Advance data from vital and health statistics, No. 217. Hyattsville, MD: National Center for Health Statistics. (DHHS Publication No. PHS-92–1250)

O'Day, B. L. and P. J. Corcoran. 1994. "Assistive Technology: Problems and Policy Alternatives." *Archives of Physical Medicine and Rehabilitation* 75:1165–1169.

Phillips, B. and H. Zhao. 1993. "Predictors of Assistive Technology Abandonment." *Assistive Technology* 5:36–45.

Rehabilitation Act, P.L. 93–112 (1973).

Technology-Related Assistance for Individuals with Disabilities Act, P. L. 100–407 (1988).

Telecommunications Act, P. L. U.S.C. 104–104, 110 Stat. 56 (1996).

Technology-Related Assistance for Individuals with Disabilities Act of 1988 as amended in 1994, P. L. 100–407 and 103–218.

Ticket to Work and Work Incentives Improvement Act of 1999, P. L. 106–170, 113 Stat. 1860 (codified as amended in scattered sections of 42 U.S.C.).

World Health Organization. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

Abledata, http://www.abledata.com/

ASSOCIATION FOR THE ADVANCEMENT OF ASSISTIVE TECHNOLOGY (AAATE) (EUROPE)

The Association for the Advancement of Assistive Technology in Europe (AAATE) is an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It was founded in 1995.

AAATE activities include a biannual conference, Special Interest Groups, the scientific journal Technology and Disability, seminars, and workshops. Current Special Interest Group topic areas include Robotics and Education.

AAATE interacts with sister organizations the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA) to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—*Glenn Hedman*

See also Assistive Technology; Australian Rehabilitation and Assistive Technology Association (ARATA); Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) (United States); Rehabilitation Engineering Society of Japan (RESJA) (Japan).

Websites

Association for the Advancement of Assistive Technology in Europe, http://139.91.151.134

ASTHMA

Asthma is an ancient condition and a modern chronic disease. Wheezing, struggling for breath, awakening every night with a cough that will not stop—these signs of an acute asthma attack, accompanied by a feeling of suffocation, form the central experience of asthma. Descriptions of wheezing, heavy breath, and desperate suffocation can be found in the earliest medical texts. The term had its origin in the ancient Greek, ασθμα, which described gasping or breathlessness, and first appeared in the *Iliad* of Homer to describe a hero out of breath after battle.

Before 1800, *asthma* was generally used as a generic term. Depending on the context and the author, it could describe the symptom of shortness of breath in anyone from any cause. By the 1820s, asthma was a disease we would recognize as much like our own ideas about the disease, a chronic illness characterized by wheezing and shortness of breath with its origins in pathological changes in the lungs. Other disorders that caused shortness of breath, most notably heart and kidney disease, no longer carried the label "asthma." Indeed, after early autopsies of "asthmatics" in the 1810s showed that most had heart disease, emphysema, or tuberculosis, asthma became defined as a chronic lung disease with no specific pathological findings at autopsy. Despite changes in diagnosis and treatment, asthma remained an entity without clear boundaries. The symptoms of asthma—coughing, shortness of breath, the flush of exertion, pain in the chest from the use of accessory breathing muscles—are shared by many respiratory disorders, infectious and noninfectious, chronic and acute. In the nineteenth century a cough or wheeze could be the first sign of a cold, asthma, bronchitis, tuberculosis, or a dozen other diseases. As stethoscopes, x-rays, and other tools and techniques became available, asthma was increasingly viewed as a distinct disease.

Because there has not been a single test, gene, lesion, sensitivity, antibody, or other biological or chemical marker of asthma, the disease has been defined by its symptoms. Several physicians in the eighteenth and nineteenth centuries who wrote about asthma also suffered from it. These doctors worked to convince their colleagues that asthma had a physical mechanism and was not simply a reflection of nervousness or emotional imbalance. Their dual status as experts and sufferers gave them credibility to challenge their colleagues' more stigmatizing perspective.

Because of changes in diagnosis, treatment, theory, and practice, every generation has its particular "asthma." The patient who suffered from asthma in 1850 would have been advised to visit Saratoga Springs or consider a trip to the Swiss mountains or the Mediterranean coast. In 1900, the same patient might have been offered adrenaline, cocaine, or one of a variety of patent remedies to inhale or smoke. In 1950, the same person's asthma might have been treated with steroids or an intensive analysis by an émigré disciple of Freud to work through suppressed emotions or a smothering maternal relationship. By 2000, the standard treatments for asthma were inhaled medications, symptom-relieving β-2-agonist inhalers such as albuterol and preventive treatments such as inhaled corticosteroids and inhaled sodium cromoglycate. Some patients also pursued allergy treatments including antihistamines and allergen immunotherapy—receiving weekly or monthly injections of purified pollens, venoms, and other allergens to modify their bodies' reactions to these substances.

The early 1900s saw improvements in available drugs for asthma, with the debut of adrenaline in 1900, theophylline in 1922, and ephedrine in 1924, all drugs with stimulant properties used to treat the acute asthmatic crisis. Cortisone, available in 1949, was established as a treatment for asthma within the first years of its use. Definitions of asthma have changed repeatedly as new treatments altered the way the disease was understood. In the era of stimulant therapy, bronchial spasm, hyperresponsiveness, or "twitchy airways" defined the disease. In an era of steroid treatment, the emphasis shifted to inflammation. Current treatments combine aspects of allergen avoidance in sensitive individuals with bronchodilating inhalers for both acute symptoms (chemically related to adrenaline) and anti-inflammatory inhalers to reduce the chronic reactivity of the lungs that can lead to chronic shortness of breath and severe attacks.

Since the 1960s, asthma prevalence, hospitalizations, and mortality have been rising in most of the industrialized world. In the United States from 1982 to 1994, asthma prevalence rates increased 61 percent, rising from 3.1 percent of the U.S. population to 5.4 percent, and by 2002 the national average asthma prevalence was over 10 percent. In some urban areas in the United States, up to 30 percent of children are reported to be asthmatic. These changes appear to be happening at both ends of the severity spectrum, with severe asthma and mortality worsening at the same time that there is expansion of the diagnosis toward milder cases of wheezing and shortness of breath with exercise or in the setting of upper respiratory infections that a generation ago would likely not have been diagnosed at all.

From 1970 to 1995, asthma hospitalization rates almost tripled in the United States. Asthma hospitalization rates among children under age 15 rose faster than in any other age group with 5.8 hospitalizations for asthma per 10,000 members of the U.S. population under age 15 in 1970 and 36.7 hospitalizations per 10,000 in 1995, a six-fold increase. By the mid-1990s, hospitalization rates for asthma in the United States began to level off, attributed more to the efforts of insurance companies to limit hospital stays than to decreases in population morbidity.

There has been a persistent linkage in the epidemiological literature around the world between asthma and measures of increasing Westernization, urbanization, and industrialization. The narrative of asthma as a "disease of civilization" is almost irresistible, inspiring images of the dirty, diseased city and the healthy countryside.

The epidemiology of asthma in the United States points to greater prevalence and severity of asthma (measured as rates of mortality and hospitalization) in inner-city areas with large poor and minority populations. Living in inner-city areas appears to confer special risk, but it is unclear whether the most important features of inner-city asthma severity and mortality are driven by poverty, environmental conditions (including allergens and atmospheric pollutants), housing conditions, health habits, access to health care, or other factors.

Asthma deaths, though terrifying, are rare, occurring in a tiny fraction of severe asthmatics, amounting to approximately 5,000 deaths per year for the past 10 years in the United States, out of an estimated population of 14 to 28 million asthmatics. These severe asthmatics typically have multiple risk factors for death, often including severe disease, poverty, and poor access to health care. In the United States from 1979 to 1998, asthma mortality rates doubled from approximately 1 per 100,000 to 2 per 100,000. While this increase was concerning, it took place against a background decline since the 1950s, when asthma mortality peaked at 4.4 per 100,000. In fact, the most obvious feature of the trends in asthma mortality in the United States is that in some years there are sharp discontinuities—increases, decreases, or inflections in the curve. These reflect changes in the coding of deaths under the International Classification of Diseases (World Health Organization 1992). Changes in classification have frequently shifted deaths between the categories of asthma, chronic bronchitis, and more recently chronic obstructive pulmonary disease (COPD). And while the sum of mortality from all of these disorders continues to climb, in part because of the continued impact of tobacco on population health, the significance of rising then falling asthma mortality in the past 25 years is not completely clear.

Is asthma truly rising in prevalence, or do more people now label their shortness of breath as asthma and seek treatment for the condition? It is possible that on the mild end of the asthma spectrum the prevalence rates can be partially explained as an increase in patients considering themselves sick and more physicians willingly prescribing the safer new generation of asthma drugs? The long-distance runner who is asthmatic according to specific criteria of bronchial hyperreactivity, and therefore seeks treatment, is quite a different asthmatic than the frail wheezing child of the past. This element of choice for the individual, visible in asthma, is seen throughout health and illness. People choose when to seek help, how, and what advice to accept or reject. What some label noncompliance others see as autonomy. Asthma is a disease without a cure, a diagnosis that an individual carries forever, and one that despite improved treatments can still force a change of occupation, residence, and lifestyle like so many other disabilities.

—Carla Keirns

See also Acute and Chronic Conditions.

