

# An Institutional History of Disability

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The primary objective of this chapter is to describe the institutional history of disability in Western society, establishing explicit connections between the social context in which people have lived and the ways in which disability has or has not been identified and addressed as a social problem. Our central thesis is that changing social and political perspectives on poverty during the seventeenth and eighteenth centuries, coupled with the development of increasingly medicalized interpretations of disability during the nineteenth and twentieth centuries, contributed to increasing segregation and stigmatization of persons with disabilities. However, a related thesis is that the congregation of people with similar disabilities for treatment and services also made possible the development of group identities, which ultimately facilitated the rise of political activism in the modern era.

## *Impairment and Disability*

Throughout Western history, disability has existed at the intersection between the particular demands of a given impairment, society's interpretation of that impairment, and the larger political and economic context of disability. The contrast between disability and impairment informs a key underlying premise of this chapter: Disability exists as it is situated within the larger social context, while impairment is a biological condition. Lennard Davis (2000) has succinctly described the relationship between disability and impairment as follows:

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Disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference.... An impairment is a physical fact, but a disability is a social construction. For example, lack of mobility is an impairment, but an environment without ramps turns that impairment into a disability.... a disability must be socially constructed; there must be an analysis of what it means to have or lack certain functions, appearance and so on. (P. 56)

Davis notes that disability was not constituted as a social category prior to the eighteenth century, even though impairments were no doubt quite prevalent in the general population.

Writing a history of disability in the West is a challenging undertaking. We will comment briefly on just three of the key problems facing researchers. First, the utilization of primary source evidence, the gold standard of historical research (Brundage 1989; Schafer 1980), is extremely limited in the literature, especially for periods preceding the nineteenth century (Brockley 1999). Recent historical accounts of disability have relied more heavily on primary source documentation but have generally limited their focus to the institutional nature of service delivery in the United States, beginning in the nineteenth century (Bredberg 1999; Brockley 1999; Ferguson 1994; Trent 1995; Wright and Digby 1996). While the constraints of writing a disability history within the confines of a concise book chapter have forced us to use secondary sources frequently, primary sources have been used when possible to reveal the rich historical fabric of a diverse and varied existence.

A second limitation of many published historical accounts is that the archive mainly describes formal services and treatment approaches from the standpoint of the professionals who controlled the delivery of services (e.g., Barr 1904; Earle 1898; Obermann 1968; Scheerenberger 1983; Sheldon 1921); this institutional perspective has often eclipsed the perspectives of persons with disabilities and even their families. The reliance on professionals' records has reflected and legitimated professional behavior (Hirsch 1995). Historians, for example, have tended to rely on the public record of residential institutions while largely ignoring lay perspectives toward disability (Jackson 1998). Such a practice has occurred even though only a small fraction of the entire disabled population has ever been institutionalized, particularly prior to the twentieth century. Moreover, people with disabilities have only infrequently recorded accounts of their experiences, so historians are left to interpret "lived experience" vicariously through the filter of professionals who did leave extensive records (Porter 1987b; Rushton 1988). Thus, historians are often put in the perilous position of interpreting the history of people with disabilities based on the claims of professionals, although this posture has been soundly rejected in recent years by the disability movement (Anspach 1979; Carabello and Siegel 1996; Shapiro 1993; Ward and Schoultz 1996), which today advances the philosophy of "nothing about us without us" (Charlton 1998).

The third limitation is that histories of disability are rarely representative of a broad cross-disability perspective that depicts the historical interconnections across the full spectrum of mental, physical, and sensory disability. In this chapter, we will address disability history across this broad spectrum, but we will also explicitly examine the history of mental disability in greater depth.

### *Overview of the Chapter*

The chapter begins with a discussion of the extensive presence of people with impairments in ancient times and moves forward chronologically to the present day. Ancient Western notions of impairment in Greece and Rome accepted the belief that persons with congenital impairments embodied the wrath of the gods and should be killed. Yet this view coexisted with the fact that those who acquired their disabilities later in life were often integrated into society as workers, citizens, and soldiers. During the Middle Ages, widespread belief in demonology as an etiology of impairment was counterbalanced by religious movements preaching compassion and

support toward persons with disabilities. Development of the first residential institutions for persons with disabilities is traced to the Middle Ages as well.

In the early modern period through the close of the eighteenth century, disability was strongly influenced by the rise of the scientific method during the Renaissance and by changing public perceptions toward poverty and disability. The radical intellectual revolution born of the Enlightenment, including scientists' subsequent emphasis on distinguishing mental illness from intellectual disability, is considered in some depth in this section of the chapter. Enlightenment thinking transformed fundamental concepts about the essential relationships between humans, nature, and God. This transformation involved the increasing legitimacy of science in society and led to the ascendancy of physicians, educators, and caretakers in the lives of persons with disabilities. Scientific inquiry into the medical aspects of impairment has been characterized by the development and application of increasingly complex diagnostic and etiological classification schemes. This process of categorizing persons with disabilities into the minutiae of their impairments resulted in the development of specialized treatments and residential and educational services but also established and reinforced notions of the boundaries between normalcy and aberrance in Western society.

Disability in the American colonies during the seventeenth and eighteenth centuries is examined along with the subsequent development and proliferation across Europe of institutions for persons with mental disabilities and schools for the deaf and blind. In the American colonies, and later in the United States, persons with impairments were often perceived to menace the economic well-being of the community. The practices of auctioning off the care of disabled persons to the highest bidder or running them out of town with threatened or real violence reflected an intimate connection between poverty and disability in this period of history.

Our discussion of disability history in the nineteenth century acknowledges the significance of political organization by deaf advocates—the first rumblings of activism by people with disabilities. That nascent movement sharply contrasted with the contemporaneous exploitation of people with disabilities as freak show attractions and the ascendancy of the eugenics era. The onset of the twentieth century was marked by a dramatic expansion of residential institutions for persons with mental disabilities and by the rapidly increasing segregation of children and youth with disabilities in public schools. We trace developments for persons with physical disabilities, independent living, and the emergence of family, community, and consumer advocacy, and we discuss litigation that forged a constitutional right to treatment for persons with mental disabilities in the United States. The chapter also discusses international disability rights initiatives such as the United Nations' *Standard Rules*, the Americans with Disabilities Act, and various European antidiscrimination legislation such as Great Britain's Disability Discrimination Act of 1995. The chapter concludes with a consideration of disability priorities in the twenty-first century.

## ANTIQUITY

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### *Prehistory*

Individuals with physical impairments have been part of the social order since well before the evolution of humans. There is also anthropological evidence of impaired members living in prehistoric subhuman primate groups. Berkson (1974, 1993) argues persuasively that

monkey and ape groups include individuals who have fallen from trees or who have been injured by predators. [They] may survive in natural animal groups when their injury does not actually interfere with foraging or escape from predators. In other words, the injury may not be handicapping.

Injured animals may survive and live in a group because group living itself can provide aid to adaptation. Mother monkeys provide care that compensates for even severe injuries, and other members of the group may "baby sit" injured babies, as they do other young of the group . . . where predation pressure is low and food is plentiful, handicapped animals may live to be adults. (Berkson 1993:5-6)

Citing work by Solecki (1971) and Stewart (1958), Berkson (1993) describes a published description of an adult Neanderthal male with severe arm and head injuries incurred at an early age. He accommodated the injury by using his teeth to hold objects. Berkson also uncovered research documenting the fact that disabling arthritis and other chronic impairments were common in Neanderthals (Goldstein 1969; Straus and Cave 1957). He concludes that individuals with both minor and even highly significant impairments were part of primate societies "even before the evolution of modern *Homo sapiens*" (p. 6). Thus, the presence of impairments among subsequent prehistoric *Homo sapiens* should not surprise us.

### *The Old Testament*

Documentation of the treatment and life experiences of people with impairments during the earliest periods of recorded history is extremely limited. Edicts about disability offer some insight into prevailing attitudes, but the messages that they convey are mixed. The Old Testament commanded, "Thou shalt not curse the deaf nor put a stumbling block before the blind, nor maketh the blind to wander out of the path" (Leviticus 19:14). Daniels (1997) argues that this Hebraic command in Leviticus is the first attempt by any nation to legislate for the protection of the deaf. Daniels further asserts that deaf persons without speech were viewed as children under Hebrew law and provided with the same protections as children.

People were also reminded about their responsibilities toward one another with the injunction that "there will always be poor people in the land. Therefore, I command you to be open-handed toward your brothers and toward the poor and needy in your land" (Deuteronomy 15:11).

In contrast, the Old Testament also warned that

if you do not carefully follow His commands and decrees . . . all these curses will come upon you and overtake you: the Lord will afflict you with madness, blindness and confusion of mind. At midday, you will grope around like a blind man in the dark. (Deuteronomy 28:15, 28-29)

These paradoxical statements reflect competing attitudes toward disability. While society seems to have recognized a charitable obligation to people with disabilities, disability was also perceived as a punishment meted out by God. The belief that illness was inflicted by an angry deity or by a supernatural power was widespread among ancient peoples (Rosen 1968). The Old Testament also supports the notion that people with disabilities were classified with prostitutes and menstruating women as unclean and were thereby prohibited from making sacrifices as priests. According to Stiker (1997), people with disabilities were allowed to otherwise participate in religious observances. The early Christian church, however, held that faith came from hearing (Romans 10:17), and therefore the deaf were necessarily without faith in the eyes of the church (Daniels 1997).

In records dating back to 2000 B.C.E., the births of children with congenital impairments were used to predict future events for a community. In the Babylonian region, ancient Semitic Chaldean diviners of the future maintained a list of birth deformities and the specific prophetic meanings each foretold. The manifestation of disability was viewed as a portent of things to come (Warkany 1959).

### *Ancient Greece and Rome*

Average life expectancy in ancient Greece and Rome did not generally exceed 37 and 44 years, respectively, for women and men. Due to the omnipresence of disease, war, poor prenatal care, malnutrition, and injury sustained during the hard work performed by most people, impairments and deformities were doubtless prevalent. Even such minor injuries as broken limbs would have produced disabling impairments in a majority of the population who were too poor to obtain medical care (Garland 1995). As Garland (1995) has noted,

Life in the ancient world was nasty, brutish, and short. The most privileged were those who happened to be freeborn, well-to-do males in perfect health. But the overwhelming majority did not, of course, belong to that ideal category. (P. 11)

In the midst of this society beset by endemic impairment, the Greeks and Romans had varied interpretations of persons with such conditions. Babies born with congenital deformities were often regarded as signs that their parents had displeased the gods. However, public support was available to individuals whose impairments precluded them from working. In some exceptional situations, having an impairment was not a barrier to attaining power. The Roman Emperor Claudius had significant congenital deformities, and Spartans elected a short-statured man as their king. In any case, care for persons with impairments would have been reserved for those few who were wealthy enough to afford it—disability for the vast majority of Greeks and Romans would have increased the extent to which they were marginalized and excluded from society and living in deprived economic conditions (Garland 1995).

The notion that Greeks practiced infanticide of children with disabilities has been widely accepted (e.g., Mackelprang and Salsgiver 1996; Scheerenberger 1983; Woodill and Velche 1995). However, this practice was not as widespread as has been believed (Garland 1995). In ancient Greece and Rome, infanticide was practiced for economic reasons when there were too many children. In Sparta, however, children born with obvious physical deformities were put to death regardless of a family's means (Stiker 1997; Warkany 1959). Spartan law mandated the practice of killing newborns who had been born with deformities, while there is some limited evidence that Athenians may have been more inclined to raise such children (Garland 1995). Infants with deformities were sometimes perceived to represent the anger of the gods, and murdering such babies was a sacrifice intended to mollify the gods.

Aberrancy within the species not only threatens the future and continuation of this species, but also announces, threatens, signifies a condemnation by the gods: a condemnation of the group . . . an aberrancy within the corporeal order is an aberrancy in the social order. (Stiker 1997:40)

Stiker (1997) further notes that the subjection of infants with deformities to death by exposure was specifically for infants we would today say have physical disabilities. Infants with hearing impairments, vision impairments, and mental retardation were not categorized as “deformed” and were not put to death, except perhaps for those most profoundly limited intellectually who could have been “diagnosed” early on.

It is likely, however, that many children with physical impairments survived even in Sparta because their impairments would not have been evident until they passed the age at which killing them would have been contemplated (Gaw 1906b). Furthermore, adults with congenital disabilities were a presence in ancient Greece (Stiker 1997). M. L. Edwards's (1996, 1997) reviews of the scant documentary records from ancient Greece indicates that deformity was not perceived as absolutely negative by the Greeks but that this perspective was developed by historians during the nineteenth century, who applied contemporary contempt for people with disabilities to their assessment of the ancient world. She further concludes that the assumption that deformity in a child was automatically associated with economic burden is not appropriate since many people with disabilities had jobs and earned income. It is difficult to determine from

these conflicting records the extent to which the infanticide of children with disabilities was practiced; what is clear is that people with congenital disabilities, broadly defined, existed in society, indicating that infants with disabilities were not uniformly put to death.

Given high rates of disease and war, there was likely a higher prevalence of disability in ancient communities. Greeks who sustained injuries on the battlefield would often be expected to continue to fight, as mobility was not always a requisite for combat participation. Existing court records provide compelling evidence that the linkage between disability and entitlement to monetary support from the government was not absolute. Individuals with disabilities in Greece would have had to prove that they truly were economically needy and not just physically disabled to receive a small food grant (Edwards 1997).

Greek records also substantiate a public acknowledgment of providing support for those who were classified as unable to work. Dating from at least the sixth century B.C.E., Athens offered modest public support for those individuals who were unable to work due to their impairments. The *Constitution of Athens* provides information regarding the process of providing this support:

The Council inspects those who are disabled. For there is a law which bids those who possess less than three minai and who are incapacitated and incapable of work to undergo inspection by the Council, which is to give them two obols per day each at public expense. (Garland 1995:35)

Military medicine was in widespread use in ancient Greece, as was public support of men disabled by war (Stiker 1997). Pensions were granted to soldiers who had been injured in battle, and food was provided to others with disabilities who could prove their economic need. The conclusion that Edwards (1997) draws regarding the status of people with disabilities during ancient Greek times is telling:

The consequences of physical handicaps varied according to the context and to the individual. Without a codified notion of "able-bodied" on one hand and "disabled" on the other, people were not automatically assigned to one category or the other on the basis of medical diagnosis or appearance. . . . We see very few instances in which people with physical handicaps were banned a priori from certain roles . . . people with disabilities in Greek society were integral to the society. There is no indication that people with physical handicaps in the ancient Greek world identified themselves or were identified as a distinct minority group. (Pp. 43-44)

Surviving historical and literary accounts have indicated that prosthetic devices were used by persons who sustained injuries during battle or had congenital limb malformations (Bliquez 1983). Herodotus recounts a warrior amputating his own foot to free himself and escape his impending execution. In 479 B.C.E., this warrior supported himself fighting on the battlefield by using a wood prosthesis. In a tomb dating to 300 B.C.E., a skeleton was found with an artificial lower right leg. This prosthesis was made of bronze, indicating that its owner was a person of some wealth.

Early Roman law chiefly protected the property rights of people with disabilities. Persons who were designated as intellectually deficient in early Roman times were provided with guardians to assist in the management of their affairs (Winzer 1993). Deaf persons capable of speech were granted authority to discharge legal obligations such as marriage and property ownership. Deaf persons without speech were classified alongside persons with intellectual disabilities, mental illness, and infants and were forbidden to perform any legal acts (Gaw 1906a, 1906b, 1907; Hodgson 1953).

In the Roman Empire, short-statured slaves and slaves with intellectual disabilities were often maintained by wealthy men for entertainment purposes. "Keeping" such individuals was considered good luck. The earliest records of court jesters date from Egyptian pharaohs of the Fifth Dynasty who kept short-statured people (Welsford [1935] 1966). Both ancient China and

pre-Colombian American civilizations had short-statured people serve as court jesters as well (Willeford 1969).

Later Roman law enumerated the specific rights of people with disabilities. In the sixth century A.C.E., the Justinian Code classified persons with disabilities in detail and delineated rights pertaining to different types and degrees of disability; for example, people with mental disabilities were not permitted to marry. Drawing on the Jewish discrimination between degrees of deafness (Daniels 1997), the Justinian Code identified five classes of deafness (Gaw 1906a, 1906b, 1907). The code became the basis of law in most European countries from the sixth to the eighteenth centuries.

Writings from the New Testament offer insight into attitudes about disability shortly after the time of Christ. Mark records Jesus' healing of a blind man by spitting and laying hands on the man's eyes (Marcus 1999; Mark 8:22-26). Mark and Matthew also record Jesus' healing of a man with paralysis (Black 1996; Mark 2:1-12; Matthew 8:5-13). The New Testament relates other stories of people with leprosy, epilepsy, mental illness, deafness, and blindness being healed by Christ (Black 1996). These healing tales may be interpreted to mean that people "have disabilities . . . to show the power of God" (Black 1996:29). When asked whether a blind man's sin or his parents' sin had caused the man's blindness, Jesus replied that it was neither but rather a mechanism for "God's work [to be] revealed in him" (John 9:3; Black 1996:29). However, the fact that the disciples believed that the man's blindness was caused by sin may be indicative of prevailing wisdom regarding the supernatural etiology of this condition at the time.

Interpreting disability in antiquity is difficult in that the time span considered is vast, and competing attitudes toward disability are evident at many points. Writings from the Old Testament suggest paradoxical attitudes, which exhorted society to be generous and kind toward individuals with impairments, while also declaring that impairment was a mark of the wrath of God. Ancient Greece and Rome offer similarly complex interpretations of impairment. The killing of newborns with congenital impairments existed in some form throughout Greece and Rome, and society clearly perceived the birth of a child with congenital anomalies as the mark of the anger of the gods. However, the provision of pensions to soldiers injured on the battlefield was also a part of ancient Athenian life, and citizens with impairments were widely known to have worked at different trades. Impairment at the time of Christ was similarly fraught with different meanings, offering both redemption opportunities for kind strangers and signifying superstition. In the ancient world, impairment was accepted, at least in part, as an aspect of the course of life.