Further Readings

Brookes, Tim. 1994. *Catching My Breath: An Asthmatic Explores His Illness.* New York: Times Books.

Johnston, Sebastian L. and Stephen T. Holgate, eds. 2002. *Asthma: Critical Debates.* Oxford, UK, and Malden, MA: Blackwell Science.

Peumery, Jean-Jacques. 1984. *Histoire Illustrèe de l'Asthme: de l'Antiquitè á Nos Jours.* Paris: R. Dacosta.

Platts-Mills, Thomas, ed. 1999. *Asthma: Causes and Mechanisms of an Epidemic Inflammatory Disease.* Boca Raton, FL: Lewis.

Sander, Nancy. 1994. *A Parent's Guide to Asthma: How You Can Help Your Child Control Asthma at Home, School, and Play.* New York: Plume.

Strobel, Martine. 1994. *Asthma bronchiale: die Geschichte seiner medikamentosen Therapie bis zum Beginn des 20. Jahrhunderts.* Stuttgart: Wissenschaftliche Verlagsgesellschaft mbH.

Weiss, Kevin B., A. Sonia Buist, and Sean D. Sullivan, eds. 2000. *Asthma's Impact on Society: The Social and Economic Burden.* New York: Marcel Dekker.

World Health Organization. 1992. *International Statistical Classification of Diseases and Related Health Problems: ICD-10,* 10th revision. Geneva: World Health Organization.

ASYLUMS

See Brigham, Amariah; Fernald, Walter

`ATA IBN ABI RABAH (645–733)

Nubian teacher

`Ata ibn Abi Rabah was a highly respected legal adviser and teacher at Mecca (Makkah) during the first century of Islam. He may have specialized in the rites of pilgrimage, a practice incumbent on all Muslims. Of Nubian descent, he was described as "black in colour, blind of an eye, flat-nosed, having the use of only one arm, lame of a leg, and woolly-haired; when advanced in life he lost the use of his sight" (*Ibn Khallikan's Biographical Dictionary* 1842–1871). These features would have been socially disadvantageous in Arabia, yet they were outweighed by the fact that his knowledge of law, and of the traditions of the prophet Muhammad, came directly from several of the companions of Muhammad.

—*Kumur B. Selim*

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

Further Readings

Ibn Khallikan's Biographical Dictionary. 1842–1871. Translated by Mac Guckin de Slane, Vol. 2, pp. 203–205. Paris.

Schacht, J. 1960. "'Ata' b. Abi Rabah." P. 730 in *Encyclopaedia of Islam*, new edition, Vol. 1. Leiden, the Netherlands: Brill.

ATTITUDES

Attitudes are evaluations that help decide how an individual will respond to the individual, group, object, or idea that is evaluated. When applied to persons with disabilities, attitude theories have concerned the content of attitudes, applicability of attitude content across cultures, formation of attitudes, and attitude change. In recent years, attitudes have become an important component of a social definition of disability. A key aspect of the social definition is that an individual's disability may be as much or more a function of negative attitudes and misconceptions of others in society than it is a function of the individual's particular limitations or conditions. Attitudes can create or remove barriers to full life for persons with disabilities. For example, attitudes can play a crucial role in facilitating or hindering implementation of legislation to counteract prejudice against people with disabilities. Understanding attitudes toward people with disabilities and learning how they can be changed may be a key factor in improving the lives of people with disabilities.

L. L. Thurstone (1946) defined an *attitude* as "the intensity of positive and negative affect for or against a psychological object" (p. 39). As the role of thought processes came under growing scrutiny by psychologists, definitions of attitudes shifted from being centered on responses to being seen as mechanisms influencing behavior, and increasingly included components of thought processes and behavioral intentions in addition to emotional responses. The shift from affective response to behavioral formation is reflected in the evolution of measures of attitudes toward persons with disabilities. Attitude measures developed in the 1960s and 1970s tapped general evaluations, beliefs, and intentions, with items containing general statements of beliefs about persons with disabilities, such as "Disabled people are often unfriendly" and items measuring affective responses, such as "The way disabled people act is irritating." By the 1980s, measures of attitudes included behavioral intentions, such as willingness to socialize with persons with disabilities. By the 1990s, attitudes began to be conceptualized according to their relevance to community inclusion efforts and implementation of the Americans with Disabilities Act.

Another aspect of the definition of attitudes is what is meant by the concept of evaluation. Once limited in scope to general positive or negative feelings about an object, evaluations involved in attitudes are now seen as having multiple dimensions. Osgood suggested that all attitudes may be reduced to positions on three dimensions. An object may be evaluated as to whether it is good or bad (moral dimension), strong or weak (potency dimension) and active or passive (activity dimension). A similar categorization has been used in classifying historical and societal attitudes toward persons with disabilities. This viewpoint suggests that in times and societies when persons with disabilities were regarded as good, strong, and active, they were deified, that is, believed to have special divine gifts. For example, the great astronomer Tycho Brahe (1546–1601) had a man with mental retardation as a close companion. Brahe wrote down the words spoken by the man, and then endeavored to put them together in order to form divine prophecies. However, in times when persons with disabilities were regarded as bad, strong, and active, social norms and policies would favor their destruction, as was the case during the height of the eugenics movement at the beginning of the twentieth century.

STRUCTURE OF ATTITUDES

Recent measures of attitudes toward persons with disabilities usually assess different types or facets of attitudes. For instance, the Community Living Attitudes Scale, a contemporary measure of attitudes toward inclusion of persons with intellectual disabilities, assesses contradictory and specific aspects of more general questions regarding community inclusion and participation. The Empowerment subscale asks about the extent to which persons with intellectual disabilities should make their own decisions even in the face of opposition by family members and professionals. In contrast, the Sheltering subscale assesses attitudes toward the protection of persons with intellectual disabilities from harm. Likewise, the Similarity subscale measures the extent to which respondents believe people with disabilities are similar to other people, while the Exclusion subscale assesses attitudes toward separating people with disabilities from the rest of society.

The shift from general evaluations to multiple facets of specific attitudes has occurred as philosophies of service and support for persons with disabilities have moved toward community inclusion. Increased inclusion efforts have revealed numerous specific instances when attitudes create barriers. For example, a person may hold the general belief that persons with disabilities should have job opportunities, but be reluctant to hire a person with a disability for a specific job. Because general positive evaluations may mask more negative specific attitudes, measures of attitudes have moved toward assessing behavioral intentions on specific issues. This movement is reflected in recent measures of attitudes toward mental retardation and eugenics, attitudes toward specific educational practices for children with disabilities, attitudes towards inclusion in education, disability rights and the Americans with Disabilities Act.

A final issue in the structure of attitudes is the extent to which the attitude structures found in U.S. studies generalize to other populations. Much of the disability attitude research has been conducted in the United States, and some has been done in other nations. Recent research suggests that dimensions of community inclusion attitudes generalize to samples in Japan, Korea, Israel, and Australia. However, these other nations emphasize these dimensions to different degrees than do samples in the United States. For example, a study of Israeli staff serving people with intellectual disabilities found that they emphasize protecting persons with disabilities from harm to a greater extent than they emphasize individual rights and self-determination, whereas the reverse was true of staff in the United States. It has also been suggested that in cultures characterized more by collectivism than individualism, measures assessing the effects of an individual's disability on families and communities may need to be developed to assess attitudes more accurately and completely.

ATTITUDE CHANGE

Another important aspect of attitude research is studying attitude change. Social psychologists have conducted substantial research into methods for changing attitudes, much of which applies well to attitudes toward persons with disabilities. The oldest theory of attitude change is the idea that attitudes change when the rewards for maintaining them change, an idea based in early learning theories. According to this theory, attitude formation is dependent on the incentives that are offered. Cognitive consistency theories, on the other hand, suggest that people strive to maintain consistency in their attitudes, and between their attitudes and their actions. Inconsistency is a painful state, which motivates a person to change either attitudes or behavior. Other theories of attitude change focus on the individual's conformity to others' attitudes or pressure to change from peer groups.

Another theory of attitude change draws both on cognitive consistency theories and on social psychological experiments demonstrating that hostility between groups can be reduced if common interests can be found and emphasized. If people come to see persons with disabilities as like themselves and not as different, the desire for consistency in their attitudes will motivate change in other disability-related attitudes. Thus, the more persons with disabilities are constructively included in normal community life, the more negative attitudes toward them should decline. In fact, several literature reviews have found prior positive contact with people with disabilities to be related to positive attitudes. Positive contact can also be an effective method of improving attitudes, especially when combined with information about people with disabilities. Recent research has shown that including disability-related course work, rationales for inclusion, and rotations or practicum experiences in the training of teachers, social workers, and health care providers can strengthen attitudes about the similarity of persons with disabilities to others, which may then lead to other attitude improvements.

An area of particular concern for attitude change interventionists is the persistence of a preferential hierarchy based on disability type. Several researchers have found that people with intellectual or psychiatric disabilities are viewed more negatively than people with physical disabilities.

Attitudes toward persons with disabilities play a key role in the inclusion of children with disabilities in education, and the employment of persons with disabilities. Educational inclusion has become common, yet not universal, practice in North America, Europe, and other continents. Attitude research has contributed to the success of educational inclusion efforts. Researchers have explored the attitudes of students with and without disabilities, teachers, and administrators and pointed out the necessity of providing appropriate supports for educational inclusion to succeed. Research on attitudes toward employment of persons with disabilities has found that global attitudes toward the employment of persons with disabilities tended to be positive. However, more specific behavioral intentions of employers were conflicted or negative when the costs of accommodation, training, supervisory demand, absenteeism, and other factors were considered.

More needs to be understood about attitudes toward persons with disabilities in the workplace and other contexts, and how such attitudes can be changed. Attitudes toward persons with disabilities are likely to be related to quality of services and acceptance in community life. As a marginalized group, persons with disabilities often face discrimination and exclusion. Public attitudes influence public policy and its implementation. Knowledge of attitudes of service providers and community members can identify areas in which persons with disabilities are most likely to encounter resistance, as well as highlight concerns which need to be addressed in education and advocacy.

—David B. Henry

See also Employment; Inclusion and Exclusion; Stigma.

Further Readings

Antonak, Richard F. and Livneh Hanoch. 1988. *Measurement of Attitudes toward People with Disabilities: Methods, Psychometrics and Scales.* Springfield, IL: Charles C Thomas.

Heal, Laird W. 1988. "The Ideological Responses of Society to Its Handicapped Members." In *Integration of Developmentally Disabled Individuals into the Community,* edited by L. W. Heal and J. I. Haney. New York: Brooks.

Henry, David B., Christopher B. Keys, David Jopp, and Fabricio Balcazar. 1996. "The Community Living Attitudes Scale: Development and Psychometric Properties." *Mental Retardation* 34:149–158.

Hernandez, Brigida, Christopher Keys, and Fabricio Balcazar. 2000. "Employer Attitudes toward Workers with Disabilities and Their ADA Employment Rights: A Literature Review." *Journal of Rehabilitation* 66:4–16.

Mateer, F. 1917. "The Moron as a War Problem." *Journal of Applied Psychology* 1:317–320.

Slater, Catherine. 2003. "History of Disability." Retrieved January 22, 2004 (http://caslater.freeservers.com/disability1.htm).

Thurstone, Louis L. 1946. "Comment." *American Journal of Sociology* (July 1946–May 1947): pp. 39–40.

Vidal, Anne-Marie. 2001. "Interview with Sabrina Dudley Johnson." Retrieved January 22, 2004 (http://www.ourfm-cfidsworld.org/html/sabrina_dudley_johnson.html).

Yuker, Harold E. 1988. *Attitudes towards Persons with Disabilities.* New York: Springer.

AUDIO DESCRIPTION

Audio description renders visual images into spoken word for people who are blind or visually impaired. It is the process of narrating visual aspects of theater, museum exhibits, films, television programs, parades, and other public venues in such a way that a partially sighted or blind recipient may access the presentation more comprehensively. It provides descriptions of key visual elements such as actions, scene changes, text captions, wardrobe, sets, scenery, facial expressions, colors, textures, and composition.

Gregory Frazier is credited with developing the concept of audio description in the 1970s. In 1981, Margaret Rockwell Pfanstiehl, visually impaired, and her husband, Cody Pfanstiehl, were the first to provide audio description to theater audiences at the Arena Stage Theater in Washington, D.C. In addition, they founded Audio Description Services, which promoted theater descriptions throughout the United States.

In the mid 1980s, WGBH in Boston became the first public television station to provide audio description. Using the secondary audio program (SAP), viewers can hear the regular sound track as well as a prerecorded audio description. The United Kingdom's Broadcasting Act of 1996 requires a minimum proportion of audio-described programming. Japan, Spain, and other countries voluntarily provide some audio-described television programming, and the United States provides up to 10 hours of audio-described programming per week.

Theater performances are narrated live, while playbill information can be prerecorded. A trained audio describer speaks into a microphone, which is transmitted directly to visually impaired patrons through an earpiece. In this way, the description is heard individually and does not disturb other patrons. Description of Hollywood films at cinemas, available on a limited basis, is provided with similar equipment, while video/DVD films use the SAP capability of the video player. Similarly, prerecorded material can be provided via personal headsets to patrons of museums, art galleries, nature walks, and other exhibits.

It is important for audio descriptions to be precise and concise to fit the short spaces between dialogues, and to be objective and specific to allow the audience members to draw their own conclusions. Audio descriptions should maintain the artistic integrity of the work without qualification or interpretation. For example, instead of stating, "She looks upset," the describer should translate her facial expression or action, such as "She is crying with her face in her hands."

Television audio description is currently under debate in the United States. In 2000, the Federal Communications Commission (FCC) passed regulations requiring 50 hours of described programming per quarter by each major broadcasting company. These regulations were overturned in 2002. While many U.S. blindness groups fought strongly to get these regulations in place, the National Federation of the Blind (NFB) and the Motion Picture Association of America (MPAA) led its opposition. The NFB advocated that an easier and more straightforward version be mandated, which includes on-screen text, especially for broadcast alerts, weather reports, and advertisements. The MPAA claimed First Amendment violations because of significant changes in the creative work required for audio description.

—Terri Thrower

See also Assistive Technology; Blindness and Visual Impairment; Television.

Further Readings

Peli, E., E. M. Fine, and A. T. Labianca. 1996. "Evaluating Visual Information Provided by Audio Description." *Journal of Visual Impairment & Blindness* 90:378–385.

Schmeidler, Emilie and Corrinne Kirchner. 2001. "Adding Audio Description: Does It Make a Difference?" *Journal of Visual Impairment & Blindness* (April): 197–212.

Websites

Audio Description International, http://www.adinternational.org/

AUDISM

The term *audism* was coined in 1975 by Tom Humphries to name the discrimination against persons who are Deaf. According to Humphries, *audism* would appear in a dictionary as the following:

> **audism** (o diz m) *n.* The notion that one is superior based on one's ability to hear or behave in the manner of one who hears.

The primary manifestations of audism, Humphries (1975) noted, is "in the form of people who continually judge deaf people's intelligence and success on the basis of their ability in the language of the hearing culture." It also appears when deaf people themselves "actively participate in the oppression of other deaf people by demanding of them the same set of standards, behavior, and values that they demand of hearing people" (n.p.).

As Humphries defines it, *audism* is a set of beliefs held by individuals (either hearing or deaf) that stem from the common assumption of the superiority of hearing over deafness. People who hold and practice these beliefs could be labeled "audists." At this level of analysis, Humphries's definition of audism would be roughly analogous to the notion of "individual racism" in which an individual holds beliefs and exhibits racist behaviors, ranging from assumptions about the intelligence of speakers of ebonics to racist jokes to the most obvious act of hate crimes. Thus, the initial discourse of audism came in the form of identifying "individual audism" as it manifests in the beliefs of individuals, whether hearing or deaf themselves.

It was not until the 1990s that the term *audism* appeared in several publications, beginning with Harlan Lane's 1992 *Mask of Benevolence,* where Lane defined *audism* as "the corporate institution for dealing with deaf people . . . [it] is the hearing way of dominating, restructuring, and exercising authority over the deaf community" (p. 43). Lane draws on the work of French philosopher Michel Foucault and others to interrogate the organizations that attempt to care for the Deaf but actually perpetuate the conditions of disability. Since the beginnings of deaf education and the science of audiology, Lane demonstrates, educational and medical institutions have assumed authority over deaf persons, claiming to act in their best interests while not allowing them to have a say in the matters that concern them the most. From the crude and tortuous methods of French doctor Jean Marc Gaspard Itard to the surgical procedure of cochlear implants, and from the strict oralism of Johann Conrad Amman to the current trend of mainstreaming, Deaf people have been physically and pedagogically coerced into adopting hearing norms, whether they wanted to or not.

Lane's analysis has added this important historical and systemic perspective to the notion of audism. This systemic perspective coincides with definitions of structural or systematic racism. Borrowing from David Wellman, Beverly Daniel Tatum (1997) defined racism as "a system of advantage based on race." "This definition of racism is useful," Tatum wrote, "because it allows us to see that racism, like other forms of oppression, is not only a personal ideology based on racial prejudice, but a system involving cultural messages and institutional policies and practices as well as the beliefs and actions of individuals" (p. 7). The implications of this definition are far reaching, for it brings the notion of "privilege" to the fore, which allows us to grasp the benefits allotted to white individuals within a white system of advantage. Such advantages range from the ease with which many white people get housing to the availability of "skin color" Band-aids (McIntosh 1988). Hearing privilege may come in the form of unfettered access to information, for which they cannot be faulted; however, settings that are designed to cater to deaf persons (i.e., schools) famously create barriers to communication by denying deaf persons access to a sign language and a visually rich learning environment. Therefore, there is a whole system that still favors hearing persons in environments designed for deaf people. Thus, we may succinctly use this definition to articulate the definition of *institutional audism* as a system of advantage based on hearing ability (Bauman 2004).

In this vein, Humphries's and Lane's contributions to the concept of audism have helped to make previously hidden structures of thought and beliefs visible. Institutional oppression is inherently difficult to detect, for it often masks itself as practices that follow a common sense. The production of common sense—that is, the hegemony of hearing-as-norm—has roots that extend to fundamental metaphysical questions of human identity. Thus, the discourse on audism has extended from the individual and institutional sites to include the metaphysical site. Thus, *metaphysical audism* refers to the orientation that links human identity and being with language defined as speech (Bauman 2004:242). Historically, humans have identified as the speaking animal; those who cannot speak are seen as akin to humans in body but animals in mind. In this orientation, we see ourselves as becoming human *through* speech. Brenda Brueggemann (1999) summed up this condition of audism in the form of a syllogism: "Language is human; speech is language; therefore deaf people are inhuman and deafness is a problem" (p. 11).