## MIDDLE AGES

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In the fourth to sixth centuries A.C.E., monastically inspired hospices for blind persons were established in what is now Turkey, Syria, and France. These hospices were organized as refuges for people with disabilities within existing religious enclaves (Winzer 1993). Bishop Nicholas cared for persons with intellectual disabilities in a hospice in southern Turkey during the fourth century, and the Belgian village of Gheel initiated the support of persons with mental disabilities in family care settings in the thirteenth century (Roosens 1979; Stevens 1858). The latter community provided vocational opportunities in a community setting that included an infirmary and a church centered around the shrine of St. Dymphna (Kroll 1973; Pollock 1945; Rumbaut 1972). By the sixth century A.C.E., institutions to segregate people with Hansen's disease (leprosy) were developing sporadically. Germany and Italy had hundreds of these facilities by the Early Middle Ages (Howard 1789; Weymouth 1938).

### Demonology

Many disabling conditions, including intellectual disability, mental illness, deafness, and epilepsy, were thought to have supernatural or demonological causes during the medieval period.

The devil was believed to cause epilepsy (Alexander and Selesnick 1964). Belief in demonic possession as a primary etiology of mental illness led to attempted cures based on religious ideas about exorcism (Clay 1966; Neaman 1978). Attempts to cure people with disabilities from early medieval times reflect supernatural beliefs in the abilities of magic and religious elements. For instance, Anglo-Saxons offered the following antidote to mental illness:

A pleasant drink against insanity. Put in ale hassock, lupine, carrot, fennel, radish, betony, water-agrimony, marche, rue, wormwood, cat's mint, elecampane, enchanter's night-shade, wild teazle. Sing twelve Masses over the drink, and let the patient drink it. He will soon be better. (Russell 1980:45)

Interest in persecuting witches developed gradually, culminating in the craze that began in 1450 (Russell 1980). During the Middle Ages, the first heresy executions occurred in France in 1022, and thousands of so-called witches were subsequently executed (Russell 1972). Persecution was frequently led by the Catholic Church, although Protestant European countries also followed papal orders regarding the execution of witches. Pope Innocent IV authorized the seizure of heretics' goods, their imprisonment, torture, and execution (Russell 1980). In 1484, Pope Innocent VIII declared war on witches (Russell 1980). While it is acknowledged that disabled persons were among those who were persecuted, the extent to which this occurred is not known. It seems likely that persons whose impairments were not amenable to contemporary treatment, particularly those with mental illness, would have been disproportionately affected by the witch craze (Winzer 1993).

Some of those individuals later persecuted for witchcraft in colonial New England most likely had mental illness, even given the crude understanding of mental illness at the time. Erikson (1966) recounts instances of clearly mentally disabled colonial women being put to death for their various crimes. American psychiatrists of the mid-nineteenth century described colonial New England's witchcraft as manifestations of mental illness. These psychiatrists interpreted the persecution of people with mental illness as pitiable but not necessarily peculiar. They expressed surprise that physicians misapplied the label "witch" to women who had mental illness ("Witchcraft and Insanity" 1849).

### *Compassion and Support*

Despite the negative impact that widespread superstition had on people with disabilities during medieval times, there is evidence that other attitudes about disabilities, particularly mental illness, were also common (Kroll 1973; Neugebauer 1979; Rosen 1968). Kroll (1973) argues that the absence of demonology in medical texts from the medieval era, the scattered advocates for the natural causes of mental illness, and the town's assumption of responsibility for people with mental disabilities are strong evidence that demonological beliefs were only a part of the picture. However, views toward disability were complex and apparently included "elements of empirical rationality and humane interest" (Rosen 1968:139). Further evidence of positive or at least sympathetic attitudes toward people with disabilities is manifested in the fact that some towns actually funded pilgrimages to distant religious sites for people with epilepsy and mental illness to seek cures (Rosen 1968).

The relationship between poverty and disability during the medieval period is also significant. Malnutrition and infectious diseases were endemic, doubtless contributing to significantly higher rates of impairment, making persons quite visible in their communities. The chances of living to adulthood averaged just 50 percent during the medieval period (Jankauskas and Urbanavicius 1998). In thirteenth-century France, Italy, and England, tax records indicate that as much as 75 percent of the population was too poor to pay taxes and was particularly susceptible to dire consequences if they became disabled (Farmer 1998). This profound poverty meant that adults not capable of working were often a tremendous burden to their families. Even in families where both spouses worked, women often supplemented their low wages with begging (Farmer 1998). In this context, begging by people with disabilities seems more related

to their poverty than to their disability. Begging during the Early Middle Ages was not stigmatized as it later would be. The existence of the poor was accepted as part of the natural order, and the poor were perceived to offer opportunities for wealthier citizens to do good by providing alms (Spierenburg 1984). In this context, persons with disabilities doubtless had more widespread acceptance as part of the poor.

Evaluating records from the canonization of St. Louis provides extensive evidence that people with disabilities sought cures for their disabilities at his tomb and that during the medieval period, people with disabilities survived by relying on a variety of supports: family members, neighbors, employers, charitable institutions, and begging (Farmer 1998). Charitable institutions appear to have been the least likely source of support for people with disabilities, often only providing assistance until an individual was sufficiently recovered to leave the hospital and beg for alms. There is also evidence that family, friends, and neighbors, in addition to providing material support as they were able, would assist people with disabilities to beg in the streets even by carrying them if necessary (Farmer 1998). The networks of support that appeared to exist, even for women who were recent immigrants, provide evidence that medieval attitudes toward disability were more complex than is often believed and not entirely negative.

Examining court records between the thirteenth and seventeenth centuries in England, Neugebauer (1978, 1979, 1996) found that demonological beliefs about the origins of brain disorders were not the only etiological beliefs held by society. The Crown's legal incompetency jurisdiction differentiated between intellectual disability (termed *natural fools* and, later, *idiots*) and mental illness (termed *non compos mentis* and, later, *lunacy*) (Neugebauer 1996). The *Prerogativa Regis* in the latter half of the thirteenth century endowed the Crown with specific responsibilities for protecting the person and property of individuals whose mental disabilities rendered them legally incompetent. Differentiation of "idiots" and "lunatics" by the *Prerogativa Regis* enabled the Crown to take custody and profits generated from lands owned by "idiots." In the case of individuals with mental illness, the Crown had the responsibility to ensure the safekeeping of lands held by "lunatics." The Crown, however, was not entitled to profits generated by the "lunatics" lands that it supervised (Neugebauer 1996).

Perhaps even more significant, verbatim transcripts of custody hearings indicate that the means used to determine the presence of mental disability relied on tests of literacy, numerical ability, reasoning, knowledge as to place and kin, and so on (Neugebauer 1996). The records of these examinations indicate that the essential questions used to determine the presence of mental disability were relatively constant from the thirteenth through the seventeenth centuries, indicating relative stability in the understanding of mental disability during this prolonged period (Neugebauer 1996; Swinburne 1590).

### *Residential Institutions Emerge*

During the Middle Ages, Greek and Roman medical and philosophical traditions were introduced into Europe by the Arabs, who had conquered most of the continent and penetrated Spain and France. Asylums for people with mental disabilities had previously been established by the Arabs in Baghdad, Fez (Morocco), and Cairo in the eighth century and subsequently in Damascus and Aleppo in 1270 (Alexander and Selesnick 1964). Since the Arabs held the general belief that mental disability was divinely inspired and not demonic in origin, care in these facilities was generally benevolent.

In England, the Priory of St. Mary's of Bethlehem was founded in 1247 in London with the explicit purpose of supporting the Order of Bethlehem by gathering alms to provide a base for members of the order visiting from abroad (MacDonald 1981). Although the order may have begun supporting physically ill persons as a hospital as early as 1330, it did not begin caring for mentally disabled persons, except perhaps incidentally and temporarily, until 1403. After this date, mentally disabled persons gradually displaced the physically sick as the primary focus of the facility, but "it was nearly a hundred years later before there is evidence that London's magistrates thought that *only* the mad should be admitted" (Andrews et al. 1997:90). Today, Bethlem Hospital is the longest continually operating mental hospital in Europe.

In Spain, a hospital dedicated exclusively to mental disability was founded by Father Joffre in Valencia in 1409 (Rumbaut 1972). Other asylums also opened in fifteenth-century Spain in Zaragoza (1425), Seville (1436), Valladolid (1436), Palma Majorca (1456), Toledo (1480), and Granada (1527) (Bassoe 1945). A general hospital known to have housed persons with mental disabilities was also opened in Barcelona in 1412. No less an authority than France's great psychiatrist Phillippe Pinel believed Spain's asylums to be the world's most humanely and wisely administered mental hospitals from the fifteenth through the eighteenth centuries. In *Traité Médico-Philosophique sur l'alienation Mentale* (1809), he specifically cited the excellence of the Zaragoza asylum, "the founders of which aimed to construct mental disorder by charm inspired by the cultivating of fields, the instinct which prompts people to render the earth fertile and secure the fruits of their industry" (Pinel 1809:238).

A madhouse was constructed as part of the Georghospital in Elbing in 1326, in what is modern-day Germany. The Grosse Hospital in Erfurt, Germany, included a "mad hut" when it was constructed in 1385. Prior to the building of separate facilities for people with mental illness, general hospitals or infirmaries accepted people with mental disorders (Rosen 1968). However, given the lack of care institutions during the medieval era, people with mental disabilities must have been a relatively common presence in their communities (Digby 1996).

It has become part of the lore that people with mental disabilities were cast out to sea in so-called ships of fools during the Middle Ages (Maher and Maher 1982). The notion of the ship of fools was created in 1494 with the publication in German of a book of the same name by Brant (Swain 1932). There is no evidence that these ships actually existed, however (Maher and Maher 1982). Brant was a preacher who used the fool as a metaphorical device to rebuke his congregation to be pious (Swain 1932).

During the twelfth century, institutions for the quarantine of people with Hansen's disease (leprosy) became prolific (MacArthur 1953). Howard (1789) chronicles the existence of numerous facilities, termed *leprosariums*, throughout Europe, many of which evolved as part of the charitable work done by religious orders (Kipp 1994). This confinement experience with leprosy represents the first time that institutional, segregated facilities were systematically used in Europe to address the issues presented by people with disabilities. Isolation of lepers was a harbinger of the perceived merits of segregation and confinement of other disabled populations, although institutional treatments for people with disabilities other than leprosy were slower to develop. As leprosy virtually disappeared in Europe by the sixteenth century (Weymouth 1938), many converted leprosariums became privately operated madhouses for people with mental illness and, in some cases, for persons with intellectual disabilities (Alexander and Selesnick 1964). Leprosy, however, subsequently spread to the Americas and had a substantial impact. De Souza-Araujo (1937, 1946, 1948) has described in great detail the spread of leprosy from Portugal, Spain, France, Holland, and Africa to Brazil beginning in the fifteenth century. The first Brazilian leprosarium opened in Rio de Janeiro in 1766, followed by the establishment of scores of such facilities nationwide.

During the Middle Ages, begging was a common way for people with disabilities to support themselves when their families were unable or unwilling to do so. Guilds and brotherhoods of blind beggars were organized to address issues of competition and conflict (Covey 1998; French 1932). One of the strongest guilds was developed in 1377 in Padua, Italy. This guild regulated begging and organized pensions for elderly blind beggars (Covey 1998; Gowman 1957). As the active role of the Catholic Church in promoting charity diminished following the Reformation, "little of the medieval fabric of hospices, almshouses and refuges" was left for care of "unfortunates" (Porter 1987a:121). Since monastic institutions were seized by the government during the Reformation and charity concomitantly diminished, the number of beggars increased dramatically. The passage of the Elizabethan Poor Law in England in 1601 was enacted partly in response to the large number of beggars (Covey 1998). And in 1657, Paris outlawed begging within its city limits (Foucault 1965).

In summary, the Middle Ages were notable for the contradictory beliefs held about disability. One common conception of disability was that some disabilities, particularly deafness, epilepsy, and mental disabilities, had demonological origins. This point of view contributed to the perse-

cution of people with disabilities as witches and the use of magic to attempt to cure the disabling condition. A second conception of disability was also widespread—that persons with disabilities were part of the natural order, situated with other poor people and subject to the random havoc occasioned by the plagues in Europe. Stiker (1997) argues that the widespread nature of the plagues actually de-emphasized difference (impairment) more than in any epoch. There is significant evidence that people with disabilities used networks of support in their communities to survive in times that were harsh for nearly everyone. These two competing aspects of disability in medieval society appear to have coexisted, lending credence to the claim that there was no universal definition or interpretation of disability through this period.

## EARLY MODERN PERIOD THROUGH THE EIGHTEENTH CENTURY

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### *Renaissance and the Scientific Method*

In the fourteenth through sixteenth centuries, beginning primarily in Italy, humanism in art was accompanied by advances in the anatomical and physiological study of hearing, vision, and the human body by Versalius, da Vinci, William Harvey, and others (P. Edwards 1996). In the mid-sixteenth century, Girolamo Cardano pioneered instructional approaches for people with hearing and visual impairments. He also attacked the prevailing practice of witch hunting (Gannon 1981; Wright 1969). While the last witchcraft execution in England took place in 1684, English laws halting the persecution of witches were not repealed until 1736 (Russell 1980).

Despite the advances in human understanding that were secured during the Renaissance, beliefs in the bestial nature of, and possession by, people with mental disabilities continued during the early modern period. During the sixteenth century, Reformation leaders John Calvin and Martin Luther independently preached that persons with mental disabilities were possessed or created by Satan (Colon 1989; Kanner 1964).

During the Renaissance, voluntary beatings of the head were employed to treat people with many mental diseases, including depression, paralysis, and intellectual disability (Bromberg 1975). Physicians would also bore holes in the head or purge persons with mental disabilities to release the “stones” or “black bile” thought to cause illness (Gilman 1982). Treatment for epilepsy included the ingestion of a mountain goat’s brain or the still-warm gall of a dog killed at the moment of the seizure (Tuke 1878, [1882] 1968). One treatment of deafness consisted of frying earthworms with goose grease and dropping the solution into the ears (Winzer 1993). While these endeavors to cure illness and disability seem fantastic by today’s standards, they focused on biological etiologies and treatments and therefore signified a change in the prevailing beliefs that the causes of disability and illness were supernatural. Cures during this period were related to primitive understandings of anatomical functions and to physicians’ abilities to intervene to address bodily difference and dysfunction.

Analysis of an array of legal records in England during the early modern period indicates that society perceived two groups of people with mental disabilities: the “safe” and the “dangerous.” The safe would have included most people with intellectual disabilities and many people with mental illness who were not perceived to be violent (Fessler 1956; Rushton 1988; Suzuki 1991). These individuals were cared for largely by their families, with an unclear and diverse amount of assistance from their local communities. The “dangerous” of the mentally ill were either cared for by their relatives, by local constables, or by sending them to a house of correction (Suzuki 1991).

In early modern England, there is further evidence that the general understanding of intellectual disability was understood to arise from birth and to be relatively fixed, whereas people

understood that mental illness often had an onset in later life and could be quite transitory. While there were ambiguities in philosophical, medical, and legal interpretations of intellectual disability, fundamental aspects of differentiation clearly existed (Andrews 1998). The perceived need to differentiate between mental illness and intellectual disability seems to be more related to the application of property law than to treatment, which was essentially nonexistent at this time.

An important development of the sixteenth century was the initiation of education of deaf persons, which began in Spain and the Turkish Ottoman court. In Spain, instruction began with deaf aristocratic children who had been hidden in monasteries and convents by their wealthy families. This education was undertaken by the monks with whom they lived (Plann 1997). During the next century, deaf education in Spain was still limited to the wealthy classes, but it moved beyond the monasteries. In 1620, Juan Pablo Bonet of Madrid published the first treatise on the education of the deaf (Gannon 1981; Whitney 1949; Wright 1969). Sixty years later, George Dalgarno published the first finger alphabet designed specifically for deaf persons (Wright 1969).

Miles (2000) found that deaf persons employed in the Turkish Ottoman court were actually training one another in the use of sign language as early as 1500 and for the next two centuries. Their signing system became popular and was used regularly by hearing people, including Sultans and diplomats. Miles observed that

the use of this language, and the training of deaf people *by* deaf people for responsible employment in a highly privileged but risky environment, was evidently developing from the early sixteenth century at a time when Western Europeans very seldom thought deaf people could be educated or could make any useful contribution to society. (P. 129)

The English statesman and philosopher Francis Bacon ([1605] 1900) believed that the supernatural and speculative philosophies of the Middle Ages and Renaissance had contributed nothing to the advancement of knowledge. He was impressed with the revolutionary discoveries of Copernicus and Galileo, who, for the first time, had proven certain characteristics of the universe. He was impressed with Marco Polo's travels and with the invention of gunpowder. Bacon introduced the notion of science as *systematic study*. He called for experiments to be conducted based on the collection of empirical data (Bacon [1605] 1900; Park and Daston 1981). The secrets of nature could be revealed, he argued, by the systematic observation of its regularities. In 1605, Bacon published *The Advancement of Learning, Divine and Humane*. In it, he refuted the notion of divine punishment as a cause of mental illness. He suggested four lines of inquiry that would guide psychological research for the next 300 years: studies of mental faculties and the interaction of body and mind, individual case studies, anatomical inquiry and postmortem studies, and the interaction between society and the individual (Bacon [1605] 1900).

### *Poverty and Disability*

A profound change in attitudes toward poverty occurred across Europe during the thirteenth through seventeenth centuries that would have an impact on people with disabilities. Poverty traditionally had been associated with followers of Jesus in the Christian European countries, and beggars represented a means for almsgivers to please God (Spierenburg 1984). Ideas about the changing perception of poverty, from a necessary and even blessed state to a curse, began to slowly evolve from the thirteenth century. By the sixteenth century, this transformation was more or less complete, and poor people were deemed suspect. This metamorphosis of attitudes resulted in the eventual development of incarcerating facilities for the poor, particularly for people with mental illness (Spierenburg 1984). As previously noted, begging was outlawed in the streets of Paris in 1657, further marginalizing people with disabilities and separating them from what had been an important source of income for centuries.