It is within this orientation (language is human/speech is language) that deaf people have frequently been described as animals, especially by those who have taught them. One of the earliest practitioners of audism, Johann Conrad Amman (1873) wrote in 1700 about deaf persons: "How dull they are in general. How little do they differ from animals" (p. 2). A century and a half later, an American oralist, Lewis Dudley, wrote that the deaf students are "human in shape, but only half-human in attributes" (quoted in Baynton 1996:52). The metaphorics of deaf-as-animal became especially widespread in the aftermath of Darwin's theory of evolution. For many educators of the deaf in the late-nineteenth and early-twentieth centuries, Doug Baynton explained, "To be human was to speak. To sign was a step downward in the scale of being" (p. 55). Yet it was not only the oralists who constructed their deaf pupils as animals. The famous successor of the Abbè de l'Epèe in France, Abbè Roch-Ambrose Sicard (1984), asserted even more vehemently that the deaf were even lower than animals prior to education. He referred to the uneducated deaf pupil as "a perfect nonentity, a living automaton . . . the deaf person lacks even that unfailing instinct directing animals destined only to have that as their guide" (p. 84).

If "deaf people are inhuman," then the logical consequence is that deafness becomes a problem of immense proportions. If poor deaf creatures are to be included in the human family, they must be made to be more fully human, that is, a speaking animal. At this point, the metaphysics of audism gives way to the systemic level where institutions of education, medicine, and law work to make the deaf creature a more normal, fully speaking human being.

Since the revelation of the grammatical nature of sign languages, and the recent work in neurolinguistics, we know that all humans (whether hearing or deaf) are born with the equal capacity to receive and produce a manual as well as a spoken language. Indeed, if this is true of humans born today, then we must assume that we have always had the potential to be the signing as well as the speaking animal. This insight now enables us to assert that Western traditions have been operating with an incomplete definition of language and hence of human identity. A theory of audism then, may work toward the deconstruction of this presumed natural status of speech in the Western metaphysical heritage so that speech may be seen not as *the only,* but as *one of* the modalities of human language. In this vein, a critique of the Western audist orientation dovetails with a critique of *phonocentrism,* a project set under way in Jacque Derrida's *Of Grammatology* (1974). Thus, the discourse of audism has implications, not only for those most directly affected by it but also for those who have critiqued, for one reason or another, the predominance of speech and phonetic writing as the sole means of human language modalities.

Now that these three levels of audism—individual, institutional, metaphysical—have become defined and published, a more thorough dictionary definition may be offered:

audism (o diz m) *n.*

1. The notion that one is superior based on one's ability to hear or behave in the manner of one who hears.
2. A system of advantage based on hearing ability.
3. A phonocentric orientation that links human identity with speech.

Now that the term is rapidly becoming more common in the Deaf community, it may function much like a lens that brings into focus what was previously obscured behind trappings of institutionalized procedure and protocol. Foregrounding these aspects of the oppression of deaf and hard-of-hearing persons allows resistance to be articulated as struggle for human rights and dignity for a linguistic minority to have access to a fully human language that best fits their visual learning needs. Thus, the discourse around audism allows its users to perceive the overarching drive to normalize Deaf persons into hearing persons as a severe instance of discrimination and oppression at the hands of a ruling majority.

—H-Dirksen L. Bauman

See also Alexander Graham Bell; Deaf Culture; Sign Language; Speech and Language.

Further Readings

Amman, Johann Conrad. 1873. *A Dissertation on Speech.* London: S. Low, Marston, Low and Searle.

Bahan, Ben and H-Dirksen L. Bauman. 2000, March. "Audism: Toward a Postmodern Theory of Deaf Studies" Conference presentation, Deaf Studies VI, Orlando, FL.

Bauman, H-Dirksen L. 2004. "Audism: Understanding the Metaphysics of Oppression." *Journal of Deaf Studies and Deaf Education* 9(2): 239-246.

Baynton, Douglas. 1996. *Forbidden Signs: American Culture and the Campaign against Sign Language.* Chicago: University of Chicago Press.

Brueggemann, Brenda Jo. 1999. *Lend Me Your Ear: Rhetorical Constructions of Deafness.* Washington, DC: Gallaudet University Press.

Derrida, Jacques. 1974. *Of Grammatology.* Translated by Gayatri Spivak. Baltimore: Johns Hopkins University Press.

Humphries, Tom. 1975. "Audism: The Making of a Word." Unpublished essay.

Lane, Harlan. 1992. *Masks of Benevolence: Disabling the Deaf Community.* New York: Alfred Knopf.

McIntosh, Peggy. 1988. "White Privilege and Male Privilege: A Personal Account of Coming to See Correspondences through Work in Women's Studies." Working Paper 189, Wellesley College Center for Research on Women.

Sicard, Roch-Ambrose. 1984. "A Course of Instruction for a Congenitally Deaf Person." In *Deaf Experience: Classics in Deaf Education,* edited by Harlan Lane, translated by Franklin Philip. Cambridge, MA: Harvard University Press.

Tatum, Beverly Daniel. 1997. *Why Are All the Black Kids Sitting Together in the Cafeteria?* New York: Basic Books.

Wellman, David. 1993. *Portraits of White Racism.* Cambridge, UK: Cambridge University Press.

AUGMENTATIVE COMMUNICATION

Augmentative communication comprises methods of communicating without speech. It includes the use of communication aids such as alphabet boards and electronic communication devices that speak as well as unaided communication methods such as sign language and gestures. People who are unable to speak or speak clearly rely on augmentative and alternative communication (AAC) methods to exchange information, express needs, maintain relationships, and participate in the activities of their community. People typically use multiple AAC methods and may use different methods with different people. For example, a child with dysarthric speech may be understood by his parents; however, for classroom participation and phone conversations he may need to augment his communication with an electronic communication device.

AAC methods are typically differentiated as aided or unaided. Unaided communication methods include vocalizations and speech attempts as well as gestures and body movements. It includes those communication methods used and understood by most people, such as facial expressions, looking (eye gaze), pointing, and other common gestures as well as methods and individualized signals that may only be understood by familiar people. For example, a child may raise her arm to talk about someone who is tall and look toward a kitchen to talk about food, hunger, or the person who cooks. In addition, people with limited ability to move may use subtle finger movements or eye blinks as codes for answering "yes" or "no" questions.

Sign language is also considered an unaided communication method. There are many different sign languages, specific to different cultures, such as American Sign Language and British Sign Language. Elements of sign language may be used by people who are unable to physically produce all the hand shapes and coordinated two-handed movements typical of sign languages. Individuals with limited speech and multiple impairments may be taught to use individual signs or adapted signs from a sign language. For example, a child with cerebral palsy may learn to use sign positions to quickly communicate needs or wants, such as touching a fist to his forehead to indicate "father" and touching his mouth to indicate "eat."

Aided communication methods include use of electronic and nonelectronic communication aids. Nonelectronic aids include writing tools, as well as boards and books with letters, words, pictures, and/or other symbols. There are many types of communication symbols; however, Blissymbolics, a language composed of more than 2,000 graphic symbols, is currently used in 33 countries. Also, Boardmaker, a graphics database for making communication aids, contains more than 3,000 picture communication symbols translated into 24 languages. People may communicate by eye-pointing or directly touching symbols with their fingers or other body parts. If someone cannot point, a communication partner may point to symbols until the person indicates which symbols he or she wants.

The category of electronic communication aids includes more than 100 dedicated communication devices, as well as computer-based communication systems and AAC software. The selection of devices is based on individual needs and capabilities of the person in his or her environment. For example, people who can spell typically choose devices that have synthesized speech to speak messages that are typed. Most devices allow people to sequence words/symbols to create messages or recall pre-stored phrases. People who cannot operate devices by touching symbols or letters may use alternate access methods such as scanning, joystick, and mouse emulation.

—Patricia A. Politano

See also Assistive Technology; Autobiography; Communication; Computer Technology; Sign Language; Speech and Language.

Further Readings

Bliss Communication International. 2001. “Blissymbolics.” Toronto, ON: Bliss Communication International (http://home.istar.ca/~bci/).

Freid-Oken, Melanie and Harold Bersani. 2000. *Speaking Up and Spelling It Out.* Baltimore: Paul H. Brookes.

Hattie B. Monroe Barkley Memorial Augmentative and Alternative Communication Centers. 2004. “AAC Vendors Information.” Lincoln: University of Nebraska–Lincoln. Retrieved April 5, 2004 (http://aac.unl.edu/).

Warrick, Anne. 1998. *Communication without Speech: Augmentative and Alternative Communication around the World.* Toronto, ON: International Society for Augmentative and Alternative Communication.

Websites

Boardmaker, http://www.mayer-johnson.com/software/Boardmkr.html

International Society for Augmentative and Alternative Communication, http://www.isaac-online.org

AUGUSTINE, SAINT
(354–430 CE)

Roman philosopher and Christian reformer

One of the four fathers of the Catholic Church, Saint Augustine of Hippo was born in Tagaste (Algeria) and died in Hippos (Annaba), his life spanning the formal collapse of Antiquity and the rise of the Middle Ages, with the fall of Rome (410). In between, he wrote approximately 5 million words, which substantially reshaped the early Church and the nature of its subsequent development; in particular he helped to reform the newly Christianized Rome and to unify the concepts of salvation and faith. His principle works include the *Confessions* (ca. 397–400), *On Christian Doctrine* (ca. 397), and *The City of God* (413–426).