England's Poor Law of 1601 was a watershed that specifically designated responsibility for poor and other people unable to provide for themselves. If a person was unable to procure a living for himself or herself, the first line of responsibility was his or her family. Barring the possibility of family provision of support, local communities were charged with providing for such persons in need (Rushton 1988, 1996). "Competent sums of money for and towards the necessary relief of the lame, impotent, old, blind, and such other among them" were to be set aside by the local community (43 Elizabeth 1601, cited in Axinn and Levin 1982:10). These laws became the general model in the American colonies, and local responsibility for people with disabilities who were unable to provide their own care was the common practice (Axinn and Levin 1982).

During the early modern and Renaissance periods, a complex relationship existed between community support, religious and medical institutions, and family resources in coping with mental disability (Adair, Melling, and Forsythe 1997). While the implementation of the English Poor Law was distinguished by the provision of relief in the community, on the Continent, the provision of public welfare "was usually within the context of structures likely to produce a sense of social stigma and alienation. Continental institutions are thus seen as compulsory and segregated from the outside world, and characterized by day-to-day procedures inherently de-humanizing" (Cavallo 1998:91). During the early modern period in Italy, for example, there is evidence that people with disabilities sought admission to hospitals for the poor in large numbers and were thereby subject to stigmatization.

English administrative records of the overseers of the poor indicate that people with intellectual disability were widely supported through the Poor Law, and policies of relief were relatively well organized during the early modern period (Rushton 1996). People with mental illness fared differently from those with intellectual disability. While most people with disabilities remained in the community with their families, there is evidence that people with mental illness were more likely to be incarcerated in gaols and houses of correction than their peers with intellectual disability (Rushton 1996). What is particularly important about the administration of welfare at this time is that it "marked a shift from the predominantly familial system that dominated the medieval period" (Rushton 1988:34). Examining welfare records in England, Rushton found that custodial care was virtually never contemplated for people with intellectual disability or mental illness, but families sought relief when their poverty was related to the impairment of a family member.

The first almshouse in the United States was established in Boston in 1662 and served a heterogeneous population, including persons with physical and mental disabilities, blind persons, deaf persons, the poor, the elderly, and orphans. However, the development of institutions for disabled persons was slow in the United States until the 1820s (Rothman 1990). Privately operated "madhouses" also began to spread across Britain during the Enlightenment period (Parry-Jones 1972). The first English workhouse was established in Bristol in 1697. By the end of the eighteenth century, there were 127 workhouses in England alone. Contagious invalids were turned away from workhouses, but people with mental disabilities were not. Workhouses spread rapidly across Europe by the beginning of the nineteenth century (Foucault 1965). Despite the spread of institutional care for people with mental illness in England between 1650 and 1850, families remained the main source of support during this period for poor people with mental illness (Suzuki 1998).

### *Philosophical Enlightenment*

The *Enlightenment* or *Age of Reason* is a cultural historian's term for revolutionary changes in thinking that began in Europe in the seventeenth century. The Enlightenment represented the intellectual platform for the rise of contemporary Western civilization and drew heavily from the contributions of Francis Bacon, Isaac Newton, and John Locke. Two themes in Enlightenment thinking are related to changes in the care and treatment of people with disabili-

ties. First, a “sensationalist” theory of knowledge laid the foundation for bold new psychological and educational interventions by arguing that experience and reason—rather than innate ideas and divine punishment—were the sources of all knowledge and that social and environmental modification could thus improve humans and society by manipulating society and the environment (de Condillac [1754] 1930; Locke 1690). The second Enlightenment idea of importance to people with disabilities was the growing belief in the merits of natural science to advance the species (P. Edwards 1996).

The Enlightenment’s sensationalist school of philosophy spawned changes in attitudes, new institutions, voluntary charitable societies, interest groups, and literary work. In 1656 in Paris, the great “Hôpital General,” France’s charitable hospital, was formed as a single, semi-judicial administrative entity out of several existing establishments, including the Salpêtrière and the Bicêtre (mental hospitals for women and men, respectively) and several smaller general hospitals (Andrews et al. 1997). The first public charity hospital in France had opened in Lyons in 1612 and functioned in an analogous manner (Foucault 1965). Confinement no doubt accelerated in Paris with the enactment of the aforementioned edict in 1657 that prohibited begging.

Thus, *poverty, disability, and the inability to work* came to rank prominently among the major problems of the city. The soon to emerge “sensationalist” philosophies of the Enlightenment, however, provided the moral imperative and the tools for new and constructive interventions with the interconnected problem of disability and poverty (Winzer 1986).

### *Distinguishing between Intellectual Disability and Mental Illness*

While English property law differentiated between intellectual disability and mental illness beginning in the thirteenth century, John Locke’s 1690 work, *An Essay Concerning Human Understanding*, presented the most influential distinction to date between “idiots” and “madmen”:

The defect in [idiots] seems to proceed from want of quickness, activity, and motion in the intellectual faculties, whereby they are deprived of reason: whereas mad men seem to suffer by the other extreme. For they do not appear to me to have lost the faculty of reasoning: but having joined together some ideas very wrongly . . . they argue right from wrong principles. . . . But there are degrees of madness as of folly; the disorderly jumbling [of] ideas together, is in some more, and some less. In short, herein seems to lie the difference between idiots and mad men, that mad men put wrong ideas together, and so make wrong propositions, but argue and reason right from them: but idiots make very few or no propositions, but argue and reason scarce at all. (P. 236)

Although Rushton (1996:50) argued that Locke merely “provides a gloss on the pre-existing legal concepts rather than a critical challenge to them,” he also acknowledges that Locke had a significant influence on Blackstone’s later legal interpretations of intellectual disability. Goodey (1996) credits Locke with establishing the dichotomy between mental illness and intellectual disability that ultimately influenced social policy doctrine for people with intellectual disability. Even before Locke, in 1614, the Portuguese physician Montalto wrote a major medical work in which he distinguished mental illness from intellectual disability and described the diagnosis, prognosis, and treatment for intellectual disability (Woolfson 1984). This work, written while Montalto was personal physician to Italian Grand Duke Ferdinand I, has been largely ignored by historians.

Swinburne’s (1590) definition of intellectual disability, published a century earlier, is important as well, in that it points to the importance of basic reasoning ability and suggests the elements of an assessment test to evaluate the provenance of “idiocy”:

An idiote or a naturall foole is he who notwithstanding he bee of lawfull age, yet he is so witlesse, that he can not number to twentie, nor can tell what age he is of, nor knoweth who is his father, or mother, nor is able to answer to any such easie question. Whereby it may plainelye appeare that he hath not reason to discerne what is to his profite or damage, though it be notorious, nor is apt to be informed or instructed by anie other. Such an Idiote cannot make any testament nor may dispose either of his lands, or goodes. (P. 39)

Shortly after Locke penned his 1690 essay, Daniel Defoe, journalist and the author of *Robinson Crusoe*, recommended, to no avail, creating government-sponsored residential institutions for persons with intellectual disabilities, to be paid for with an author's tax (Defoe [1694] 1894; Goodey 1996). In 1720, Defoe also made a real deaf-mute person the hero in his book *The History of the Life and Adventures of Mr Duncan Campbell*, and he described sign language and approaches to deaf education in considerable detail.

### *Institutions for People with Mental Illness Established*

In 1700, county asylums for "idiots, blind, and cripples" were proposed in England ("County Asylums Proposed" 1982). Parliament enacted a law in 1714 authorizing confinement, but not treatment, for the "furiously mad" and exempted them from the whippings routinely applied to rogues, beggars, and vagabonds. In 1704, Bethlem Hospital had 130 residents. There were 64 admissions, and 50 persons were cured and discharged that year (Strype 1720). Bethel and St. Luke's Mental Hospitals opened in Norwich in 1724 and in London in 1751, respectively. British Parliament repealed the witchcraft acts in 1736, and pressure mounted to improve conditions in the private madhouses. A statute was enacted regulating madhouses in 1774, and this was followed by a major parliamentary inquiry from 1815 to 1816 covering England, Scotland, and Ireland. According to one noted British authority, glaring deficiencies were noted between the best practices delineated in books about mental disability and actual conditions found in such facilities (Parry-Jones 1972).

In the eighteenth century, madhouses and criminal prisons were combined facilities in what is modern-day Germany. In these facilities, inmates were expected to work to contribute to the upkeep and expenses of the facility, particularly women through spinning (Spierenburg 1984). In Holland and Germany, private confinement was sought by wealthier families for their relatives with mental illness, frequently to avoid dishonor to the family by the person's behavior (Spierenburg 1984).

While the institutionalization of people with mental illness who were violent began during the fifteenth century, by the eighteenth century, facilities accepted people with mental illness who were not violent (Spierenburg 1984). This was the case in England, Germany, Holland, France, and Spain as well as in the New Spain (Mexico).

### *Developments in the American Colonies and Early United States*

In colonial America, the first petition to secure payment for the guardianship of a person with intellectual disability was submitted to England's King Charles I in 1637. Support was sought for custody of Benoni Buck of Virginia (Harris 1971; Hecht and Hecht 1973; Neugebauer 1987). However, Puritans in colonial America still believed that disability was a result of God's divine displeasure (Covey 1998). Increase Mather, president of Harvard and father of witchcraft zealot Cotton Mather, wrote about the birth of children with disabilities as evidence of God's retribution. His son Cotton Mather later preached and wrote the same (Covey 1998; Winship 1994).

The American colonies largely appropriated English laws for their governance, including the Poor Law initially passed in 1601 under Queen Elizabeth. Since towns had ultimate responsibility for the poor under the law, communities took steps to discourage “vagabonds, beggars, or idle persons” (Peterson 1982:109) from settling therein. People who were considered likely to become a public charge would be “warned out” of town, with public whipping—the penalty for not leaving. People with mental illness were particularly susceptible to being warned out; however, there is also evidence that they received public support. The earliest provision for the maintenance of a mentally disabled individual in the Pennsylvania colony, for example, dates to 1676. In that year, the Upland Court in Delaware County, Pennsylvania, ordered that “a small Levy be Laid to pay for the buildings of ye house and the maintaining of ye said madman according to the laws of ye government” (Morton 1897:4).

In 1752, with leadership from the physician Thomas Bond and Benjamin Franklin, the first general hospital was established in the American colonies in Philadelphia. Care for persons with mental illness was a major motive in the founding of this hospital. The principal argument expressed in the petition filed with the Pennsylvania Provincial Assembly and subsequently embodied in the authorizing legislation of May 11, 1751, was to address the growing problem of mental disability in the colony. The petition read as follows:

To the honourable House of Representatives of the Province of Pennsylvania, The Petition of sundry Inhabitants of the said Province, Humbly sheweth,

THAT with the Numbers of People, the number of Lunaticks or Persons distempered in Mind and deprived of their rational Faculties, hath greatly encreased in this Province.

That some of them going at large are a Terror to their Neighbours, who are daily apprehensive of the Violences they may commit; And others are continually wasting their Substance, to the great Injury of themselves and Families, ill disposed Persons wickedly taking Advantage of their unhappy Condition, and drawing them into unreasonable Bargains, &c.

That few or none of them are so sensible of their Condition, as to submit voluntarily to the Treatment their respective Cases require, and therefore continue in the same deplorable State during their Lives; whereas it has been found, by the Experience of many Years, that above two Thirds of the Mad People received into Bethlehem Hospital, and there treated properly have been perfectly cured.

Your Petitioners beg Leave farther to represent, that tho' the good Laws of this Province have made many compassionate and charitable Provisions for the Relief of the Poor, yet something farther seems wanting in Favour of such, whose Poverty is made more miserable by the additional Weight of a grievous Disease, from which they might easily be relieved, if they were not situated at too great a Distance from regular Advice and Assistance; whereby many languish out their Lives tortur'd perhaps with the Stone, devour'd by the Cancer, deprived of Sight by Cataracts, or gradually decaying by loathsome Distempers; who, if the Expense in the present manner of Nursing and Attending them separately when they come to Town were not so discouraging, might again, by the judicious Assistance of Physic and Surgery, be enabled to taste the Blessings of Health, and be made in a few Weeks, useful Members of the Community, able to provide for themselves and Families.

The kind Care our Assemblies have heretofore taken for the Relief of sick and distempered Strangers, by providing a Place for their Reception and Accommodation, leaves us no Room to doubt their showing an equal tender Concern for the Inhabitants. And we hope they will be of Opinion with us, that a small Provincial Hospital, erected and put under proper Regulations, in the Care of Persons to be appointed by this House, or otherwise, as they shall think meet, with Power to receive and apply the charitable Benefactions of good People towards enlarging and supporting the same, and some other Provisions in a Law for the Purposes above mentioned, will be a good Word, acceptable to God and to all the good People they represent. (Morton 1897:8)

Initially, cells in the basement of the hospital's temporary quarters were set aside for persons with mental disabilities. Four years later, a special wing in the hospital was used for this purpose, and in 1836, the cornerstone of a separate building was laid for the Pennsylvania Hospital for the Insane ("A Sketch" 1845). In its first years, the treatment of persons with mental disabilities in the Pennsylvania Hospital consisted of an assault on the body and the senses. Morton's (1897) comprehensive history of the hospital describes the treatment of "phrenze" in 1791 as consisting of being

drenched or played upon, alternately with warm and cold water (which may have accounted for some of the pulmonary fatalities elsewhere mentioned). Their scalps were shaved and blistered; they were bled to the point of syncope; purged until the alimentary canal failed to yield anything but mucous, and, in the intervals, they were chained by the wrist, or the ankle to the cell wall. (P. 125)

The noted American psychiatrist Benjamin Rush may have introduced some improvements in care during his nearly 30 years of continuous service at the hospital between 1783 and 1813, but he is most widely remembered for introducing two mechanical contrivances for treatment (Rush 1812). One, called a gyrator or revolving machine, was used in cases of "torpid madness" to spin the body and raise the heart rate to 120 beats per minute. A second device, the tranquilizing chair, was intended to reduce sensory-motor activity and reduce the pulse. Rush, the only physician signer of the Declaration of Independence, also prescribed bloodletting, a common medical practice he learned in his studies at Edinburgh University, along with low diet, purges, emetics, and cold showers and baths (Morton 1897:164).

Veterans of the Revolutionary War were the first people with disabilities in the new United States to receive a pension, providing compensation for war-related impairments. In 1776, the first national pension law was adopted, and the sentiment of the Continental Congress reveals compassionate and concerned attitudes regarding those men whose impairments were sustained during the war:

Permit not him, who, in the pride and vigor of youth, wasted his health and shed his blood in freedom's cause, with desponding heart and palsied limbs to totter from door to door, bowing his yet untamed soul, to meet the frozen bosom of reluctant charity. (Glasson, as cited in Obermann 1968:137)

One of the first American states to establish provisions for people with intellectual disability and mental illness was Kentucky. In 1793, the state passed legislation authorizing payment to families too poor to continue caring for members with either mental illness or intellectual disability without assistance (Estabrook 1928). A trial system for determining the person's identity as an "idiot" or "lunatic," as well as their need for such support, was established. This pension system continued throughout the nineteenth century and was still in existence in 1928. Annual payments remained at \$75 from 1870 to 1928 (Estabrook 1928). It is noteworthy that professionals felt that the use of this pension encouraged idleness in people with intellectual disabilities and that the only appropriate form of support was institutionalization (Estabrook 1928).

Another American response to meeting the need for care of people with mental disabilities that could not be met by their families was the practice of "bidding out." In this system, a person with mental illness or intellectual disabilities was auctioned off to the lowest bidder, who would receive the bid amount to provide care for a year. This practice of "bidding out" was administered by counties in many states for people with intellectual disability and mental illness until about the 1820s, when it was perceived to become too expensive (Breckinridge 1939). Bidding out was a common form of welfare throughout the nation (Peterson 1982).

### *Schools for Deaf and Blind Persons Opened in Europe*

The eighteenth century saw the gradual proliferation of residential schools for both deaf and blind persons. Schools for the deaf began in Spain and France and gradually spread to other European countries and the United States. The roots of deaf education began in north-central Spain with the birth of Pedro Ponce de León around 1510. de León, a Benedictine monk working in the monastery of San Salvador de Oña in the province of Burgos, is credited with being the first teacher of the deaf in the Western world. The exact date he began his work is not known, but by the mid-sixteenth century, he had initiated a school within the monastery for his students, many of whom were the children of wealthy Spanish families. He apparently used a manual alphabet and conventional signing and instructed about 20 students (Daniels 1997). After de León's death in 1584, Juan Pablo Bonet further disseminated de León's methods, publishing in 1620 in Spanish *The Art of Teaching the Deaf to Speak*. This book is recognized as fully derivative of de León's work; however, no original manuscripts of de León's earlier contributions have been located to date (Daniels 1997).

Ponce de León's methods appeared in mid-eighteenth century France, carried forward by Charles Michael de l'Epée. In 1755 de l'Epée, a Paris priest, established the world's first public residential school for deaf persons in Paris (Gannon 1981; Minski 1957; Wright 1969). By 1783, the school had 68 pupils (Daniels 1997). Signs were the communication technique preferred by de l'Epée (instead of the oral communication championed by his rival Péreire), and the support provided for his school by the king had a lasting influence on deaf communication (Lane 1989; Sacks 1989).

In 1760, Thomas Braidwood established the first British school in Edinburgh, Scotland (Gannon 1981; Minski 1957; Wright 1969). The first school for deaf persons in Germany was opened in 1778 in Leipzig by Samuel Heinicke. Abba Silvestri opened the first Italian school for deaf persons in Rome in 1784 (Gannon 1981). Germany's Heinicke favored "pure oralism," in the belief that articulation was necessary for deaf people to obtain respected status in society (Gannon 1981; Minski 1957; Wright 1969).

Abbé de l'Epée believed that deaf persons were representative of primordial ancestors, not unlike Rousseau's ([1762] 1991) notion of "man in the state of nature," and that their silence made them extremely similar to the first people on earth. He invited the public to visit his school, with the intent that doing so facilitated insight into the "natural path of human mental and linguistic development" (Rosenfeld 1997:157). Scientists and statesmen from Europe and the United States visited his school, and Enlightenment philosophers were intrigued with his educational methods and the unique opportunity represented by studying deaf persons and their sign language.

Although de l'Epée believed that sign language was a primitive form of communication, he believed that it was effective for deaf people. de l'Epée died in 1789 and was succeeded by the Abbé Sicard, who had previously headed a school for the deaf founded in the Bordeaux region of France in 1786. Sicard subsequently hosted Thomas Gallaudet of the United States during the latter's visit to Paris in 1816 and assisted Gallaudet in establishing the first school for the deaf in the United States (in Hartford, Connecticut) the following year.

In 1784, Valentin Haüy opened the first residential school for blind students in Paris (Allen 1899; Farrell 1956; Roberts 1986). He developed the first embossed print and used it to teach reading. The first school for blind students in England was opened in Liverpool in 1791 by Edward Rushton. Between 1804 and 1820, schools for blind children and youth opened in Vienna, Steglitz (Germany), Milan, Amsterdam, Prague, Stockholm, St. Petersburg, Dublin, Copenhagen, Aberdeen, Brussels, Naples, and Barcelona (Farrell 1956). The first U.S. institutions for blind students were opened in Boston (Perkins Institute) and New York City in 1832. Pennsylvania followed one year later, and Ohio opened a public school for blind students in 1837 (Allen 1899, 1914; French 1932).

The early modern period through the eighteenth century was a time of far-reaching change for persons with disabilities. Systematic differentiation between people with mental illness and intellectual disability was established to ensure correct adjudication of property laws. Compre-

hensive education of deaf and blind children began in Spain and France, respectively. This period saw the first manifestations of criminalizing and regulating idleness and poverty, which had a direct impact on people with disabilities who were usually poor. Institutional solutions to the problems ostensibly posed by poverty and disability—houses of correction, workhouses, asylums, and madhouses—became more common as the eighteenth century ended. The intellectual revolution of the Renaissance and Enlightenment contributed to fundamental changes in the relationships between humans, society, and God. For the first time, people were deemed to be capable of intervening in what had been perceived to be the immutable natural order: a belief that society and human beings could be perfected. This revolution in thinking stimulated extensive efforts to develop treatment interventions for people with disabilities, including the deaf, blind, and people with mental disabilities, and it led to the ascendancy of a professional class of physicians, educators, and caretakers. The medicalization and professionalization of disability reinforced the development and proliferation of institutions and schools across Europe and subsequently in North America. The trend toward institutionalization would gain greater momentum during the nineteenth and twentieth centuries.

## THE NINETEENTH CENTURY

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### *Educational Developments*

Residential schools for deaf and blind students grew rapidly during the nineteenth century, as did institutionalized segregation of people with mental illness and intellectual disability. Therapeutic advances occurred for people with speech impairments, and controversy developed regarding two competing philosophies for educating deaf persons—oralism and manualism.

Schools for children with physical disabilities opened somewhat later in Europe than did those for deaf and blind students. The first school designed exclusively for children with physical disabilities was opened in 1832 in Bavaria by John Nepinak. Schools subsequently opened in other parts of Germany, France, England, Switzerland, and Italy. Denmark established the first program of industrial training for children with physical disabilities. A program of segregation in workshops became common in European schools by the middle of the nineteenth century (Obermann 1968).

In 1829, Louis Braille published an explanation of his embossed dot code, which was an improvement on a system developed by Barbier in 1808 (French 1932; Roberts 1986). Competing systems of communication would exist until 1932, when American and British committees finally signed an agreement to adopt Standard English Braille as the uniform type (Roberts 1986). In 1858, the American Printing House for the Blind was chartered in Louisville, Kentucky. This organization would become the premier printer of materials for blind persons in the United States, and in 1879, Congress legislated an annual appropriation of \$10,000 for the printing of educational materials for blind persons (Allen 1914; American Printing House for the Blind 1999).

An intimate link between the fields of deafness and intellectual disability developed at the dawn of the nineteenth century. In 1800, Jean Itard (1775-1850) joined the medical staff at Sicard's National Institution for Deaf Mutes in Paris to study speech and hearing. The previous summer, a feral child was discovered in southern France, and scholars in Paris were anxious to examine him in the belief that the boy approximated "man in the state of nature." Thus, basic philosophical questions about human learning and development prominent in French Enlightenment thinking of the day could be systematically studied. Since the "wild boy" was mute, he was placed in the school for deaf persons in Paris. Pinel, who first examined the boy at the Bicêtre, was initially convinced that the boy, later named Victor, was unteachable. However, Itard committed the next five years of his life to instructing Victor, using educational ap-

proaches pioneered during the mid-eighteenth century by one of the first professional French teachers of deaf persons, Jacob Péreire. Péreire's teaching methods drew heavily on Rousseau's interpretation of Locke's "sensationalist" empirical psychology (Winzer 1993). Itard's approach emphasized individualization of instruction in five areas: sensory stimulation, speech, socialization, concept development, and transfer of learning (Itard 1802).

Itard initially believed that Victor suffered from early social and educational deprivation, and he thought his teaching had failed because Victor developed only minimal speech and was not fully restored to a useful life in society. Nevertheless, Itard's work subsequently stimulated highly successful interventions for children with intellectual disabilities by his pupils Edouard Séguin and Maria Montessori. Itard is also known for his early contributions to the oral education of deaf persons, the medical specialty otolaryngology, the use of behavior modification with children with disabilities, and the special education of persons with mental and physical disabilities (Itard 1821a, 1821b; Lane 1989). One of Itard's greatest contributions to his age's understanding of intellectual disability stemmed from his rejection of overly inclusive diagnoses of "idiocy." Also, in an underacknowledged paper he published in 1828 ("Mutism Caused by a Lesion of the Intellectual Functions"), Itard described how to distinguish between children with intellectual disability and those with pervasive developmental disorders such as autism (Carrey 1995).

Séguin expanded Itard's sensory techniques into what he termed the "physiological method," emphasizing sensory-motor training, intellectual training (including academics and speech), and moral training or socialization (Simpson 1999; Talbot 1967). Early in his career, Séguin (1846) acknowledged his debt to Péreire and noted that intellectual disability, deafness, and congenital blindness shared two key characteristics: early age of onset and permanence of the condition. It followed that there would be similarities in remedial techniques. Séguin's work was embraced by the French Academy of Sciences in 1844 and subsequently became the standard worldwide reference. After heading schools for children with intellectual disabilities at the Bicêtre and in private schools for 20 years, Séguin left Paris for the United States in 1848 to escape political instability (Simpson 1999; Talbot 1967). Elsewhere in Europe, special residential schools for persons with intellectual disabilities were established by Guggenbuhl in Switzerland in 1842, by Saegert in Germany in 1842, and by Connolly and Reid in England in 1846 (Barr 1904; Bucknill 1873; Fernald 1893). It was common during this period for superintendents of facilities in one nation to visit Paris's facilities and report on the methods observed ("A Visit to the Bicêtre" 1847a, 1847b, 1847c).

The nineteenth century also witnessed dynamic changes in the education of other people with disabilities. In 1810, John Thelwall published the first book to be concerned solely with speech disability, *Letter to Henry Cline* (Rockey 1980). Thelwall is regarded as England's first speech therapist, and the nineteenth century marks the beginning of the differential diagnosis, evaluation, and treatment of speech disorders (Rockey 1980). The development of speech correction techniques in continental Europe was largely the province of educators of deaf persons, while in England, orators, clergymen, actors, and singing teachers were principally involved (Rockey 1980).

In Spain, deaf educator Tiburcio Hérnandez at the Royal School decreed a return to oralism following the 1814 opening of the school after Spain's War of Independence. While Hérnandez adopted the subordinate use of signs, borrowed from Frenchmen Abbé de l'Epée and Sicard, he advocated the primacy of oralism (Plann 1997). Hérnandez held derogatory views of deaf students, believing them to be essentially defective and unintelligent. Students were thus encouraged to learn manual trades because of persistent beliefs in their intellectual deficits. The domination of oralism in Spanish education of deaf students did not end with Hérnandez's 1823 execution during a period of political upheaval. Students were subjected to considerable physical abuse, which led to an uprising by some of the pupils against the teachers. For the rest of the nineteenth century in Spain, there was a marked rejection of teachers who were deaf, and education of deaf students became entrenched as the domain of experts who could hear.

In France during the nineteenth century, society continued to perceive deaf people negatively, often as a stereotype of naive, incompetent children. The Deaf Institute in Paris, a

state-sponsored facility for deaf persons, served both educational and social welfare purposes. Two professors at the institute, however (Bébian and Paulmier), advocated the use of sign language and fostered a belief in the existence of deaf culture (Quartararo 1995).

### *First North American Mental Hospitals and Residential Schools*

The first mental hospital established on the North and South American continents was opened in Mexico City two centuries before similar initiatives were undertaken in the United States and Canada. San Hipólito Hospital was established in 1566 near San Hipólito Chapel in Mexico City by the Spanish philanthropist Bernadino Alvarez. Alvarez was joined in the effort by several clergymen from an order that subsequently came to be known as "Los Hipólitos." New hospital structures were erected in 1739 and 1777, and the administration of the facility was taken over by the municipal government in 1821. The facility was closed in 1910, when all patients were transferred from this facility and from a second asylum for women that had opened in 1700, to a new institution called La Casteñada Asylum. The women's asylum, "La Canoa Hospital for Mental Disease," also known as the "Divino Salvador Hospital," was a product of the efforts of local carpenter José Sayago and his wife, who provided shelter, food, and care for poor mentally disabled women who were an everyday sight on the streets in the Capitol of the New Spain (Ramirez-Moreno 1937, 1942).

The first American almshouse was constructed in Boston in 1662, and the first mental asylum was constructed in Virginia in 1773. However, such institutions did not become common in the American landscape until the Jacksonian era, beginning in the 1820s. At this time, the nation was faced with increasing urbanization and manufacturing and changing demographics that included the first major influx of immigrants. These changing conditions led to social turmoil, and institutional solutions for social problems were sought for the first time in the United States. There is widespread disagreement among historians and social scientists as to the reasons for the appearance of institutions in the United States beginning in the 1820s (Mora 1992). Rothman (1990) contends that it was absolutely not inevitable for institutions to develop in the United States but that they represented an innovative solution to pressing social problems and profound changes in the economic and social structure of the country. He argues that the concurrent development of orphanages, asylums for people with mental illness, prisons, alms-houses, and reformatories was the result of a nation grappling with tremendous social upheaval and a desire to manage the social order by controlling deviant members. Others have argued that the development of institutions followed the European example and was the product of American interest in solving social problems by adhering to the natural course established by Europe (Mora 1992; Grob 1990). Symonds (1995) has argued that mental institutions developed in England during the nineteenth century as a sociological response to perceptions of the threat of deviance, which is consistent with Rothman's (1990) conclusions about the development of such facilities in the United States.

During this period, residential schools in the United States began for deaf persons with the 1817 opening of the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut, by Thomas Gallaudet and Laurent Clerc (Fay 1893). Within two years, this first school for deaf students in the United States was accepting students from 11 states (Ely 1893). The national character of the school stemmed in part from the fact that in 1819, the federal government granted the school an endowment of 23,000 acres of land in the Alabama territory (Breckinridge 1927).

The state of New York established the second U.S. school in 1818 in New York City (Gannon 1981). Many of the first schools in the United States were initially begun as day schools and later evolved into residential schools (Gordan 1885). The first separate schools for blind students in the United States began instruction within months of one another in 1832 in New York

City and at the Perkins Institute in Boston (Allen 1899; Farrell 1956; Frampton and Kerney 1953).

The bishop of Québec erected the first building in Canada exclusively dedicated to the confinement of mentally disabled individuals in 1714 (Hurd 1910). The building was located adjacent to the Québec General Hospital. However, people with mental illness and intellectual disability had been cared for in two general hospitals in Québec since at least 1694 (Griffin and Greenland 1981). As previously noted, the colonial government of Virginia opened the first mental hospital in the United States exclusively dedicated to mental disability in 1773 in Williamsburg (Eastern State Hospital). The opening of this facility had virtually no impact as a model on other states. The impulse to establish this facility stemmed from Virginia's English colonial governor, Francis Fauquier, who was motivated through a sense of noblesse oblige to establish similar institutions abroad (Grob 1973). The establishment of this first facility in the United States was not preceded by a public campaign, as would become the common practice for subsequent American facilities. The Virginia facility's capacity was 24 to 36 persons, and the governing authorities "never publicized the work of the hospital, and thereby reinforced its essentially local character" (Grob 1973:29). The facility shut down for 4 years beginning in 1782 due to the American Revolution. The state of Maryland then opened the fledgling nation's second state mental institution in 1798—fully 25 years after the opening of the first facility in Virginia. The third state institution for people with mental illness opened 25 years later, in Kentucky in 1824 (Grob 1973).

Private initiatives in the northeastern United States led to the creation of several mental hospitals modeled after the York Retreat in England. York was a private facility opened by the Quaker William Tuke in 1792. Between 1817 and 1847, private institutions opened in Philadelphia, Boston, New York, Connecticut, Vermont, and Rhode Island (Earle 1845; Hamilton 1944; Kirkbride 1845; Wood 1853). By the time the Butler Hospital opened in Providence in 1847 (Rochefort 1981), however, it had become clear that the exclusiveness and higher costs of private hospitals rendered them inadequate to meet the needs of the poorer classes, particularly the growing populations of urban poor in America's developing cities (Grob 1973; Hamilton 1944).

The development of mental asylums accelerated following Dorothea Dix's advocacy beginning in the 1840s (Brown 1998; Grob 1994; Rothman 1990). Dix traveled across the country, inspecting conditions of people with mental illness kept in prisons, living with their families, and in "bidded-out" contracts. She lobbied individual state legislatures for the construction of asylum facilities for the mentally disabled by writing memorials that described her findings (Brown 1998). In her first memorial, written after canvassing conditions in Massachusetts, Dix (1843) described

the present state of Insane Persons confined within this Commonwealth, in cages, closets, cellars, stalls, pens! Chained, naked, beaten with rods, and lashed into obedience! . . . Irritation of body, produced by utter filth and exposure, incited [one woman] to the horrid process of tearing off her skin by inches; her face, neck, and person, were thus disfigured to hideousness. (P. 7)

Institutions for people with mental illness continued to be constructed, frequently due to Dix's agitation. During the 1840s to 1870s, she was involved in the construction or expansion of more than 30 such facilities across the United States and in Britain (Brown 1998). Mental asylums of the earliest period were generally designed to house fewer than 300 people and were organized under the leadership of psychiatrist-superintendents. These men adhered to the moral treatment method pioneered by Pinel and Tuke (Grob 1966). However, the first institutions were marked by specific divisions in the care and treatment of the poor from the privileged classes (Tuke 1815). This initial segregation within public facilities between the middle class and the poor was the beginning of practices that would eventually become a hallmark of American institutions (Rothman 1990; Trent 1995). During the first half of the nineteenth century, physician-superintendents of the first mental asylums in the United States believed that

mental illness was curable (Grob 1966; Kirkbride [1880] 1973). Kirkbride, superintendent of the Pennsylvania asylum, argued that in cases where uncomplicated insanity was "properly and promptly treated, and having this treatment duly persevered in, may be regarded as curable . . . 80%" of the time (Kirkbride [1880] 1973:23).

### *Overcrowding and the Demise of the Moral Treatment*

Beginning almost immediately after they were constructed, mental institutions experienced severe overcrowding as prisons sought to release their most dangerous and disturbed inmates to the newly available facilities (Grob 1966). Overcrowding and expansion soon made the superintendents' attempts at moral treatment impossible as the management of large facilities became paramount. In the later decades of the 1800s, as treatment gave way to confinement and custodial care in larger facilities, cure rates concomitantly dropped, and psychiatrists reported that mental illness was largely incurable (Earle 1877; Grob 1966; Rothman 1990; Scull 1991).

As populations in these asylums swelled, conditions of overcrowding became serious by the end of the nineteenth century. The sheer number of inmates in most facilities, along with growing administrative responsibilities in increasingly complex institutions, translated into less time with patients for the superintendent. The moral treatment subsequently faded, along with beliefs in the curability of mental illness as custodial functions of the asylums became primary (Grob 1966; Rothman 1990).

By the late 1800s, the earlier optimism of rehabilitating patients with mental illness and sending them back to their home communities had been replaced with a rigid pessimism that decried the possibility of cure and demanded the lifelong custody of patients reported as extremely dangerous to their home communities (Earle 1877; Grob 1966; Rothman 1990). Grob (1966) argues that superintendents gave way to the inevitability of poor conditions, given severe overcrowding and limited contact with patients. Rothman (1990) and Scull (1991) contend that superintendents used the opportunities presented by expanding demand for mental asylum space to legitimate their own existence and secure their power. Our review of the *American Journal of Insanity* from its 1844 inception to 1900 reveals extensive discussions of the architecture of asylums and the management of such facilities. However, there were fewer than 10 articles that dealt with patient treatment or care. This lends credence to Rothman's (1990) and Scull's (1991) claims that superintendents were more interested and absorbed in the management of their facilities than in therapeutic issues.