At least two Augustinian aspects relate to disabilities: his life and works. The man himself endured a mysterious, painful chest condition in his 32nd year, impairing his teaching and cutting short his meteoric rise in Roman academics. His convalescence, however, allowed his baptism by (Saint) Ambrose and his eventual elevation to the bishopric of Hippo. As he entered old age, Augustine was plagued by recurrences of this condition and by many debilities of aging. Both experiences notably affected his faith and his writings.

In his works we find numerous connections with disability, two of which are mentioned here. Critically, Augustine formulated the core of the evolving ecclesiastical precept of Christian charity with its far-flung impact on disability. In addition, Augustine’s neoplatonic dualism offers tantalizing insights into the Christian supremacy of the soul and yet the author’s profound dependence on experiences of the body to interpret the soul. Much work remains to be done to integrate Augustinian precepts with modern disability theory.

—Walton O. Schalick III

See also Charity.

Further Readings

Augustine, 1992. *Confessions.* Edited by James O’Donnell. Oxford, UK: Oxford University Press.

Brown, Peter. 1969. *Augustine of Hippo: A Biography.* Berkeley: University of California Press.

Websites

Augustine of Hippo, http://www.georgetown.edu/faculty/jod/augustine

AUSTIN, MARY HUNTER

(1868–1934)

American author

Raised in Illinois by a disabled Civil War veteran and a mother who was a nurse and temperance activist, Austin's youth involved an early awareness of the familial impact of disability. After college, Mary Hunter moved to California, where she soon married Stafford Wallace Austin and gave birth to their only child, Ruth Austin (1892–1918). Ruth's developmental disability (possibly autism) soon became apparent; Mary Austin struggled to provide or arrange adequate care for her daughter, and in 1904 placed the girl in a private hospital in Santa Clara, where she would remain until her death. Mary Austin's disappointment, guilt, and sadness about her daughter inspired her to work for marriage reforms and sex education. In her Western short stories, disabled characters appear often, and themes of "nature versus nurture" are common. Austin's 1932 autobiography, *Earth Horizon,* was frank about the isolation Mary experienced as a young mother, the blame she placed on her husband, and the pressure she felt in her career: "Caring for a hopelessly invalid child is an expensive business. I had to write to make money," she explained, in a 1927 essay.

—Penny L. Richards

See also Family.

Further Readings

Richards, Penny L. 2003. "Bad Blood and Lost Borders: Eugenic Ambivalence in Mary Austin's Short Fiction." Pp. 148–163 in *Evolution and Eugenics in American Literature and Culture, 1880–1940: Essays in Conflict and Complicity,* edited by Lois Cuddy and Claire Roche. Lewisburg, PA: Bucknell University Press.

Stineman, Esther Lanigan. 1989. *Mary Austin: Song of a Maverick.* New Haven, CT: Yale University Press.

AUSTRALIA

See Disability in Contemporary Australia: Disability Studies: Australia

AUSTRALIAN REHABILITATION AND ASSISTIVE TECHNOLOGY ASSOCIATION (ARATA)

The Australian Rehabilitation and Assistive Technology Association (ARATA) provides a forum for exchange of information between professionals and consumers involved in assistive technology. ARATA achieves this through conferences, regional chapters, and a quarterly newsletter.

Special interest groups (SIGs) also give ARATA members a means of sharing ideas on specific areas of assistive technology. SIGs exist in augmentative and alternative Communication, manufacturers and suppliers of communication/computer assistive technology, computer users and environmental control systems, service delivery and government policy, wheeled mobility and seating, and human perspectives of technology.

ARATA interacts with sister organizations the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Association for the Advancement of Assistive Technology in Europe (AAATE), and the Rehabilitation Engineering Society of Japan (RESJA) to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Assistive Technology; Association for the Advancement of Assistive Technology in Europe (AAATE) (Europe); Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) (United States); Rehabilitation Engineering Society of Japan (RESJA) (Japan).

Websites

Australian Rehabilitation and Assistive Technology Association, http://www.e-bility.com/arata/index.php

AUTISM

Autism is one of the most controversial and provocative disability topics. From diagnostic methods to questions of origin, autism maintains an ambiguous existence. Autism evades classification; depending on perspective and discipline, autism appears under many classificatory rubrics. Autism is often defined as a neurological condition, psychiatric/psychosocial profile, pervasive developmental disorder, comprehensive communication disorder, or disintegrative sensory pathology. Researchers in medicine, hard sciences, social sciences, and the humanities, as well as parents, teachers, and professionals, actively contest the meaning, cause, and implications of autism. In any case, neither theory nor statistics exhausts the full scope of autism. Furthermore, any accurate account of autism necessitates the voices, thoughts, and experiences of autistic individuals.

AUTISM SPECTRUM

Autism constitutes a continuum of impairment. Hence, contemporary autism specialists articulate a spectrum of autism variations. The autism spectrum ranges from highly verbal, high-functioning individuals with superior intelligence, to nonverbal persons with low IQs. These impairments may or may not be disabling depending on their location along the autism continuum and environmental barriers. About 10 percent of people with autism have some form of savant skills—special limited gifts such as skill in memorizing lists or calculating calendar dates, drawing ability, or musical skills. Many people with autism have unusual sensory perceptions.

HISTORICAL CONTEXT

Leo Kanner, a child psychiatrist at Johns Hopkins University, first recognized autism as a syndrome in 1943. Kanner described a social impairment characterized by some of the following traits: aloofness; lack of social reciprocity; absence of eye contact; an inability to effectively communicate; repetitious, stereotyped behavior such as rocking, hand flapping, or preoccupation with seemingly arbitrary facts like types of vacuum cleaners; and strong resistance to changes in environment or routines.

Part of the controversy surrounding autism derives from Bruno Bettelheim's archaic theories. After being interned in German concentration camps at Dachau and Buchenwald from 1938 to 1939, Bettelheim immigrated to the United States. As the head of the Orthogenic School at the University of Chicago, he employed a controversial theory of autism, which blamed mothers' emotional indifference. Bettelheim claimed these so-called refrigerator mothers were to blame for their child's autism. Many autistic children institutionalized in his school were isolated and abused under the auspices of therapy. Ultimately, the research community discredited and renounced Bettelheim's theory of autism. In 1990, Bettelheim committed suicide.

MODERN DIAGNOSTICS

The fourth *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) of the American Psychiatric Association constitutes the dominant diagnostic tool. The Autism Diagnostic Interview-Revised (ADI-R) operationalizes the American Psychiatric Association's *DSM-IV* criteria for diagnosing autism. Both the ADI-R and *DSM-IV* consider effects in three main areas: communication, social development, and restricted, repetitive behaviors. Furthermore, the *DSM-IV* corroborates diagnostic practices used by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). According to the *DSM-IV*, Autism is a type of pervasive developmental disorder. It interferes with a person's ability to communicate with and relate to others. Autism is a lifelong condition. Autism affects how a person perceives and processes sensory information. Signs of autism almost always develop before a child is three years old, although the condition is frequently undiagnosed until later. Typically, parents first become concerned when they notice their toddler does not respond or interact like other children of the same age. Toddlers with autism do not usually babble or talk normally, and they may seem to have hearing problems. Early diagnosis and treatment helps young children with autism develop to their full potential. However, standard treatment guidelines to achieve this goal have not yet been established by the pediatric community.

Autism is often difficult to diagnose. Unlike fragile X or Down syndrome, autism cannot be located in any chromosomal structure. Most research suggests that people with autism have irregular brain structures. More study is needed to determine the cause of these irregularities, but current research indicates they are inherited. While there is some evidence that suggests neurological or physiological differences in the brains of autistic people, medical authorities still rely on behavioral characteristics to assert an autism diagnosis. Parents who have had one child with autism are more likely than other couples to have a second child with autism. There is no way yet identified to prevent autism, but experts agree that early educational intervention, often in conjunction with medicine or therapy, increases an autistic individual's chances for social success and a high quality of life.

—Heather Stone

See also Asperger Syndrome.

Further Readings

American Psychiatric Association. 2000. "Autistic Disorder." Pp. 70–75 in *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed.—text revision. Washington, DC: American Psychiatric Association.

Finn, Molly. 1997. "In the Case of Bruno Bettelheim." *First Things* 74 (June/July): 44–48.

Filipek, P. A., et al. 2000. "Practice Parameter: Screening and Diagnosis of Autism." Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology* 55:468–479.

Grandin, Temple. 1986. *Emergence: Labeled Autistic*. Navato, CA: Arena.

———. 1996. *Thinking in Pictures.* New York: Vintage.

Teplin, S. W. 1999. "Autism and Related Disorders." Pp. 589–605 in *Developmental-Behavioral Pediatrics*, 3d ed., edited by M. D. Levine et al. Philadelphia: W. B. Saunders.

Thorsos, Deborah Ivy. 2000. *Sour Sweet: Adversity into Creativity.* Renton, WA: First Word.

Vastag, B. 2001. "Congressional Autism Hearings Continue: No Evidence MMR Vaccine Causes Disorder." *Journal of the American Medical Association* 285(20): 2567–2569.