Writing of his experiences of incarceration in the New York Asylum at Utica, a patient with mental illness recounts extraordinary abuse, patient overcrowding, and horrific conditions at the facility during the mid-nineteenth century ("Five Months" 1982). Elizabeth Packard (1868) wrote of being physically abused at the Illinois State Insane Asylum at Jacksonville, and after her eventual release, she campaigned for the civil rights of mental patients in Illinois and other states. Lydia Button (1878) wrote an autobiography recounting abusive conditions she and other inmates endured while institutionalized at the State Asylum in Kalamazoo, Michigan. By all accounts, Packard and Button were not mentally ill but were victimized by a legal system that permitted husbands to institutionalize their wives during the nineteenth century (Peterson 1982). However, the treatment of these individuals is representative of the institutional experiences of many other people with mental illness during the mid-nineteenth century in the United States. Conditions in English mental asylums during the beginning of the nineteenth century were equally severe. Visitors related stories of seeing people with mental illness confined in rooms without heat or clothing, chained, and physically abused (Browne 1837).

Before the first distinct residential institution for persons with intellectual disabilities had opened in the United States in 1848, 31 institutions for persons with mental illness had been established (Hamilton 1944). There were 4,730 residents, a small percentage of whom had intellectual disabilities; 27 of the facilities were public, and 4 were private.

The psychiatrist Philippe Pinel was a major figure in the care of people with mental illness at the close of the eighteenth century. He is most popularly known for his bold act in 1792 of simultaneously unchaining 50 patients in a Paris mental hospital. The act echoed the "liberty, equality, and fraternity" spirit of the French Revolution popularized by Rousseau ([1762] 1991). Pinel's ([1801] 1977) *Treatise on Insanity* had worldwide influence on the developing field of psychology and psychiatry. Nearly 50 years after its publication, the editors of the *American Journal of Insanity* noted that "we know not of any work on insanity superior to this . . . none more worthy of our daily study" ("The Moral Treatment" 1847:4). In Belgium a generation later, psychiatrist Joseph Guislain similarly unchained mental patients at the asylum in Ghent, earning the nickname of the "Belgian Pinel" (Brierre de Boismont 1867). Despite the efforts of Pinel and Guislain and, in Italy, Chiarugi's notoriety in promulgating the moral treatment (Alexander and Selesnick 1964), there is evidence that it did not originate with them; rather, changing therapeutic philosophies were emerging before Pinel wrote his treatise and even before Chiarugi's works were known in England. English physician William Pargeter wrote *Observations on Maniacal Disorders* in 1792, prior to Pinel's arrival at the Bicêtre (Jackson 1988). Pargeter advocated for humane care of people with mental illness by arguing against the use of restraints, beatings, and forced remedies in advance of Pinel and Tuke (Jackson 1988; Pargeter [1792] 1988). Like Pinel and Chiarugi, he emphasized the importance of the management of insanity in lieu of medicine and punishment:

The chief reliance in the cure of insanity must be rather on management than medicine. The government of maniacs is an art, not to be acquired without long experience, and frequent and attentive observation. Although it has been of late years much advanced, it is still capable of improvement. (Pargeter [1792] 1988:49)

The emphasis that Pargeter, Pinel, Chiarugi, Guislain, and Tuke placed on management has been interpreted by later analysts as an emphasis on social control and coercion. Thomas Szasz (1973) has argued that involuntary institutionalization of persons with mental illness established a relationship between doctor and patient during the rise of psychiatric power in the seventeenth and eighteenth centuries that is akin to that of master and slave. Szasz further argues that this relationship between doctor and patient still exists in contemporary Western society.

In 1790, only six U.S. cities had more than 8,000 people, and the population of the United States was 3.9 million. By 1850, there were 85 such metropolises, 26 cities had more than 25,000 persons, and the total U.S. population was 23.2 million people (Hamilton 1944). In the period between 1824, when the nation's third state mental institution opened, and 1851, 19 state-operated facilities were established in 15 states, including New York (3), Virginia, South Carolina, Massachusetts (2), Tennessee, Maine, New Hampshire, Georgia, Indiana, New Jersey, Louisiana, Pennsylvania (2), Missouri, Illinois, and California (Hamilton 1944). All of these state facilities, which collectively housed 4,730 persons in 1850, were opened before the first separate and distinct U.S. institution was constructed for people with intellectual disabilities.

Between 1850 and 1890, 55 state psychiatric institutions were opened in the United States, and the census of patients with mental illness in mental hospitals grew dramatically to 40,942 persons (Hamilton 1944:86). It would nearly double by 1890 to 74,028 and double again to 187,791 in 1910. Overcrowding in mental institutions became pronounced during the latter half of the nineteenth century in the United States. During this time, facilities essentially abandoned their therapeutic capacities in favor of custodial arrangements designed to protect society from the perceived threat posed by people with mental illness (Rothman 1990; Scull 1991). However, one innovative response to overcrowding was family care, a program of placing people with mental illness in the homes of unrelated families. In the United States, family care was initiated first in Massachusetts in 1885 (Pollock 1945). A similar program had been in place in Scotland dating back to at least the 1860s (Pollock 1945). The use of family care for people with mental illness represents the first efforts to provide state-sponsored services in community set-

tings. While a few other states followed Massachusetts's lead, family care for people with mental illness never became widespread in the United States (Pollock 1945). Large-scale community-based services would not develop for people with mental illness until late in the twentieth century (Grob 1994).

Growing concern about the number of people with disabilities in the United States resulted in their enumeration by the census. Beginning in 1830, counts were taken of deaf and blind persons, and in 1840, the census began counting people labeled "idiotic" and "insane" (Gorwitz 1974). The 1840 census reflected pervasive racism. All black residents in some towns were classified as insane (Gorwitz 1974). Between 1870 and 1880, the proportion of the population counted as insane rose from 97 to 183 per 100,000, while the proportion of the population counted as intellectually disabled rose from 64 to 153 per 100,000 (Gorwitz 1974). This dramatic increase can be attributed, at least in part, to the fact that census enumerators received extra compensation in 1880 for each person with mental illness or intellectual disability that they counted (Gorwitz 1974). The rapid increase in the mentally disabled population was seen as evidence that society needed to take drastic measures to address mental disability (Knight 1895). These concerns ultimately fueled the agenda of the eugenics movement. The publication and dissemination of the results of such "scientific inquiry" were widely used in propaganda campaigns to catalyze public support for sterilization and marriage restriction laws (Pernick 1996). By 1912, numerous states prohibited the marriage of persons with mental disabilities and epilepsy or allowed such marriages only after age 45 (Smith, Wilkinson, and Wagoner 1914).

Historians and advocates have argued that the professionals involved with the operation of institutions for people with mental illness (Rothman 1990; Scull 1979) and intellectual disability (Blatt 1977; Trent 1995; Tyor 1972; Tyor and Bell 1984) were personally invested in perpetuating the life of these institutions, often at the expense of the residents. Social historians studying leprosy have made similar claims (Navon 1998). Cochrane (1963), Gussow (1989), and MacArthur (1953) argued that Christian missionaries supported the need for segregation and did not criticize the negative images of people with leprosy so that they would continue to receive funding for their missionary efforts.

## *Deaf Community Organizing*

During the mid-nineteenth century, the number of schools for deaf and blind students grew rapidly both in the United States and in Europe. In 1856 in the United States, a donated estate in Washington, D.C., was used to establish a residential school for 12 deaf and 6 blind students, the Columbia Institution for the Instruction of the Deaf and Dumb and the Blind (Gallaudet 1983; Lane 1989). In 1864, President Lincoln signed legislation authorizing Columbia to confer college degrees. Columbia later became Gallaudet University (Gallaudet 1983; Lane 1989).

Suppression of sign language was championed by Alexander Graham Bell in the United States at the end of the nineteenth century. In 1872, he opened a speech-based school for teachers in Boston intending to banish the use of sign language and encouraging deaf persons to "pass" as hearing individuals (Gannon 1981; Lane 1989). In 1880, at the International Congress on Education of the Deaf, which met in Italy, a resolution passed that banned the use of sign language in the education of deaf children (Gannon 1981; Gallaudet 1983). Also in 1880, the National Association of the Deaf was organized by deaf people. This organization would become the leading association fighting the oralists for manual instruction of deaf people in the United States (Baynton 1996).

One of the first self-advocacy organizations by people with disabilities was the British Deaf and Dumb Association (BDDA), now the British Association of the Deaf. The BDDA initially organized in 1890 in direct response to the International Congress's sign language ban and the view that deaf persons did not need to be involved in matters that concerned them. The 1880 International Congress on the Deaf had only two deaf teachers in attendance (British Association of the Deaf 1999).

### *First U.S. Institution for People with Intellectual Disability*

Superintendents of asylums for the mentally ill were among the first in the United States to call for separate provisions for people with intellectual disabilities. Reflecting on the path-breaking developments in Europe, Samuel Woodward, superintendent of the Worcester State Hospital in Massachusetts, and Amariah Brigham of New York's Bloomingdale facility both recommended in their 1845 annual state hospital reports that their states should make a public educational provision for children and youth with intellectual disabilities (Brigham 1845; Woodward 1845).

In 1846, Samuel Gridley Howe—the noted reformer, leader of the education of blind students, and committed oralist in the education of deaf students—was appointed to chair an epidemiological committee regarding intellectual disabilities appointed by the Massachusetts legislature. Howe carried out the nation's first investigation of the prevalence of intellectual disabilities and presented recommendations to establish an experimental school. Howe's report is replete with purported connections between the etiology of intellectual disability and the immoral behavior of one's parents (Howe 1848). His perspective was no doubt indicative of attitudes of the day that disability was a punishment for violating natural law.

The residential school that Howe recommended opened in October 1848 in south Boston in a wing of the Perkins Institute for the Blind (Howe 1851). A few months earlier, in July 1848, Hervey Wilbur had opened a small private school in his own home for the instruction of children with mental retardation in Barre, Massachusetts (Elm Hill Private School and Home 1911). A few years later, Wilbur left Barre to be superintendent of the new institution at Syracuse, site of the first institution for people with intellectual disabilities constructed specifically for that purpose in the United States. The Syracuse institution opened in 1855 (Fernald 1893; FitzGerald 1900).

It became common for states to initially open experimental schools (Kerlin 1877), and other states followed Massachusetts's and New York's lead. Pennsylvania opened a private school in 1852 that was incorporated in 1853 as the Pennsylvania Training School for Idiotic and Feeble-minded Children. In 1855, this school was moved to its present site at Elwyn, Pennsylvania. Ohio, Connecticut, Kentucky, and Illinois established residential schools in 1857, 1858, 1860, and 1865, respectively (Fernald 1917). The Illinois school was administered for its first decade under the auspices of the Illinois School for the Deaf. Twenty-six years after Howe opened the United States' first school for 10 children, seven states had established publicly operated or assisted institutions for 1,041 residents, and there were two private facilities in Massachusetts (Fernald 1917). Although the national census of institutions for people with intellectual disabilities was now growing steadily, almshouses housed more people with intellectual disabilities until 1906 (U.S. Bureau of the Census 1914).

### *From Training Schools to Custodial Asylums*

Institutions for people with intellectual disabilities, similar to those for people with mental illness, grew rapidly both in size and number following their initial construction in the mid-1800s. Early training efforts were quite successful, and many of the children with intellectual disabilities were returned to their communities as "productive workers" (Stewart 1882; Trent 1995). Economic hardship hit the nation following the Civil War, and severe recessions occurred in the 1870s and again in the 1880s. Due to extensive unemployment, it became increasingly difficult for superintendents to discharge trained residents who could not compete for already scarce jobs in their home communities. Superintendents also noted the value of using unpaid resident labor to offset the costs of running the institutions (Fenton 1932; Knight 1891). The exploitation of resident labor, or peonage, prevailed both in institutions for people with mental illness and in ones for those with intellectual disability (Bartlett 1964; Bonsall

1891; Fenton 1932; Johnson 1899; Knight 1891; MacAndrew and Edgerton 1964) until the late 1960s (Scheerenberger 1983).

By 1880, the training schools envisioned by Howe and Seguin had evolved into custodial asylums with reduced emphasis on educating residents and returning them to community life (Trent 1995; Wolfensberger 1976). The optimism of the 1840 to 1870 "amelioration" period confronted two difficult realities, including negative attitudes toward persons with mental retardation held by the general public and the lack of supportive social services, family support, and work opportunities in the community. Wilbur (1888), at the fifteenth annual gathering of the National Conference of Charities and Corrections, observed that institutions would offer lifelong protective custodial care. Other professionals in the field joined Wilbur in calling for lifelong institutionalization of people with intellectual disabilities (Barr 1902; Bicknell 1895; Fish 1892; Fort 1892; Johnson 1896). Samuel Gridley Howe had strongly opposed this trend, arguing in an 1866 speech that people with disabilities "should be kept diffused among sound and normal persons. Separation, and not congregation, should be the law of their treatment." The states, he said, should "gradually dispense with as many [custodial institutions] as possible" (cited in Wolfensberger 1976:26).

But the states did not dispense with custodial institutions. They continued to build them, expand them, and stress self-sufficiency and economical management in all aspects of facility operation. In 1900, the census of mental retardation institutions in the United States was 11,800 persons (Fernald 1917). Many institutions were located in remote areas and farmed extensive lands. Residents worked laundries, farms, and workshops, not so much to develop skills for community out-placement but rather to contribute to the self-sustaining economy of the institution. While most superintendents championed the growth of large institutions during this period (Trent 1995), Seguin (1870) warned against this phenomenon. He wrote, "Let us hope that the State institutions for idiots will escape that evil of excessive growth . . . in which patients are so numerous that the accomplished physicians who have them in charge cannot remember the name of each" (p. 21).

At the dawning of the twentieth century, institutions for persons with intellectual disabilities were firmly established in the developed nations of the world. Barr (1904), who wrote the first U.S. textbook on intellectual disability, completed an international survey and reported that 21 nations were operating 171 institutions for people with intellectual disability. There were 25 institutions in the United States by 1900 (Kuhlmann 1940). Barr also noted that "following the experiments worked out in the continental cities and in England, the special classes for backward children opened first in Providence, Rhode Island and [are] now part of the educational systems of New York, Philadelphia, Chicago, and Boston" (p. 71).

In the United States, the course of the initial development of institutions for people with mental illness and intellectual disabilities had numerous similarities. Superintendents of both types of facilities used existing social and economic issues to develop secondary goals for their facilities after their initial goals of training failed. Both sets of leaders aggressively agitated for the next phase of institutional development—custodial care (Rothman 1990; Scull 1991; Trent 1995).

### *Freak Shows*

Institutions were not the only manifestation of society's attitudes toward people with disabilities during the nineteenth century. So-called freak shows displayed people with physical and mental disabilities throughout the nineteenth century in the United States and Europe (Bogdan 1988; Rothfels 1996; Thomson 1996, 1997). People with intellectual disabilities were among those exhibited, their "abnormal" characteristics exaggerated into caricatures of the grotesque (Bogdan 1988; Thomson 1997). These exhibits were extremely popular at circuses, fairs, and expositions. People with disabilities who were displayed at freak shows were fre-

quently “sold” to the show organizers, who maintained the right to display them for the duration of their lives (Bogdan 1988).

In displaying people with disabilities in these shows, exotic stories of wild and far-flung origins of the exhibited people were fabricated by the show organizers (Bogdan 1988; Thomson 1997). Thomson (1997) argues that the exploitation of people with disabilities in the United States served to reinforce average Americans’ notions of their own normality, by emphasizing disability and often race as profound and monstrous differences. Freak shows served to institutionalize notions of disability as the ultimate deviance, thus solidifying Americans’ needs to perceive themselves as normal (Thomson 1997). Freak shows reached the height of their popularity at the end of the nineteenth century, at a time when eugenic beliefs in the superiority of the white middle class were crystallizing. In the United States, freak shows continued until the 1940s, when competing forms of entertainment, as well as economic hard times, led to their demise (Bogdan 1986).

While freak shows were at their heyday during the mid- to late-nineteenth century, there is evidence that by their decline in late-eighteenth century England, they had been popular for centuries among all classes (Park and Daston 1981; Semonin 1996). Semonin (1996) describes the “taste for monsters” as “an almost universal craze among English citizens of all ranks” (p. 69). In medieval and modern England, people with disabilities, racial and ethnic minorities, and people with unusual attributes were termed “monsters,” and their display in markets for profit was commonplace (Semonin 1996). It was common for people to visit Bethlem during the medieval and later periods for the “entertainment” provided by the inmates (MacDonald 1981).

### *Threat of the Eugenicists*

The period from 1880 to 1925 was a time when persons with intellectual disabilities were viewed as deviant social menaces, and intellectual disability was seen as an incurable disease (Barr 1902; Butler 1907; East 1917; Fernald 1915; Gosney and Popenoe 1929; Kerlin 1887; Scheerenberger 1983; Sloan and Stevens 1976; Switzky et al. 1988; Trent 1995; Watkins 1930; Winspear 1895). The eugenic belief widely held during this period was that intellectual disability was inherited as a Mendelian characteristic that degraded the species (Barr 1902; Fernald 1915; Galton 1883; Rafter 1988; Roberts 1952). Intellectual disability was linked in numerous studies to criminality, immoral behavior, and pauperism (Dugdale [1877] 1910; Evans 1926; Fernald 1915; Goddard 1912; Rafter 1988). Intelligence tests, developed shortly after the turn of the century, were employed widely in the major cities of the United States to identify children with intellectual disabilities and place them in segregated special classes. Intelligence tests were also used to support ethnocentric and class biases against immigrants in the United States (Davenport 1921; Fernald 1915). Subsequent to the implementation of intelligence testing at ports of entry, deportations for mental deficiency increased 350 percent in 1913 and 570 percent in 1914 (Gould 1981). Rampant abuse existed in the classification of both immigrants and poor Americans as mentally deficient. Workers were “trained” to classify people as mentally deficient by sight (Gould 1981).

Economic problems occurred at the same time that Galton’s ideas of social Darwinism were beginning to take hold in the United States and abroad. Superintendents’ writings reflect changing attitudes toward their charges as their institutional populations soared; the menace and burden of people with intellectual disabilities were frequently discussed (Barr 1895; Bicknell 1895; Fernald 1912; Kerlin 1887). Society needed protection from these menaces, and institutional care became the way to achieve these goals. Trent (1995) argues that the superintendents readily espoused the new social Darwinism and its messages of fear about deviant persons because it offered a way for them to legitimate and consolidate their authority.

The eugenics movement in the United States was accompanied by extensive instances of physicians refusing to treat, thereby facilitating the death of infants born with disabilities and birth defects (Pernick 1996). Newspaper accounts publicized the withholding of lifesaving treatment of babies with disabilities during the decade after 1915, and movies propagating the eugenics agenda became quite common (Pernick 1996).

In England, concern about people termed *mental defective* led to the 1886 passage of the "Idiots Act," which called for further clarification of the distinction between "idiots" and "lunatics" (Gladstone 1996) and preceded the eugenics movement in that country (Carpenter 1996). Passage of the 1899 Education Act led to the growth of institutions for people with intellectual disability and epilepsy in England (Carpenter 1996; Koven 1994).

Social Darwinism had an impact on the deaf community in the United States as well. At the end of the century, the debate between manualists and oralists intensified. Oralists claimed that people who used sign language were less evolved than people who spoke and were like apes or racial minorities (Baynton 1993; Porter 1894). This debate eventually resulted in the near eradication of manual education of deaf students, which was supplanted by oral education, a trend that was strongly opposed by deaf adults but continued well into the mid-twentieth century (Baynton 1996; Semi-Deaf Lady 1908). Zealously opposed to signed instruction, hearing teachers and other oralists used physical abuse of students to suppress sign language (Baynton 1996; Lane 1989; Porter 1894). In 1920, 82 percent of the 13,917 deaf students in school were taught speech ("Statistics of Speech" 1920).

The deaf movement that began in the United States in the late nineteenth century expressed a desire for independence and an evolving commitment to the emergence of deaf culture (de Saint-Loup 1996). The foundation of this movement was the use of sign language, which had been opposed by notable figures such as Alexander Graham Bell. Bell even explicitly rejected marriage among deaf people (Bell [1883] 1969). Deaf culture was further facilitated by the printing and circulation of newspapers among deaf residential schools across the nation. By 1893, at least 29 schools had 35 newspapers (Haller 1993). It is a testament to the strength of the deaf community that sign language survived and thrived during nearly a century of repression, and it is now a primary communication strategy in educating deaf children.

In summary, the nineteenth century is best characterized as the century of institutions and interventions. Schools and institutions for persons with physical disabilities, deafness, blindness, mental illness, and intellectual disability took root throughout Europe and North America. Professionals developed differential diagnosis to particularize disability and devised treatment interventions and educational schemes focused on specific impairments. The medical model of defining and classifying disability became thoroughly accepted in this century. However, the segregation of individuals with similar impairments also afforded people with disabilities opportunities to begin to develop group identities. By the close of the nineteenth century, deaf persons advocating for manual education and control of their own schools had begun to coalesce into the first disability political action groups.

## THE TWENTIETH CENTURY

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### *Segregation and Expansion of the Institutional Model*

At the opening of the twentieth century, the eugenics era was gaining momentum, and social reformers sought segregation and prohibitions on marriage and procreation by people with disabilities. Conditions in facilities for people with mental disabilities were deteriorating, and deaf persons were fighting to be able to use sign language in their schools.

Despite the rapid expansion of institutions for people with mental disabilities after the turn of the century, poor farms or almshouses were also a significant aspect of state provision for people with intellectual disabilities and mental illness. By the 1920s, poor farms were "dumping grounds" for all undesirables, including people with disabilities and the poor. In 1922, Ohio reported that 70 percent of poor farm inmates had "feeble-mindedness," or what is today known as intellectual disability. North Carolina estimated that 85 percent of inmates were "mentally abnormal." Iowa reported that in 1924, 45 percent of its poor farm inmates were mentally ill (Evans 1926:7-8). In a nationwide study of inmates of poorhouses, 36 percent were found to

be "feeble-minded, borderline defective, psychopathic, psychoneurotic, epileptic, or suffering from mental disease" (Haines 1925:138).

The sterilization of institutional residents with intellectual disabilities was commonplace in some states (Ferster 1966; Watkins 1930). Between 1907 and 1949, there were more than 47,000 recorded sterilizations of people with mental disabilities in 30 states (Woodside 1950). Of particular interest was the sterilization of people with intellectual disability who would eventually be discharged into the community (Popenoe 1927). Sterilization of women with epilepsy and mental illness was also widely believed by physicians to have therapeutic benefits despite overwhelming empirical evidence to the contrary (Church 1893). In the face of evidence that removal of the ovaries and Fallopian tubes was wholly ineffective, physicians continued to perform such surgery on women with an array of conditions, including hysteria, depression, epilepsy, insanity related to childbirth, and nymphomania. Surgery was also deemed appropriate to "prevent the prospect of illegitimate and defective children" (Church 1893:496).

The U.S. Supreme Court's *Buck v. Bell* (1927) decision affirmed the states' right to sterilize people with intellectual disabilities and propelled the eugenics movement to further lobby for its agenda (Kevles 1985; Radford 1994; Reilly 1991). In 1933, using California's program as a model, Nazi Germany enacted its own eugenic sterilization law (Reilly 1991). This legislation led to the forced sterilization of between 300,000 and 400,000 persons, a majority on the grounds of "feeble-mindedness." Most were institutional residents. This unprecedented oppression against disabled persons culminated in the murder by euthanasia of between 200,000 and 275,000 individuals with mental and physical disabilities between 1939 and 1945 in Germany. The eugenics movement had reached its zenith (Friedlander 1997; Gallagher 1995; Reilly 1991; U.S. Holocaust Memorial Museum n.d.; Wolfensberger 1981). Justification for the killing of people with disabilities in Nazi Germany was made on the basis of utilitarian arguments, and German health professionals and psychiatrists were among those who accommodated themselves to these policies (Burleigh 1994). Psychiatrists, particularly, had been responsible for identifying the pool of potential victims and, in some cases, participated in victim selection and murder (Burleigh 1994).

The United States and Germany were not the only nations to sterilize people with disabilities. Denmark had an active program of sterilization between 1930 and 1954, sterilizing at least 8,627 persons over this period. Sweden's program operated throughout the 1930s and 1940s, with 2,278 persons being sterilized in 1948 alone (Trombley 1988).

Contemporaneous with zealous agitation by eugenicists, evidence began to emerge that questioned the assumptions of deviance in people with intellectual disabilities. In Massachusetts, Fernald's (1919) Waverly studies demonstrated that with proper support from their families, individuals with intellectual disabilities could function well in the community. Fernald also concluded that only about 8 percent of a sample of 5,000 schoolchildren with intellectual disabilities in Massachusetts exhibited behavioral problems of any type. In addition, Wallace (1929) presented a compelling paper discrediting the link between intellectual disability and criminality. Also, the "parole plan," which could lead to permanent institutional discharge, was devised in the first decade of the twentieth century as an early release program for institutional residents with milder impairments. Paroled residents were cared for in the community by relatives, employers, or supportive volunteers (Bernstein 1917, 1918, 1921; Davies 1930; Fernald 1902; Hoakley 1922; Mastin 1916; Matthews 1921).

In 1908, with the publication of former mental patient Clifford Beers's *A Mind That Found Itself*, the mental hygiene movement began in the United States (Felix 1957). Beers's autobiographical account of his two-year institutionalization presents chilling details of life for those hospitalized at the turn of the century (Beers 1908; Peterson 1982). Describing constant physical abuse, Beers's narrative resembles those of earlier inmates of the nineteenth century. Like Elizabeth Packard, Beers was interested in reform and established an agenda to promote humane care (Peterson 1982). Influenced by Beers, leaders in psychiatry supported the reform agenda, and psychiatric hospitals began offering clinics in their communities to treat and prevent chronic mental illness (Grob 1983, 1994). In 1909, as a result of Beers's advocacy and leadership, the National Committee for Mental Hygiene was established (Felix 1957).

Shock therapies were developed and implemented in the 1920s, including the use of insulin, metrazol, and malaria to induce shock and, it was hoped, cure patients with mental illness. Electroshock began to be used on people with mental illness in Europe in the 1830s, and a few late-eighteenth-century physicians experimented with electroshock on people with epilepsy, blindness, and mental illness (Harms 1955). However, the widespread acceptance and use of electroshock did not occur until the 1930s, when the Italian Ugo Cerletti invented and publicized modern electroshock therapy. Electroshock involved the application of electricity to induce improvements in psychiatric conditions (Cerletti 1950; Harms 1955).

While psychosurgery had been performed by the Swiss surgeon Gottlieb Burkhardt in 1890, his contemporaries rejected its use (Ramsey 1952; Swayze 1995). The Portuguese neuropsychiatrist Egas Minoz developed modern psychosurgery in 1933, and from its initial use until the 1950s, nearly 20,000 patients were lobotomized (Grob 1994; Ramsey 1952; Swayze 1995; Valenstein 1986). Psychosurgery involved the severing of the frontal lobe from the rest of the brain and frequently left patients with changed personalities, diminished intellectual faculties, and other severe problems (Ramsey 1952; Swayze 1995).

Recent advocates with mental illness have rejected the use of shock therapy and psychosurgery as barbaric attempts to control people with mental illness (Lefley 1996; MadNation 1999; Peterson 1982). Litigation in the United States has resulted in determinations that patients in mental hospitals have the right to refuse electroshock treatment (Levy and Rubenstein 1996; Parry 1995).

The repression and social control of people classified as deviant are an important aspect of discussing the history of disability, particularly the history of mental illness. Historians and social scientists have offered extensive critiques of psychiatry as a social control device. Thomas Szasz (1970), one of the most vocal and articulate critics of psychiatry, has argued that society has scapegoated people with mental illness and severely abused them. Elliot Valenstein (1986) has argued that the uses of psychosurgery and the shock therapies so popular during the first half of the twentieth century were vehicles for ambitious psychiatrists to pursue their own career agendas at the cost of individuals with mental illness.

The census of American psychiatric hospitals continued to increase during the first half of the twentieth century, reaching 461,358 persons in 1940 and peaking at more than 550,000 persons in 1955 (Braddock 1981; Hamilton 1944). The size of many public facilities was truly immense, even by American standards. Hamilton (1944) reported that in 1941, 10 public facilities housed more than 5,000 residents (one had 9,177 residents), 22 had more than 4,000, 40 housed more than 3,000 individuals, and 102 of the nation's 475 mental hospitals on December 31, 1941, contained more than 2,000 patients.

In 1880, there were 1,382 persons with intellectual disability in insane asylums. By 1940, the number of persons with intellectual disabilities living in psychiatric hospitals peaked at nearly 29,000 persons (U.S. Bureau of the Census 1939, 1940). The census of separate state institutions for people with intellectual disabilities swelled to 55,466 persons by 1926 (Lakin 1979). Switzky et al. (1988) described several common practices in institutions of this era. Residents were "patients" who lived on "wards" in a facility, often called a "hospital," which was governed by a hierarchical medical structure. Resident programs were termed *treatments* or *therapy* (e.g., recreational therapy, industrial therapy, and educational therapy). Living units were locked, windows were barred, and the institution became increasingly structured "like a hospital for the care of sick animals rather than as a place for the special education of human children and adults" (Switzky et al. 1988:28). Prolonged institutionalization exacted a price from residents by promoting excessive conformity to the institutional culture at the expense of personal spontaneity, excessive fantasizing, fear of new situations, and excessive dependency on the institution (Sarason and Gladwin 1958).

Because of widespread unemployment and poverty during the Great Depression, families sought institutional care for their relatives with intellectual disabilities in increasing numbers (Noll 1996). Institutional facility censuses continued to swell, and overcrowding became commonplace (Noll 1996; Trent 1995; Tyor and Bell 1984; Watkins 1930). The Depression also brought relief with President Roosevelt's economic recovery programs. Passed in 1935, Title X

of the Social Security Act provided specific relief for blind persons but no other disability groups (Axinn and Levin 1982; Braddock 1987; Lende 1941; Scotch and Berkowitz 1990). By 1940, approximately 50,000 blind people across the United States were receiving this aid (Lende 1941). While Title V of the Social Security Act authorized Crippled Children's Services grants of \$2.85 million (Braddock 1986a), minutes of the 1936 Crippled Children's Services National Advisory Committee stated that "children with incurable blindness, deafness, or mental defect . . . and those requiring permanent custodial care" were beyond the intended scope of the new program (Social Security Board 1946:1).

The widespread segregation of people with intellectual disabilities in institutions made them targets for medical experiments. At the Wrentham and Fernald facilities in Massachusetts, institutional residents with intellectual disabilities were subjected to tests with foods that had been laced with radioactive elements. Neither the individuals with disabilities who served as subjects in these experiments nor their parents were ever apprised of the nature of the foods that were ingested. This illegal research spanned the period between 1946 and 1973 (Moreno 1999). Residents at the Willowbrook institution in New York were similarly exposed to hepatitis B without their knowledge or informed consent (Rothman and Rothman 1984).

### *Developments for Persons with Physical Disabilities*

Religious charity, as has been previously discussed, had been part of the landscape of support provided to people with disabilities and the poor for centuries. However, numerous secular charitable societies organized in the United States during the period between the 1840s and the 1880s. For example, Clara Barton founded the American Red Cross in 1881, an affiliate of an endeavor already in existence in Europe. The predecessor of the original European Red Cross had been founded to prevent death and disability on an Italian battlefield in 1859 (Obermann 1968).

Secular charitable organizations began to make an impact on persons with disabilities and, in some instances, became forerunners of the vocational rehabilitation movement in the early twentieth century. Among the most important of these was the Red Cross's establishment of the Institute for Crippled and Disabled Men in 1917. This organization was an experimental school for the rehabilitation of veterans, one of the first in the United States. Borrowing on ideas learned from visits to France, Germany, Italy, and England, the institute developed re-training programs for veterans with disabilities that were later used in U.S. Army hospitals as well. The predecessor of the Easter Seal Society, the National Society for Crippled Children and Adults was established in 1907 in Ohio (Obermann 1968).

Legal protections for laboring men were among the first formal provisions enacted for persons with physical disabilities. Germany and Austria legislated compensation for men disabled while working in 1884 and 1887, respectively. In the United States, Maryland enacted the first "workmen's compensation" law in 1902, which specifically provided a stated schedule of benefits to persons who became disabled while they were working (Obermann 1968). During the opening decades of the twentieth century, many other states followed Maryland's lead and established similar laws of their own.

Developments in workers' compensation laws led to discussions about rehabilitating disabled workers, thus providing them with the training necessary to successfully reenter the workforce. The U.S. Congress passed PL 66-236 in 1920, which was the first civilian vocational rehabilitation law in the country (Braddock 1986a; Obermann 1968). Two years earlier, Congress had authorized rehabilitation services for disabled soldiers returning from World War I. While the 1920 law primarily targeted industrially injured persons, services were to be provided to "any person, who, by reason of a physical defect or infirmity, whether congenital or acquired by accident, injury, or disease" (Obermann 1968:161). Persons with mental disabilities were not, however, eligible for rehabilitation services at this time.

Goodwill Industries was established in 1902 in Boston. Goodwill initially collected and distributed clothing and other contributions for the poor. Unemployed persons were subsequently hired to repair and renovate donations before they were sold, with the intention that the income generated would pay the workers. This program was later expanded to provide rehabilitation and sheltered work to persons with disabilities who were perceived as otherwise unable to support themselves (Obermann 1968). Goodwill Industries expanded across the United States and into other countries by the 1940s.

Charitable organizations often involved themselves in the monitoring of physical disability after the turn of the twentieth century. These organizations would conduct surveys to determine the extent of physical disability and then promulgate recommendations to address the needs of those found to have disability. A typical survey was one conducted in New York City in 1919, following a polio epidemic in 1916. The committee sent orthopedic surgeons to the homes of individuals that the survey had identified who had not received treatment and proposed that a system of services be developed that included the following components: education, vocational training, medical treatment, convalescent care, custodial care, social services, home treatment, summer outings, employment placement, braces and appliances, and work in the home (Wright 1920). The result of collaboration among 41 social service agencies in New York, this comprehensive plan for people with physical disabilities reported on nearly every aspect of life with disability and recommended greater access to education and employment opportunities as the central issues of concern.

A similar survey was conducted in Cleveland in 1916 by the Welfare Federation of Cleveland. This survey included numerous interviews with working men with physical disabilities. Their attitudes and advice are insightful. One locksmith stated, "If you have something to offer, you can usually get a job, but you must be sure that what you have to offer is of real value" (cited in Wright and Hamburger 1918:237). This man reported stories of being harassed about his disability by others, but he also told of his ability to persevere and succeed in the working world. Other men with disabilities described similar successes in maintaining employment, albeit in the face of difficult conditions.

Advances in orthopedic treatment and prosthetic devices for people who lost limbs during wartime or in industry were made during World War I. While primitive forms of artificial limbs had been used for centuries, technological advances subsequent to World War I resulted in the development of more comfortable and effective prostheses. These advances enabled greater numbers of men with disabilities to return to work after sustaining impairments. During this period, an understanding of the importance of individually fitting each person, as opposed to mass-producing devices, developed (Martin 1924).

### *Emergence of Family, Community, and Consumer Models*

Although the Depression and World War II inhibited innovation in service delivery for people with intellectual disabilities in the United States (Noll 1996; Trent 1995), some progress was made. New York state, for example, introduced foster family care in the 1930s, authorizing payment for the care of persons with intellectual disabilities in family homes (Vaux 1935). Research subsequently confirmed the beneficial effects of placement in foster or adoptive homes (Skeels and Harms 1948; Speer 1940) and the benefits of preschool intervention programs (Lazar and Darlington 1982; Skeels et al. 1938).

The 1940s witnessed greater public awareness of conditions in mental hospitals brought on by another autobiographical account of institutionalization. Publication of Mary Jane Ward's (1946) *The Snake Pit*, which was subsequently made into an Academy Award-winning movie, heightened awareness of brutal conditions in American mental hospitals (Peterson 1982). The perceived need for enhanced research efforts in mental illness led to the 1946 creation of the National Institute of Mental Health (NIMH), which also led to increased community services for people with mental illness in the United States (Braddock 1986a; Felix 1957). In 1946,

when the National Mental Health Act that created the NIMH was enacted, 24 states had community-based mental health programs. By 1957, every state had at least some community-based mental health services stimulated in part by the NIMH (Felix 1957).