Volkmar, F. R. and A. Klin. 2000. "Pervasive Developmental Disorders." Pp. 2659–2678 in *Kaplan and Sadock's Comprehensive Textbook of Psychiatry*, Vol. 2, edited by B. J. Sadock and V. A. Sadock. Philadelphia: Lippincott Williams & Wilkins.

Williams, Donna. 1994a. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic.* New York: Avon Books.

———. 1994b. *Somebody Somewhere: Breaking Free from the World of Autism.* New York: Times Books.

———. 1996. *Like Color to the Blind.* New York: Times Books.

▣ AUTOBIOGRAPHY

Insofar as it is regarded as a departure from a norm, disability, especially visible disability, seems to demand or provoke autobiographical narrative: What happened to you? In fact, a collection of autobiographical narratives edited by Lois Keith has been published under that title. Yet, until very recently, autobiographical narrative of disability has been rare. Instead, third-person narrative has dominated the representation of disability—in various literary genres, such as drama and fiction; in mass media; and in tacit cultural scripts. Disability has loomed large in myth, legend, and drama from the classical Greeks onward and in the novel from its more recent origins. Historically, then, disability has been represented primarily by nondisabled writers and almost exclusively in fictive or imaginative genres.

Such representation, moreover, has typically been hostile or, at best, patronizing toward people with disabilities. Disability has largely been represented as a trope for a moral or spiritual condition (usually, but not always with a negative valence), rather than as a lived condition of interest and value in itself. The most prejudicial "explanations" for disability have been divine disfavor or moral flaw in the individual (which are variants of a single trope). Many conventional rhetorics of disability—for example, those of triumph or spiritual compensation—tend to devalue it, portraying it as a problem for an individual to overcome through force of will or for God to offset through force of grace.

Before 1900, autobiographical representation of disability was sporadic. In the latter half of the nineteenth century, a small number of American women produced narratives of institutionalization in mental asylums. And from the mid-nineteenth to the mid-twentieth centuries, tuberculosis patients produced numerous written (but not always published) accounts of illness and invalidism. In the second half of the twentieth century, personal narrative of disability grew significantly. For his classic study *Stigma: Notes on the Management of Spoiled Identity,* Erving Goffman surveyed the extant autobiographical literature; his bibliography is thus a good resource for early narratives, most of which concern physical or sensory impairments and appeared before World War II. (One of these, Katharine Butler Hathaway's *The Little Locksmith,* was recently rediscovered and reprinted.) The return of disabled veterans after the war gave a new visibility to disability autobiographies such as Harold Russell's *Victory in My Hands;* while exceptional, insofar as circumstances associated disability with patriotic duty, sacrifice, and heroic masculinity, these narratives may constitute a market breakthrough.

The next waves of narratives had to do with disability caused by disease rather than war. The spread of polio (and its middle-class demographics) gave rise to a significant number of narratives; polio was thus perhaps the first disabling condition to generate a significant number of autobiographical narratives over a short period of time. Decades later, HIV/AIDS, an epidemic with very different demographics and politics, also generated a considerable literature. In the early years of that epidemic, however, when AIDS was tantamount to a death sentence, it was typically represented biographically, by surviving partners or relatives; only after the development of drugs that made it possible to live with AIDS as a chronic illness did autobiographical accounts proliferate. The autobiographical literatures of polio and AIDS (and breast cancer) suggest, then, that one important factor in the development of disability autobiography has been medical advances that have enabled individuals to survive serious illnesses. This is true of the growing autobiographical literature of paraplegia and quadriplegia as well; only in an era when people can live indefinitely with significant paralysis can these conditions generate much in the way of autobiographical literature.

A different phenomenon was the sudden proliferation in the 1990s of narratives devoted to a large range of conditions, some relatively obscure, some of recent cultural (read medical) creation, hence hitherto absent from autobiographical literature. Such conditions include (in alphabetical order) amnesia (Robinson), amyotrophic lateral sclerosis or Lou Gehrig's disease (Robillard), Asperger syndrome (Willey), asthma (Brookes, DeSalvo), cystic fibrosis (Rothenberg), deformity of the legs (Fries), depression (Styron), diabetes (Roney), disfigurement (Grealy), epilepsy (McLean, Robinson), locked-in syndrome (Bauby), multiple sclerosis (Mairs), obsessive-compulsive disorder (Wilensky), stroke (McCrum and Robinson), stuttering (Jezer), Tourette syndrome (Handler and Wilensky). More remarkable, conditions that might seem to preclude verbal self-representation have recently been given autobiographical treatment: autism (Grandin, Williams), Down syndrome (Kingsley and Levitz), and early-stage Alzheimer's disease (DeBaggio, McGowin). Conditions that preclude writing in conventional (i.e., manual) modalities have been represented by way of collaborative mediation. For example, Ruth Sienkiewicz-Mercer, who has cerebral palsy so severe that she cannot walk or talk, wrote *I Raise My Eyes to Say Yes* with the assistance of Steven B. Kaplan and through the mediation of customized word boards.

Autobiography is a particularly valuable and liberatory medium for the representation of disability because by definition it involves *self*-representation; the growing number of disability autobiographies is encouraging insofar as it suggests that the marketplace is opening up to the voices of disabled people. Autobiography is increasingly living up to its potential as the most democratic, most catholic (i.e., inclusive), and most accessible of literary genres. Indeed, this phenomenon seems to parallel the increasing inclusion of disabled people in public life in the United States in the wake of the Americans with Disabilities Act (1990). As legislation mandates their inclusion in public institutions, and as such individuals are revalued in the body politic, people with disabilities have felt encouraged to represent themselves—in the political as well as mimetic sense—in autobiography. They become more visible, more audible, more assertive. The relation between civil rights legislation and autobiographical discourse is a recursive one: Each at once reflects and advances the other.

Numbers are not everything, however, and self-representation is not necessarily advocacy. Even contemporary disability autobiography sometimes recycles and thus perpetuates prejudicial rhetorics. One such rhetoric is that of spiritual compensation; in this schema, the disabled individual finds compensation in the spiritual realm for a physical or sensory impairment. The formula can be found in contemporary narratives such as Reynolds Price's *A Whole New Life,* which has to do with paralysis caused by spinal tumor in midlife, and Ruth Cameron Webb's *A Journey into Personhood,* which has to do with cerebral palsy. Webb, a Ph.D. and counselor to people with disabilities, resolves her sense that God "gave" her cerebral palsy only through a transfiguring visitation in which a voice tells her to give up her anger and accept God's love. Though it is clear to the reader that Webb has suffered primarily from discrimination, she seeks solace not in political action or disabled identity but in a sense of divine sanction. In her view, disability is her problem—a challenge given her by God for inscrutable reasons—not a social or political issue.

A more common script in disability narrative, including autobiography, is that of triumph over adversity. This emplotment of disability, like other culturally preferred scenarios, is consistent with the medical paradigm, which locates disability entirely within a "defective" or "abnormal" body. Disability is presented primarily as a "problem" that individuals must overcome by way of individual will and determination rather than political action. This formula, however, is susceptible to a progressive variant: that of triumph over *discrimination.* It matters, then, whether adversity is defined as *impairment* and located in the body or as *disability* and located at the interface between individual and culture.

A subgenre that embraces the latter approach is the increasingly popular "coming out" narrative. Narrators in this vein are typically people with congenital or early-acquired disabilities; in adulthood, they undergo a change, not in their condition, but in their relation to it, such that they self-identify as disabled. They are newly assertive and proud of that identity. Their narratives may either retrace the emergence of a disabled identity, in the manner of Stephen Kuusisto's *Planet of the Blind* (in which his acquisition of a guide dog marks him as blind in a new way) or explore it more self-reflexively and in an essayistic manner, such as Georgina Kleege's *Sight Unseen,* which begins, "Writing this book made me blind." (In the case of Irving Zola, his coming out was a product of his residence, as a researcher, in a community of disabled people in the Netherlands.)

When the focus is on overcoming discrimination—that is, oppression—we move toward a rhetoric of emancipation, as is the case in the aforementioned narrative by Sienkiewicz-Mercer. In her case, collaborative self-inscription—the use of word boards to narrate her life—is integral to the project of releasing herself from the custody of state hospitals in which she was placed as a girl; personal narrative is thus crucial to her physical and psychological emancipation. While she does not achieve physical independence, Sienkiewicz-Mercer moves to a position of greater power and mobility. The narrative is not a story of overcoming her cerebral palsy. It is thus not what Arthur Frank calls a "narrative of restitution"—a narrative in which a physician would play a transformative role. Nor is it even primarily a narrative of rehabilitation. Though she does learn to use various assistive technology devices to communicate, Sienkiewicz-Mercer never manages to walk or talk; she will always require care. The comic resolution of her narrative is not a function of removing or correcting her impairment, but of getting the world to accommodate her irreparable impairments, of removing the physical, social, and cultural obstacles to her integration into mainstream society.

Indeed, *I Raise My Eyes to Say Yes* has interesting affinities with slave narratives. The narrative is reminiscent of a slave narrative both in the sense that, on the level of plot, it traces a movement from virtual imprisonment to relative freedom, and in the sense that her emancipation is a function of a broader movement to deinstitutionalize disabled people. Like many, if not all, slave narratives, it defies the ascription of mental deficiency to the body of the Other and exposes the confinement of those bodies as a contingent social phenomenon rather than a "natural" one. It has particular affinities, then, with those slave narratives elicited by sympathetic abolitionists, for Sienkiewicz-Mercer's account is in effect promoted and sponsored by individuals seeking to liberate people with disabilities and even to abolish their "institutionalization." And in this regard it represents a distinctly new, implicitly political, self-narrative of disability. Even more important, then, than the quantitative uptick in the autobiographical literature of disability, then, is a qualitative change: disabled authors are increasingly departing from or challenging conventional formulas, tropes, and rhetorics.

Another significant aspect of *I Raise My Eyes to Say Yes* is that it represents, by implication, many lives that generally go unrepresented, uninscribed because of disability. In that sense, it suggests not the limitations of people with disabilities but those of autobiography as an accessible medium of self-representation. The book communicates both the liberation of access to language and the limitations of it. That is, it suggests that autobiography as traditionally conceived, with its inherent valorization of individualism and autonomy, presents its own barriers to people with disabilities.

It may also be considered a form of *autoethnography*, as Mary Louise Pratt (1992:7) defined the term: "instances in which colonized subjects undertake to represent themselves in ways that *engage with* the colonizer's own terms. If . . . ethnographic texts are a means by which Europeans represent to themselves their (usually subjugated) others, autoethnographic texts are those the others construct in response to or in dialogue with those metropolitan representations." (It is autoethnography, too, in that it is an inmate's view of the asylum.) As this narrative suggests, then, contemporary disability autobiography may display a postcolonial impulse—the impulse to define oneself in resistance to the dehumanizing categories of the medical and health service institutions. Both as individual and institutional history, *I Raise My Eyes* supplements, challenges, and indicts official discourse, which assumes that standardized testing can adequately indicate the inner life of the subject in question.

To characterize it as standing in for other unwritten, perhaps unwritable, accounts is to suggest its affinity with a more current first-person genre: *testimonio.* John Beverley (1992:103) has distinguished testimonio from autobiography as follows: "*Testimonio* represents an affirmation of the individual subject, even of individual growth and transformation, but in connection with a group or class situation marked by marginalization, oppression, and struggle. If it loses this connection, it ceases to be *testimonio* and becomes autobiography, that is, an account of, and also a means of access to, middle- or upper-class status, a sort of documentary *bildungsroman.*" In *I Raise My Eyes,* we have a disability memoir that moves toward, though it may not fully occupy, the position with regard to the disability rights movement that testimonio occupies with regard to the movement for the rights of indigenous peoples. *I Raise My Eyes to Say Yes* is testimonio to the (considerable) extent to which its narrator speaks not as a unique individual but for a class of marginalized individuals, in ways already suggested.

One of the arguments made against *narrating* disability would seem to apply to all forms of life writing, including autobiography: that presenting disability in narrative form serves to reinforce the individual paradigm of disability. First-person discourse cannot be exempted summarily from this critique. Indeed, much autobiographical literature individualizes (and sometimes medicalizes or pathologizes) disability. Thus, although autobiography may offer a degree of access that other literary genres do not, and although it may offer a degree of control over representation that other media may not, cultural constraints continue to limit the counterhegemonic potential of disability memoir. Culture filters and manipulates even seemingly "self-generated" texts in various ways, protecting its interest in marginalizing and ignoring disabled lives.

At the same time, there are signs of promise in some recent texts—narratives from hidden corners, some of which may connect with each other in ways that challenge and undermine the limited medical paradigm of disability. Such narratives not only attest to but advance the work of the disability rights movement; in their consciousness of their own condition as culturally constructed and as shared by others, their authors move beyond the familiar formulas of disability memoir and point the way to broader critiques of the construction of disability today.

—G. Thomas Couser

See also Augmentative Communication; Blindness and Visual Impairment; Katharine Butler Hathaway; Novel, The; Harold Russell.

Further Readings

Bauby, Jean-Dominique. 1997. *The Diving Bell and the Butterfly.* Translated by Jeremy Leggatt. New York: Knopf.

Beverley, John. 1992. "The Margin at the Center: On *Testimonio* (Testimonial Narrative)." Pp. 91–114 in *De/Colonizing the Subject: The Politics of Gender in Women's Autobiography,* edited by Sidonie Smith and Julia Watson. Minneapolis: University of Minnesota Press.

Brookes, Timothy. 1995. *Catching My Breath: An Asthmatic Explores His Illness.* New York: Vintage.

Couser, G. Thomas. 1997. *Recovering Bodies: Illness, Disability, and Life Writing.* Madison: University of Wisconsin Press.

DeBaggio, Thomas. 2003. *Losing My Mind: An Intimate Look at Life with Alzheimer's.* New York: Touchstone.

DeSalvo, Louise A. 1997. *Breathless: An Asthma Journal.* Boston: Beacon.

Fries, Lenny. 1997. *Body, Remember: A Memoir.* New York: Dutton.

Goffman, Erving. 1961. "The Underlife of a Public Institution: A Study of Ways of Making Out in a Mental Hospital." Pp. 171–320 in *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* Chicago: Aldine.

———. 1963. *Stigma: Notes on the Management of Spoiled Identity.* Englewood Cliffs, NJ: Prentice Hall.

Grandin, Temple. 1995. *Thinking in Pictures, and Other Reports from My Life with Autism.* New York: Doubleday.

Grealy, Lucy. 1994. *Autobiography of a Face.* Boston: Houghton Mifflin.

Handler, Lowell. 1998. *Twitch and Shout: A Touretter's Tale.* New York: Dutton.

Hathaway, Katharine Butler. 1942. *The Little Locksmith: A Memoir.* New York: Feminist Press.

Jezer, Marty. 1997. *Stuttering: A Life Bound Up in Words.* New York: Basic.

Keith, Lois, ed. 1996. "*What Happened to You?" Writing by Disabled Women.* New York: New Press.

Kingsley, Jason and Mitchell Levitz. 1994. *Count Us In: Growing Up with Down Syndrome.* New York: Harcourt.

Kleege, Georgina. 1999. *Sight Unseen.* New Haven, CT: Yale University Press.

Kuusisto, Stephen. 1998. *Planet of the Blind.* New York: Dial.

Mairs, Nancy. 1996. *Waist-High in the World: A Life among the Nondisabled.* Boston: Beacon.

McCrum, Robert. 1998. *My Year Off.* New York: Norton.

McGowin, Diane Friel. 1993. *Living in the Labyrinth: A Personal Journey through the Maze of Alzheimer's.* New York: Delacorte.

McLean, Teresa. 1996. *Seized: My Life with Epilepsy.* London: Richard Cohen.

Mitchell, David T. and Sharon L. Snyder. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor: University of Michigan Press.

Pratt, Mary Louise. 1992. *Imperial Eyes: Travel Writing and Transculturation.* London: Routledge.

Price, Reynolds. 1994. *A Whole New Life: An Illness and a Healing.* New York: Atheneum.

Robillard, Albert B. 1999. *Meaning of a Disability: The Lived Experience of Paralysis.* Philadelphia: Temple University Press.

Robinson, Jill. 1999. *Past Forgetting: My Memory Lost and Found.* New York: HarperCollins.

Roney, Lisa. 1999. *Sweet Invisible Body.* New York: Henry Holt.

Rothenberg, Laura. 2003. *Breathing for a Living: A Memoir.* New York: Dimensions.

Sarton, May. 1988. *After the Stroke: A Journal.* New York: Norton.

Sienkiewicz-Mercer, Ruth and Steven B. Kaplan. *I Raise My Eyes to Say Yes.* Boston: Houghton Mifflin.

Styron, William. 1990. *Darkness Visible: A Memoir of Madness.* New York: Random House.

Webb, Cameron Ruth. 1994. *A Journey into Personhood.* Iowa City: Iowa University Press.

Wilensky, Amy S. 2000. *Passing for Normal: A Memoir of Compulsion.* New York: Broadway.

Willey, Liane Holliday. 1999. *Pretending to Be Normal: Living with Asperger's Syndrome.* London: Jessica Kingsley.

Williams, Donna. 1992. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic.* New York: Times Books.

Wolf, Helen Harker. 1979. *Aphasia: My World Alone.* Detroit, MI: Wayne State University Press.

Zola, Irving. 1982. *Missing Pieces: A Chronicle of Living with a Disability.* Philadelphia: Temple University Press.

AVERSIVE THERAPIES

In the education and human services fields associated with developmental disabilities, *aversives* are programmatically designed and systematically induced punishments sanctioned by professionals and directed at people with disabilities to directly control their actions and hypothetically shape their behaviors toward what are determined to be appropriate ends. Over the past two decades, numerous disability-related organizations and panels have called for an end to the use of aversives because they are abusive, dehumanizing, and psychologically and physically dangerous (see, e.g., Autism National Committee 1999; National Council on Disability 1995; TASH 2004; International Association for the Right to Effective Treatment 2003).

The National Council on Disability (1995), a federal agency making recommendations to the president and Congress on disability issues, noted:

> Prisoners [in the United States] are afforded protection under the law from [harsh and abusive] treatment. . . . Students with severe behavioral disabilities are not criminals, and yet present law allows them to be subjected to procedures which cannot be used on the most hardened criminals, or, in some cases, even on animals.
>
> Public funds intended to provide positive educational experiences and results for children should not be expended to have these children subjected to unproven, experimental, dangerous, or violent program procedures which—by design—result in pain, physical injuries, psychological damage, hunger, social deprivation, or other such negative experiences. In any other context, the use of these procedures would be considered child (or dependent) abuse or neglect. They should not be viewed as "treatment" just because a student has a disability. Through its support of these procedures used on children with disabilities, the United States could be cited for human rights violations against people with disabilities under its own Country Reports on Human Rights published annually by the Department of State.