In 1940, the National Federation of the Blind was founded, the first consumer advocacy organization for blind persons in the United States. This group opposed the nonblind leadership in the American Foundation for the Blind, which had formed in 1921 (Koestler 1976; Matson 1990). The split between organizations for blind persons and those led by blind people was international as well. In 1964, blind persons decided to separate from the World Council for the Welfare of the Blind and form their own organization (Driedger 1989).

### *The Social Model of Disability*

While some people with disabilities at mid-century wrote about their experiences as a tragedy to be overcome (e.g., Walker 1950), writings of blind Americans in the mid-twentieth century describe not blindness but the social and physical environment as the essential problem of disability. "Not blindness, but the attitude of the seeing to the blind is the hardest burden to bear" (Keller, as cited in Gowman 1957:5). "All too frequently the great tragedy of a blind person's life is not primarily his blindness, but the reactions of the family and social group toward him as a non-typical member" (Maxfield, as cited in Gowman 1957:5). Chevigny (1946) writes,

The tragic aspect of blindness does not inhere in the condition nor can it do so. In nature it is absent. It is an entirely civilized idea. The world in which a man finds himself creates the tragedy for him and in him. If I found blindness more of a major nuisance than a tragedy, therefore, it was because of the world in which I moved and had my being. (P. ix)

The intellectual basis for these ideas regarding the interaction between disability and society was powerfully advanced in Berger and Luckmann's (1967) sociological treatise on the social nature of knowledge. Their social-constructivist view was a harbinger of the social model of disability that would later emerge in the research of Saad Nagi (1970) and in disability studies and the independent living movement of the 1970s (Bowe 1978; Davis 1997; Linton 1998; Oliver 1983, 1990; Scott 1968). The World Health Organization's (1980) definitions of impairment, disability, and handicap, which proposed a distinction between the socially constructed disadvantages that accrue to persons with impairments and the physical realities of impairment, were grounded in the writings of these early theorists and advocates (Lupton 2000). Explaining the significance of this distinction, Bickenbach (1993) has argued that

handicaps are thus socially created disadvantages that arise from the social reception of impairments and disabilities. The explicit focus of this dimension of disablement is social valuations of physical states (or perceived physical states); there is no question here of normative neutrality. Moreover, nearly every aspect of the conceptual structure of the notion is shaped by and so relative to social and cultural forces. (P. 48)

### *Organizational Developments*

Beginning in the 1950s, friends and parents of people with disabilities began organizing for more extensive services for people with disabilities in many parts of the world. At that time, schools and activity centers were established, and ultimately international associations were founded, composed of national organizations interested in the prevention of disability.

Parents of people with intellectual disabilities in Washington state had actually organized to advocate for services for their children as early as the 1930s (Jones 1987); however, larger-scale

organizing by such groups did not occur until the 1950s. During the 1950s, local groups of parents from many states joined forces and formed the group that became the National Association for Retarded Children (now The Arc). These families organized to advocate for services for their children, including better conditions in institutions and the development of schools and workshops (Goode 1999). A similar nationwide organization of families of people with mental illness would not be developed until the 1979 founding of NAMI, the National Alliance for the Mentally Ill (Grob 1994; Lefley 1996).

In 1953, the Council of World Organizations Interested in the Handicapped (CWOIH, now the International Council on Disability) was formed (Driedger 1989). The constituent organizations of the World Council generally did not include people with disabilities as active leaders, however (Driedger 1989). In the United States, the 1950s and 1960s saw the formation of organizations directed by people with disabilities, a departure from organizations led by the able-bodied for people with disabilities (Roberts 1989). Single-disability-focused international organizations led by consumers with those disabilities were subsequently established, including the World Federation of the Deaf, the International Federation of the Blind, and the Fédération Internationale des Mutilés, des Invalides du Travail et des Invalides Civils (Driedger 1989).

### *Beginnings of Deinstitutionalization*

The introduction of antipsychotic drugs in the 1950s, coupled with public commitments to a community treatment approach, resulted in a rapid decline in the average daily resident population of state- and county-operated psychiatric hospitals (Grob 1994). The aggregate census began declining for two additional reasons. Penicillin, which was used to cure syphilis, led to a decrease in the number of persons with this disease in public mental hospitals. Also, following implementation of the Social Security Act of 1935, many elderly residents were moved to nursing homes (Holstein and Cole 1995; Hughes 1986). Between 1955 and 1975, the census in psychiatric hospitals dropped by 200,000 persons from a high of 559,000 (Braddock 1981; National Association of State Mental Health Program Directors Research Institute 1996). However, the declining overall census of such facilities during this period tells only part of the story. While psychiatric hospitals continued to be exceedingly overcrowded, admissions and discharges operated like a revolving door for many patients. In a typical one-year period, there were more than 147,000 admissions and nearly 188,000 discharges and deaths (Grimes 1964). Homelessness has also been a serious consequence of the deinstitutionalization movement for persons with mental illness (Grob 1994; Lefley 1996). However, the community movement for persons with intellectual disabilities has been considerably more successful in developing services and support programs and avoiding homelessness to the degree experienced by persons with mental illness (Braddock 1992).

The census in public facilities for persons with intellectual disabilities peaked at 194,650 in 1967 (U.S. Department of Health, Education, and Welfare 1972). More than 20,000 additional persons with intellectual disabilities resided in state and county psychiatric hospitals at the time. The average facility population of institutions for people with intellectual disabilities was 1,422 residents in 1962 (Survey and Research Corporation 1965). Several facilities, such as Willowbrook in New York and Lincoln in Illinois, housed 4,000 to 8,000 residents. In the 1960s, despite growing evidence to the contrary, American society still treated persons with intellectual disabilities as a group that needed to be controlled by segregation, sterilization, and isolation.

### *Political Activism and the Right to Treatment*

In light of deplorable conditions in institutions for people with mental illness, discussion began to take shape within the legal community about the right to treatment for people who were

incarcerated in these facilities. Morton Birnbaum led this initiative with the 1960 publication of his paper, "The Right to Treatment" (Birnbaum 1965; Levy and Rubenstein 1996). The first case in which an American court recognized the right to treatment was the landmark 1966 case of *Rouse v. Cameron*, which held that if an individual was involuntarily committed to a facility, at a minimum, he or she had the right to receive treatment because the purpose of confinement was treatment and not punishment (Levy and Rubenstein 1996; *Rouse v. Cameron* 1966). Subsequent cases upheld this right, which was extended in the 1970s to include people with intellectual disabilities as well (Levy and Rubenstein 1996; Parry 1995).

The election of John F. Kennedy to the U.S. presidency in 1960 ushered in the modern era of intellectual disability services in the United States and an expanded concern for people with mental illness as well. On October 11, 1961, President Kennedy issued an unprecedented statement regarding the need for a national plan in the field of mental retardation. "We as a nation," he said, "have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected" (Kennedy 1961:196). Kennedy appointed the President's Panel on Mental Retardation. The panel's 95 recommendations, released in 1962, were broad and far-reaching. They extended from issues of civil rights to the need for scientific research on etiology and prevention. The panel called for a substantial downsizing of institutional facilities and an expansion of community services; most important, it clearly embraced the principle of normalization (Nirje 1976; Wolfensberger 1972) as a guide to future innovation in service delivery.

Many of the 95 recommendations of the President's Panel (1962) were enacted into law by the 88th Congress as Public Laws 88-156 and 88-164. Public Law 88-156, the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, doubled the spending ceiling for the existing Maternal and Child Health State Grant Program and established a new mental retardation planning grant program in the states. The planning effort was unique in the history of the field in that federal legislation required all 50 participating states to produce comprehensive plans for the development of improved residential, community, and preventive services.

President Kennedy also signed into law the Community Mental Health Centers Act of 1963, which stimulated the development of such centers across the country (Grob 1994). While these centers were never funded at a level consistent with the desires of their supporters (Braddock 1987), they did develop into a network of community support for people with mental illness (Grob 1994).

The 1970s was a decade of considerable progress in public policy for people with disabilities in the United States (Silverstein 2000). There were four major catalytic events: (1) the 1971 passage of the ICF/MR (Intermediate Care Facilities/Mental Retardation) program as part of Title XIX (Medicaid) of the Social Security Act, (2) Judge Frank M. Johnson's landmark 1972 right to treatment ruling in the Alabama case of *Wyatt v. Stickney*, (3) the political organizing that led to the 1973 passage of Section 504 of the Rehabilitation Act prohibiting discrimination against disabled individuals in any program receiving federal financial assistance, and (4) the 1975 passage of the Education of All Handicapped Children Act (now known as IDEA) (Braddock 1986b; Scotch 1984).

The passage of the ICF/MR law in 1971 enabled the states to obtain federal funding for institutional services for people with intellectual disabilities if the care provided met minimal federal standards of treatment and space. Insofar as the federal government would reimburse states for 50 to 78 percent of the costs of institutional care, states had great incentives to change their services to conform to federal standards. This led to a tremendous push to deinstitutionalize because the minimum space requirements were well beyond the overcrowded capacities of nearly all the nation's institutions (Rothman and Rothman 1984). Peaking in 1967 at more than 194,000 people, the population of the nation's public institutions for persons with mental retardation and developmental disabilities has declined steadily to 52,801 persons in 1998 (Braddock et al. 2000). Advances in applied behavioral interventions have facilitated community, employment, and social integration (Jacobson, Burchard, and Carling 1992; Koegel, Koegel, and Dunlap 1996; Thompson and Grabowski 1977).

The *Wyatt v. Stickney* decision in regard to people with intellectual disability was built on the principle of right to treatment developed for people with mental illness. Judge Johnson found that people in Alabama's institutions had a constitutional right to treatment (Levy and Rubenstein 1996; Parry 1995; *Wyatt v. Stickney* 1971). This case began a tidal wave of federal class action cases related to conditions in institutions for people with intellectual disabilities, culminating in more than 70 cases in 41 states (Braddock et al. 1998; Hayden 1997; Levy and Rubenstein 1996). Similar litigation was also filed on the right to education (Martin, Martin, and Terman 1996; *Pennsylvania Ass'n. Retarded Child. v. Commonwealth of PA* 1971).

In 1973, the U.S. Congress enacted Section 504 of the Rehabilitation Act, which prohibited discrimination against people with disabilities by any entity that received federal funds (National Council on Disability 1997; Percy 1989; Scotch 1984). The promulgation of regulations that would clarify the operating provisions of Section 504 was delayed by Secretary David Mathews of the U.S. Department of Health, Education, and Welfare (HEW) and then by his successor, Secretary Joseph Califano (National Council on Disability 1997; Scotch 1984). Disabled advocates organized to force promulgation of the regulations, first by suing Secretary Mathews and then by organizing sit-ins and demonstrations in HEW offices in San Francisco, New York, and Washington (Fleischer and Zames 1998). For the first time, American television audiences saw people with disabilities occupying federal buildings to secure their rights (Roberts 1989). These demonstrations resulted in the 1977 promulgation of regulations four years after the law was signed. Judy Heumann, a leader in the fight for release of the regulations, stated, "I don't think the regulations would have been signed without the demonstrations, as they were. I am totally convinced of that. I mean the political pressure was really getting to be heavy. They had to sign those regulations" (as cited in Scotch 1984:116). Highlights of Section 504 included mandating for new construction to be barrier free, mandating accessibility in programs and activities in existing facilities, and supporting reasonable accommodations for the employment of people with disabilities (Scotch 1984).

The coalition building and advocacy by disability groups during the Section 504 political action activities was one of the first times in American history that cross-disability advocacy groups had successfully worked together on a unified disability rights agenda. This cross-disability advocacy helped to establish the foundation for the subsequent passage of the broader advocacy efforts that ultimately led to the passage of the Americans with Disabilities Act in 1990 (Fleischer and Zames 1998; National Council on Disability 1997).

In 1980, after years of seeking equal representation within the professional organization Rehabilitation International (RI), disabled people broke with RI and formed Disabled Peoples' International. Since 1922, RI had been the only international cross-disability organization that addressed the needs of people with a variety of mental, physical, and sensory disabilities (Driedger 1989). In 1980, at a World Congress of RI, a resolution was defeated that would have mandated the equal participation of people with disabilities in each country's RI organization. In response, disabled advocates then established Disabled Peoples' International (DPI), indicating no tolerance for patronizing behavior by professionals. Disabled people would direct their own destiny. DPI worked energetically to establish the presence of people with disabilities on the world stage. By 1983, it had achieved consultative status with several United Nations organizations, and by 1985, organizations of disabled people had been established in nearly every country in the world (Driedger 1989).

The fourth watershed civil rights event in the 1970s in the United States was passage of the Education for All Handicapped Children's Act of 1975, which guaranteed children and youth with disabilities the right to a free, appropriate, public education. For the first time in the history of compulsory education in the United States, parents had a federally enforced right to education for their children with disabilities. Beyond the obviously important changes in education for children with disabilities, this legislation also created a generation of parents who believed that their children were entitled to related community services. Many of these parents would become strong advocates for community services and inclusive education. In the 1995-1996 school year, 46 percent of children with disabilities in the United States were educated in regular classroom settings, while the remainder were educated in a combination of

other settings, including resource rooms, separate classrooms, and separate schools (U.S. Department of Education 1998).

The education for deaf and blind students in the United States, however, has traditionally been provided in special residential schools that began in the nineteenth century. Some have objected to the segregated education provided in such schools. For example, research conducted with women with visual impairments in England has demonstrated that the women educated in special schools felt that their experiences had been detrimental to their growth and that dependence was fostered in such settings (French 1996).

Recent analysis of educational data for blind and deaf students indicated that the number of blind students educated in residential schools has declined. Kirchner, Peterson, and Suhr (1988) found that between 1963 and 1978, the percentage of blind students educated in public and private residential schools declined from 45 percent to 24 percent. By 1996, the latest school year for which data are available, 11 percent of deaf children were being educated in residential schools (U.S. Department of Education 1998). In 1998, the number of blind children being educated in residential schools had fallen to 8 percent (American Printing House for the Blind 1999). The total numbers of deaf and blind children being educated in residential schools in 1996 were 7,311 and 2,179, respectively (U.S. Department of Education 1998).

### *Independent Living and Self-Advocacy*

The 1970s was also the decade of the rise of independent living in the United States (DeJong 1979a, 1979b; Stewart, Harris, and Sapey 1999). As previously noted, this movement gathered strength from the advocacy needed to force the promulgation of the Vocational Rehabilitation Act of 1973's Section 504 rules. Such legislation was predicated on the notion that people with disabilities need supports to live independently in their communities, not only because of their impairments but because society is constructed in such a way as to preclude their full participation (Bowe 1978). The initial catalysts for the independent living movement in the United States were drawn from a critical analysis of the processes of medicalization and professionalization in the rehabilitation system (Lysack and Kaufert 1994; Zola 1979). In Canada, the independent living movement emerged in the early 1980s, also driven by the advocacy efforts of people with disabilities (Boschen and Krane 1992).

The independent living movement embraced the notion that the barriers that confront people with disabilities are less related to individual impairment than to social attitudes, interpretations of disability, architectural barriers, legal barriers, and educational barriers (Americans Disabled for Attendant Programs Today 1995; Bowe 1978). The creation in the early 1970s of the nation's first independent living center in Berkeley, California, served as a model for the development of such centers across the country (DeJong 1979a; Roberts 1989). This first center, as well as hundreds of others that followed it, offered an array of services, including peer counseling, advocacy services, van transportation, training in independent living skills, wheelchair repair, housing referral, and attendant care referral, among others (DeJong 1979a; Roberts 1989). Central to the independent living movement is the notion that people with disabilities themselves must set the agenda for research and political action in disability policy (DeJong 1981). Ed Roberts (1989:238-39), one of the founders of the independent living movement, identified the four core principles of independent living as self-determination, self-image and public education, advocacy, and service to all. In the year 2000, there were 336 centers for independent living and 253 subordinate sites operating in the United States. They served 212,000 persons in approximately 60 percent of the nation's 3,141 counties (Innes et al. 2000).

Self-determination in the United States has focused on the independent living center as a primary coordinating organization by which disabled people engage in the advocacy and education activities needed to meet their individual and collective goals. In the Netherlands, the independent living needs of people with disabilities have been embraced by the country's main-

stream entitlement programs, wedging a system of residential care and independent living to the country's general health and social welfare systems (DeJong 1984). Denmark and Germany, nations similar to the Netherlands in welfare policy, also have connected programs for people with disabilities to their mainstream entitlement programs (Fröhlich 1982; Jørgensen 1982). In Britain, housing has been a pivotal advocacy and policy concern of the independent living movement (Stewart et al. 1999).

The advocacy organization Disabled in Action was founded in 1970 by Judy Heumann to address barriers faced by people with disabilities, and by 1972 it had 1,500 members. The group engaged in activities ranging from a march on Washington protesting President Nixon's veto of the Vocational Rehabilitation Act Amendments of 1973 to the staging of protests at inaccessible buildings and at Jerry Lewis telethons. The telethons used paternalistic, pity-oriented depictions of people with disabilities to raise funds. These initial political advocacy efforts led to the formation in 1974 of the American Coalition of Citizens with Disabilities, which became an umbrella organization for disability advocacy groups across the nation (Scotch 1989).

In America, states' efforts to "reform" institutions for people with intellectual disabilities in the 1970s gave way to efforts to reallocate institutional resources to community services activities. States began closing institutions in significant numbers for the first time in the early 1980s (Braddock and Heller 1985). In 1991, New Hampshire closed the Laconia Developmental Center and became the first state in the United States to provide all of its services to people with intellectual disabilities in the community (Covert, MacIntosh, and Shumway 1994). By 1998, 36 states had closed 118 state institutions for people with intellectual disabilities, and 4 more closures were scheduled to occur by the year 2000 (Braddock et al. 2000). In addition to New Hampshire, all public institutions for people with intellectual disabilities have also been closed in Alaska, the District of Columbia, Hawaii, New Mexico, Rhode Island, Vermont, and West Virginia (Braddock et al. 2000).