While the proclamation of the National Council on Disability has been available for more than a decade, use of aversives on people with significant disabilities continues to be widespread. As documented by the disability-advocacy organization TASH (formerly the Association for Persons with Severe Disabilities), current, common aversive practices used to control behavior include electric shock applied to the body (e.g., arm, leg, or hand) for the purpose of discouraging the specific behavior it follows by causing pain; extremely loud white noise or other auditory stimuli not uncommonly delivered through a mask-like device; forced exercise; shaving cream to the mouth; lemon juice, vinegar, or jalapeno pepper to the mouth; water spray to the face; placement in a tub of cold water or cold showers; placement in a small room, closet, or box; slapping or pinching with hand or implement; pulling the hair; ammonia capsule to the nose; blindfolding or other forms of visual blocking; placement in a dark isolated box or other methods of prolonged physical isolation; ice to the cheeks or chin; teeth brushed or face washed with caustic solutions; prolonged restraint through manual or mechanical techniques (e.g., face-down four- or five-point restraint using mechanical tie-downs or several staff applying physical pressure); and withholding of multiple meals/denial of adequate nutrition.

[QU: Is the paragraph that begins "Public funds intended . . ." still part of the quote from National Council on Disability (1995)?]

HISTORY OF AVERSIVES

Harsh treatment and daily punishment have been a consistent part of the disability experience in Western cultures for centuries. Wrote Aristotle in his *Politics* (1997), "As to the exposure and rearing of children, let there be a law that no deformed child shall live" (p. 543). Such overt hostilities, often guised as benevolence, continued unabated into the eugenics era in the United States during the first half of the twentieth century. In 1942, the American Psychiatric Association developed a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles:* "Those hopeless ones who should never have been born–nature's mistakes" (p. 14).

Though euthanasia was never widespread in the United States, the use of systematic aversives gained scientific legitimacy with the early-twentieth-century emergence of the field of psychology and its predominant paradigm of behaviorism. Edward Thorndike (1914), an early psychological behaviorist, claimed that *learning,* as opposed to reasoning, rationalism, motivation, goal seeking, and higher-level emotions, was the singular explanation for all human behavior. Learning, according to Thorndike, was the trial-and-error process of forming bonds between physical events (i.e., environmental stimuli and an individual's immediate response) and mental events (described merely as things perceived by the senses). Education was the process of stamping in what were deemed to be correct perceptions and responses to stimuli through pleasurable consequences and stamping out incorrect perceptions and responses through the use of aversives.

At the same time that Thorndike's learning theory came to dominate American behaviorism, state legislatures across the United States were passing compulsory education laws. These resulted in increasingly larger, far more rigid schools and the emergence of the first special education classrooms. The use of aversives, central to the fledgling science of learning, quickly became acceptable practice in these classes made up of struggling students segregated from the mainstream but forced by law to remain in school.

Thorndike's behaviorism focused on the individual's response to recognized stimuli, but what about individuals considered to have more severe intellectual disabilities, who, it was believed, could not meaningfully perceive or respond to stimuli? Compulsory education laws specifically excluded individuals with significant disabilities, but parents of children categorized as severely disabled were beginning in the mid-twentieth century to organize educational opportunities for their children. As professionals began to take over these new schools, they began to implement versions of the learning theory developed by psychologist B. F. Skinner in laboratories using pigeons, rats, and mice.

Beginning in the 1940s, Skinner (1974) identified classes of behavior called operants that individuals emit, but whose initial stimuli are unknowable in any absolute sense. Instead, professional focus is firmly placed on stimuli that follow the behavior. Reinforcers are stimuli that increase the probability of the operants reoccurring. Aversives are punishing consequences said to decrease the probability of the behavior's reoccurrence.

In 1949, researchers at Indiana University were the first to tie Skinnerian psychology to people with significant disabilities. In the introduction to the study appearing in the *American Journal of Psychology,* Fuller (1949) first described rather mixed results of stimulus-response (i.e., Thorndikian and classical) conditioning using people with disabilities as subjects. He noted, for instance, that while one experiment showed "subnormal children formed conditional responses to shock faster than normal children," another experiment failed in its "attempt to condition a salivary response to an 18-yr.-old idiot, probably due in part to [subject's] refusal to have a saliometer attached" (p. 587).

In contrast, the Indiana University experiment was an operant conditioning (i.e., Skinnerian) effort using an 18-year-old "vegetative idiot" (p. 588). The researchers deemed desirable the subject's movement of his right arm. To increase this operant, they withheld his food for 15 hours, then waited for the behavior to be emitted. When the subject's arm moved, they injected sweetened milk into his mouth. The experiment was hailed as a success as the subject increased his right arm movements considerably. Fuller (1949) concluded:

> According to the attending physicians, Subject had not learned anything in the 18 years of his life—yet, by using the operant conditioning technique, an addition was made to his behavior which, at his level, could be termed appreciable. . . . For years many psychologists have experimented exclusively with infrahuman subjects. Perhaps by beginning at the bottom of the human scale the transfer from rat to man can be effected. (p. 590)

The Fuller (1949) experiment served as the genesis for the mass implementation of operant conditioning in programs for individuals with significant disabilities and initiated the scientific justification for the use of aversives on this population. Sobsey and Dreimanis (1993) noted:

> To apply the laboratory science of behaviorism to special education, it was necessary to model the special education classroom after the laboratory rather than the regular classroom. The highly controlled conditions that were considered to be necessary for teaching students with special needs were alien to and incompatible with the regular classrooms. The results have been catastrophic for students with disabilities. (p. 6)

Most recently, accumulated research demonstrates that a wide range of instructional methods are available that not only are more effective than use of aversives and behavior modification in general but also do not inflict pain on, humiliate, dehumanize, or overly control or manipulate individuals with disabilities. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that are positive and will achieve the individual's needs.

The international disability advocacy organization, TASH (2004), has publicly called for an end to all use of aversives:

> Be it resolved, that TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, affirms the right of all persons with disabilities to freedom from overly restrictive procedures and from aversive or coercive procedures of any kind. TASH is unequivocally opposed to the inappropriate use of restraint and to the use of overly restrictive and aversive procedures under any circumstance and calls for the cessation of the use of all such procedures.

—Christopher Kleiwer

See also Euthanasia.

Further Readings

American Psychiatric Association. 1942. "Position on Euthanasia." *American Journal of Psychiatry* 99:13–22, 141–143.

Aristotle. [ca. 350 BCE] 1997. *Politics.* Translated by P. L. P. Simpson. Chapel Hill: University of North Carolina Press.

Autism National Committee. 1999. *The Case against Aversives.* (www.autcom.org).

Fuller, P. R. 1949. "Operant Conditioning on a Human Vegetative Organism." *American Journal of Psychology* 62:587–590.

International Association for the Right to Effective Treatment. 2003. "Position on Aversives." Waltham, MA: International Association for the Right to Effective Treatment.

National Council on Disability. 1995. "Proclamation on Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children." Washington, DC: National Council on Disability.

Skinner, B. F. 1974. *On behaviorism.* New York: Knopf.

Sobsey, D. and M. Dreimanis. 1993. "Integration Outcomes: Theoretical Models and Empirical Investigations." *Developmental Disabilities Bulletin* 21:1–15.

TASH. 2004. "Resolution on Opposing the Use of Aversives and Restrictive Practices." Baltimore: TASH.

Thorndike, E. L. 1914. *Eugenics: Twelve Lectures.* New York: Dodd, Mead.

▣ AYRES, A. JEAN (1920-1988)

American occupational therapist and scholar

A. Jean Ayres, an occupational therapist and a clinical psychologist, pioneered development of therapy for children who have subtle neurological impairments. Her work with children with cerebral palsy and learning disabilities led to the development of the sensory integration theory. This theory attempts to explain how certain learning or behavioral problems can be based in difficulties of processing sensations, such as touch, movement, sight, and sound. Children with sensory integration problems exhibit insecurity or fear of movement and consequently can have difficulty with ordinary activities such as playing with toys and doing self-care.

During her 35-year career, Ayres wrote several books and published multiple scholarly articles addressing her theory and techniques for clinical application. In 1976, she founded the Ayres Clinic where she evaluated and treated children using the approach she developed. Sensory integration therapy stresses detailed evaluation and understanding of each child's unique sensory style and challenges as a basis for providing the child appropriate opportunities to learn how to process and use sensory information to enhance skill in performance.

Today, sensory integration theory continues to evolve and is one of the most extensively researched and developed models of practice in occupational therapy. The approach has evolved away form a more exclusive focus on remediation of the underlying sensory processing impairment to emphasize environmental adaptation, self-understanding, and personal management of sensory challenges.

—Eynat Shevil

See also Occupational Therapy.

Further Readings

Bowman, Jayne O. 1989. "In Memoriam. A. Jean Ayres 1920–1988: Therapist, Scholar, Scientist, and Teacher." *American Journal of Occupational Therapy* 43:479–480.