Institutional phase-downs and closures have been accompanied by a growing emphasis on supported community living for individuals with intellectual disabilities. Between 1977 and 1998, the number of persons living in community-based settings for 1 to 6 persons expanded from 20,409 to 237,796 persons, a more than tenfold increase. Much of this tremendous expansion in community services was fueled by the federal-state partnership in the Medicaid Home and Community Based Services (HCBS) Waiver Program (Braddock et al. 1998, 2000).

The reduction in reliance on residential institutions for people with intellectual disabilities occurred in Great Britain and across Western Europe as well (Keith and Schalock 2000). In England, for example, the census of public hospitals for people with intellectual disabilities (those operated by the National Health Service) declined 83 percent, from 44,400 in 1980 to 7,400 persons in 1996. Similarly significant declines were noted in other U.K. countries. In Wales, Scotland, and Northern Ireland, census reductions of 70 percent, 51 percent, and 48 percent, respectively, were noted during the same 1980 to 1996 period (Emerson et al. 2000).

Organized self-advocacy is an important manifestation of the emergence of autonomy and self-determination for people with intellectual disabilities (Dybawd and Bersani 1996; Longhurst 1994). Membership in local and statewide self-advocacy groups such as People First has grown rapidly. Hayden and Senese (1996) identified more than 1,000 self-advocacy groups, some in every state. This represented almost a threefold expansion in the number of groups since 1990 (Longhurst 1994). In 1995, self-advocacy groups established a national organization called Self Advocates Becoming Empowered (SABE). SABE has developed an advocacy agenda calling for the phase-down and closure of all state-operated mental retardation institutions in the United States (Dybawd and Bersani 1996).

Self-advocacy by people with mental illness has included people completely opposed to organized psychiatry, psychotropic medication, and institutional treatment (Lefley 1996). The first group of ex-patients devoted to the "liberation from psychiatry" formed in Portland, Oregon, in 1969. Advocacy by this group has included litigation to combat involuntary, uninformed use of electroconvulsive therapy (ECT), litigation against ECT manufacturers, and pressing for consumer advisory functions at the state level of mental illness service administration (MadNation 1999).

Deaf students at Gallaudet University gained national attention in 1988 by advocating for a deaf president. In addition to initiating the Deaf President Now movement, the students sought a deaf majority on the university's board of directors. The university's first deaf president, I. King Jordan, was subsequently appointed, and the first deaf chair of the board, Philip Bravin, was selected (Gallaudet University 1997).

### *International Disability Rights Initiatives*

The 1990 passage of the Americans with Disabilities Act (ADA) in the United States was a watershed event for disability rights on the international stage. This law recognized that discrimination against people with disabilities in the form of purposeful unequal treatment and historical patterns of segregation and isolation was the major problem confronting people with disabilities and not their individual impairments (National Council on Disability 1997; Parry 1995). The ADA also stated that people with disabilities have been relegated to powerless positions based on stereotypical assumptions about their disabilities. As such, the ADA bars discrimination against people with disabilities in employment, public services, public accommodations, and telecommunications (Parry 1995). The ADA was enacted after a concerted effort by a coalition of mental, physical, and sensory disability rights groups to work together to secure its passage (National Council on Disability 1997). As noted, the cross-disability coalition that advocated for enactment of the ADA was built in part on the foundation initially developed by advocates pushing for the enactment and subsequent promulgation of rules for the Vocational Rehabilitation Act Amendments of 1973 (Scotch 1989).

In Britain, a similar law protecting the rights of people with disabilities, the Disability Discrimination Act, was enacted in 1995 (Doyle 1996; Gooding 1996). This law mandated reasonable adjustments to the policies and physical environments of employers with 20 or more employees, compelling the removal of barriers facing people with disabilities (Gooding 1996). The law also mandated accessibility in public transportation (Doyle 1996; Gooding 1996). While the law has been hailed as an advance in civil rights for people living in Scotland, England, Wales, and Ireland, disability advocates have expressed disappointment that the law did not go as far as it should have in protecting and facilitating enforcement of the rights of people with disabilities (Doyle 1996; Gooding 1996).

At the international level, the United Nations General Assembly unanimously adopted the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations 1994). The *Standard Rules* are not legally enforceable internationally, but they do provide basic international standards for programs, laws, and policy on disability. The *Standard Rules* grew out of earlier pressure from international disability interests to promote greater participation by people with disabilities in society. This philosophy was initially expressed in the 1971 *Declaration of the Rights of Mentally Retarded Persons* (United Nations 1971), the 1975 *Declaration of the Rights of Disabled Persons* (United Nations 1975), and the more comprehensive statement expressed in the 1982 *World Programme of Action Concerning Disabled Persons* (United Nations 1982).

The purpose of the *World Programme of Action* (WPA) is to

promote effective measures for prevention of disability, rehabilitation and the realization of the goals of "full participation" of disabled persons, in social life and development, and of "equality." This means opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development. These concepts should apply with the same scope and with the same urgency to all countries, regardless of their level of development.

The WPA requires member states to plan, organize and finance activities at each level; create, through legislation, the necessary legal bases and authority for measures to achieve the objectives; ensure opportunities by eliminating barriers to full participation; provide

rehabilitation services by giving social, nutritional, medical, educational and vocational assistance and technical aids to disabled persons; establish or mobilize relevant public and private organizations; support the establishment and growth of organizations of disabled persons; and prepare and disseminate information relevant to the issues of the World Programme of Action. (Metts 2000:20)

The United Nation's (1994) *Standard Rules* was predicated on the principles embodied in the *World Programme of Action*, which focuses on the equalization of opportunities for people with disabilities. This commitment to disabled persons goes well beyond traditional international antidiscrimination protections of property, political, and judicial rights by seeking to convey rights to rehabilitation, special education, and access to public and private facilities and programs. The European Union (1996) has also adopted general disability policies similar to the UN's (1982) *World Programme of Action*.

In addition to Great Britain and the United States, a number of nations adopted legislation in the 1990s prohibiting discrimination against persons with disabilities. Australia adopted the Disability Discrimination Act of 1993, outlawing discrimination on the basis of disability, and the constitutions of Germany, Austria, Finland, and Brazil have been similarly amended. Constitutional changes have also been adopted in South Africa, Malawi, Uganda, and the Philippines. These actions are representative of the recent flurry of legislative activity on a worldwide basis to promote the rights of people with disabilities (Metts 2000).

In the United States, the growth of public spending for disability programs during the past 30 years has paralleled the rise of parent and consumer advocacy and of the "disability business" (Albrecht 1992). In fiscal year 1997, an estimated \$93.8 billion was allocated for long-term care services and rehabilitation, housing, and veterans activities by federal, state, and local governments in the United States. General health care commanded \$50.5 billion, and \$36.4 billion was allocated for special education activities. An additional \$96.9 billion was spent for disability-related income maintenance in 1997, primarily through the Supplemental Security Income and Social Security Disability Insurance programs (Braddock 2000).

Thus, at the close of the twentieth century, the public sector in the United States was spending \$277.6 billion for disability services and income supports for more than 38 million recipients. This spending level is roughly equivalent to 12 percent of the country's total public expenditure for all purposes from combined federal and state sources in 1997.<sup>1</sup> However, a large percentage of the \$93.8 billion financial commitment for disability services and long-term care—approximately 46 percent of the funds—supported the placement of hundreds of thousands of persons with disabilities in segregated settings such as nursing homes, sheltered workshops, and mental institutions. Furthermore, a large percentage of the 5.7 million students with disabilities in special education, particularly those with significant disabilities, received services in separate classes, separate educational facilities, or public or private institutions. Sixty-one percent of students with intellectual disabilities ("mental retardation"), for example, were served in segregated educational settings in 1996 (U.S. Department of Education 1998). While it is clear that the United States has made enormous strides in the implementation of disability assistance programs over the past few decades (Silverstein 2000), the basic funding priorities in many programs, such as Medicaid and special education, have not kept pace with contemporary consumer support models based on choice, self-determination, home care, family support, and inclusive education.

## CONCLUSION

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After the seventeenth century, medical science and the rise of custodial residential institutions undermined the self-determination of people with disabilities during a period of rapid and continuous urbanization and industrialization in the West. It did this by overmedicalizing what was, in large measure, a social, educational, and economic problem, separating many disabled

people from their families, communities, and society at large. This socially sanctioned segregation reinforced negative societal attitudes toward human difference. However, the segregation of disabled people in one geographic place—in residential schools for deaf and blind persons, mental institutions for those with emotional problems and intellectual limitations, and, eventually, special public school classes and rehabilitation centers—also facilitated the development of empowered group identities that ultimately led to political activism.

Assertive political activism by people with disabilities and their families emerged primarily in the late twentieth century, and, in the United States, it draws considerable strength from the example of the civil rights movement for people of color (Birnbaum and Taylor 2000). It is, in fact, an often-repeated general truism in the disability field today that prejudicial and exclusionary practices are greater barriers to social participation for disabled people than their particular mental, physical, or sensory impairments (Scotch 1989).

People with disabilities have shared a history that has often been oppressive and included abuse, neglect, sterilization, stigma, euthanasia, segregation, and institutionalization. Disabled people, who have survived by relying on tenacity and resourcefulness and on support provided in different measures by family, friends, and local communities, are currently struggling to claim identity (Anspach 1979; Gill 1997; Linton 1998) and political power (Hahn 1985). While the deaf community has a history of struggling collectively to preserve their culture for more than a century, people with mental and physical disabilities have only emerged to champion their own interests collectively within the past three or four decades.

Advocacy by specific, single-disability groups in the United States began to evolve into cross-disability coalition building in the 1970s, 1980s, and 1990s. Cross-disability advocacy, for example, secured passage of the Americans with Disabilities Act (National Council on Disability 1997). The paternalism of nondisabled nineteenth-century figures such as Howe, Pinel, Gallaudet, and Rushton has been replaced, at least in part, with leadership and self-determination by people with disabilities themselves. Thus, at the close of the twentieth century, the foundation was gradually established in the West for a new era based on civil rights, social participation, and a cross-disability perspective.

Achieving inclusive societies, however, will require persons with mental, physical, and sensory disabilities to learn more about one another and, on common ground, to construct more powerful community, state, national, and international cross-disability coalitions than have been developed in the past. In this chapter, we argued that people across the spectrum of disability have a good deal in common historically and that recognizing and celebrating this shared history are an important step in building stronger and more effective cross-disability coalitions in the future.

The potential strength of cross-disability coalitions should grow as societies age since the prevalence of impairment in a society is directly correlated with aging. Over the course of the next 30 years, the number of persons age 65 and older will double in the United States, triple in Germany and Japan, and advance rapidly in virtually every developed nation of the world (U.S. Bureau of the Census 1997; Janicki and Ansello 2000). As more developing countries make significant economic advances, these nations will experience a concomitant rise in political advocacy by and for people with disabilities. Albrecht and Verbrugge (2000) refer to this growing phenomenon of disability across the developed and developing nations of the world as the global emergence of disability. “With or without anyone’s attention,” they argue, “global disability will be on the rise for many decades to come, fueled by population aging, environmental degradation, and social violence” (p. 305). The key disability issues for developing societies include controlling infectious diseases that lead to disability; reducing unsafe occupational conditions; managing drought and the environment; limiting ethnic, religious, and regional wars; and launching thoughtful innovations in income support, health promotion, special education, rehabilitation, and the promotion of self-determination (Hoffman and Field 1995). By adopting programs that stress consumer, family, and community values, it is hoped that many developing nations will be able to avoid replicating the developed world’s self-destructive preoccupations with segregation, institutionalization, and eugenics.

The principal disability issues currently facing the developed nations in Europe, North America, and Australasia, according to Albrecht and Verbrugge (2000), include fashioning reasonable eligibility standards for income maintenance and service programs for persons with disabilities; advancing civil rights; creating access to employment, public accommodations, and society at large; and minimizing regional, state, and substate differences in public welfare benefits and service programs. To these critically important contemporary issues, we would add that developed nations also must confront (1) ethical and cost-benefit dilemmas accompanying advances in gene therapy, biotechnology, and neuroscience research; (2) the potential for assisted suicide to lead to the widespread euthanasia of persons with disabilities; (3) the continuing segregation of millions of persons with disabilities in nursing homes, institutions, and other segregated settings throughout the world; and (4) the development of productive and reciprocally valued working relationships between consumers with disabilities seeking greater self-determination and political power and the professionals who provide and study services to people with disabilities (Barnes 1996; Humphrey 2000; Oliver 1992; Oliver and Barnes 1999). In particular, the United States must also confront the growing inequality in the distribution of the wealth of its citizenry and the profound health care and educational disparities between rich and poor (Galbraith 1998).

The disability rights struggle of the first half of the twenty-first century will fundamentally be a struggle to delink the enduring and oppressive relationship between poverty and disability. Even in the most economically developed nations of the world today, unemployment rates for disabled persons frequently approach 80 percent, and average personal income is in the bottom decile.

As researchers, we need to mount a series of rigorous, comparative, recurring empirical studies to monitor the growth of public-sector resource and service commitments for disability programs in every country of the world in which it is possible to do so. These recurring studies need to assess the allocation of resources on a nationwide basis for disability programs so that all the nations of the world can be held accountable for their commitments to disabled people and their families. Such studies would permit the priority that a nation assigns to disability to be evaluated over time and to be compared to other nations with similar levels of wealth. The information generated in such studies would be useful in program planning, and, by identifying the leaders and the laggards among the nations of the world, it would be immensely useful to disability advocates seeking to influence public policy on behalf of their constituencies. Several international organizations should be approached to sponsor this research, including the World Bank, the United Nations, the European Union, the Pan American Health Organization, and the World Health Organization. In the United States, the National Institute on Disability and Rehabilitation Research (NIDRR) should also consider launching one or more international rehabilitation research and training centers. These centers would focus on significantly expanding educational and research links on disability between and among the developed and developing nations of the world.

Albrecht and Verbrugge (2000) are right: Disability *is* emerging globally. The number of disabled people in 175 nations of the world today was recently estimated to range between 235 and 549 million people. The lost gross domestic product due to unemployment, underemployment, and services and support costs associated with disability was determined to range between \$1.4 and \$1.9 trillion per annum in current dollars (Metts 2000). Disability research institutions such as NIDRR and international development organizations such as the World Bank need to acknowledge the global emergence of disability by establishing and funding new strategies for international research leadership and action on disability in the twenty-first century.

One final point is in order. At the outset of this chapter, we noted that the paucity of primary source evidence in most written histories of disability was a significant weakness. It is lamentable indeed that most existing records and publications have inevitably described disability history from the perspective of professionals who controlled the delivery of services. We endeavored in this chapter to use primary sources extensively when possible. However, in eval-

uating the strengths and weaknesses of this chapter, it is clear that we have barely touched on the potential of one very useful type of primary source material—literary and artistic archives—to complement the institutionally oriented history presented here. Studying the representation of disability in literature and art is an important and relatively unexplored research frontier in disability studies. It is a frontier with the potential to yield a richer understanding of the history of disability, with lived experience and perspective at the center of analysis rather than at the periphery. The work of Allen Thiher (1999), Robert Garland (1995), Rosemarie Garland Thomson (1997), David Mitchell (2000), and Sander Gilman (1988, 1995) exemplifies this approach, and significant growth in research on disability and the humanities can be expected over the next decade. This scholarship will contribute greatly to the developing knowledge base on the history of disability and human diversity.

## NOTE

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1. Public-sector (federal, state, local) spending for disability programs in fiscal year 1997 was estimated by the authors based on data obtained from the following sources: \$36.4 billion on special education (Chambers et al. 1998; U.S. Department of Education 1992, 1998). Federal and state spending for services for individuals with mental illness was estimated based on data collected by the National Association on State Mental Health Program Directors (Lutterman, Hirad, and Poindexter 1999) at \$26.7 billion. Spending for individuals receiving housing support through the U.S. Department of Housing and Urban Development (2000) was reported at \$9.9 billion. Combined federal and state vocational rehabilitation and independent living services spending totaled \$2.9 billion in 1997 (D. Teimouri, Rehabilitation Services Administration, U.S. Department of Education, personal communication, February 16, 2000, and J. Nelson, Rehabilitation Services Administration, U.S. Department of Education, personal communication, March 3, 2000). In addition, federal, state, and locally financed services for persons with developmental disabilities in 1997 totaled \$24.2 billion (Braddock et al. 2000). Medicaid health care, Medicare health care, and nursing home spending for persons with disabilities, excluding such funding associated with mental illness and developmental disabilities spending, totaled \$51.8 billion (Health Care Financing Administration 1998) and \$22.3 billion, respectively (M. Diacogiannis, Health Care Financing Administration, U.S. Department of Health and Human Services, personal communication, March 15, 2000). Payments totaled \$6.4 billion for acute health care for veterans with disabilities (M. Pringle, Department of Veterans Affairs, personal communication, March 16, 2000, and W. L. Walsh, Department of Veterans Affairs, personal communication, March 14, 2000).

Income maintenance for persons with disabilities totaled \$24.5 billion for Supplemental Security Income, \$44.6 billion in Social Security Disability Insurance payments in 1997, \$5.2 billion for the Disabled Adult Child Income Maintenance Benefits (Social Security Administration 1998), \$12.7 billion for Veterans Compensation (M. Pringle, Department of Veterans Affairs, personal communication, March 16, 2000), \$7.6 billion for Housing Rental Subsidy Payments (U.S. Department of Housing and Urban Development 2000), and \$2.4 billion for Food Stamps (U.S. Department of Agriculture 1998). Total disability spending of \$277.6 billion was then divided by nondefense public (federal, state, and local) expenditures of \$2.404 trillion (Office of Management and Budget 1999) to determine the estimated proportion of public spending attributable to disability services and income support in 1997 (11.5 percent).

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