

Intellectual Disabilities— *Quo Vadis?*

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. . . while we live, while we are among human beings, let us cultivate our humanity.

—Seneca, “On Anger”

It is probably difficult for anyone newly approaching the study of Mental Deficiency to appreciate the great advances which have taken place in the past thirty or forty years. At the beginning of the Century it was regarded as a comparatively unimportant subject, and interest in it was mainly confined to a few mental specialists and social workers. Today it is realised to be a serious social problem; a large number of medical practitioners and officials of public bodies are actively engaged in it; and it is recognized as an important branch of psychological medicine.

—Tredgold (1937:vii)

Plus ça change! Tredgold’s preface to the sixth edition of *Mental Deficiency (Amentia)* is as evocative today as it was more than 60 years ago. While the language of the 1930s, in contemporary terms, is archaic and to many offensive, the book’s chapter titles are topics that are still being vigorously explored in the millennium. Issues such as the concept and nature of mental deficiency, incidence, etiology, classification and definition, pathology, psychology, educational defect, clinical varieties of primary and secondary amentia, diagnosis and prognosis, treatment and training, the law, and sociology have remained major themes throughout the latter half of the twentieth century.

While Tredgold, one of the pioneers in the study of intellectual disability,¹ applauded the advances made in this field in the early twentieth century, there would be differences of opinion as to whether the first half of the twentieth century, in fact, made significant advances that led to positive outcomes in the lives of persons with intellectual disability. A key difference between the way Tredgold and his contemporaries viewed intellectual disability and the way it is viewed by most present-day commentators rests in the interpretation of the term *serious social problem*. The former group, people diagnosed with “primary or secondary amentia,” presented a range of social problems, including a lack of moral sense somewhat akin to that of “primitive man.” The psychological basis for “misconduct” was ascribed to faulty upbringing, inherent peculiarity, inherent incapacity for development, or a delay of inhibiting mechanisms (Tredgold 1937). The predominant contemporary view is that the social issues of intellectual disability, to-

gether with those of other disability groups, rests as much with the nature of society as it does with the person with the disability. There are, of course, current commentators whose views would range from those more akin to Tredgold's position to those who would see disability to be entirely a manifestation of a society unwilling or unable to cater for people with impairments (Stainton 1998).

This chapter will first explore, from a historical perspective, the place in society of persons with an intellectual disability. This analysis will establish that these people have been consistently denied personhood; they have been seen as objects of pity, fear, or both; they have been oppressed; and, with the rise of the eugenics movement, they have been seen as a threat to the very quality of the human race. The second section will analyze a number of the forces that spearheaded changes in the attitudes toward this group of people and the subsequent provision of more enlightened supports that enabled them to participate more fully in the general community. The pivotal role played by the normalization principle, together with scientific and technological advances, will be critically explored. Finally, it will be proposed that the full realization of personhood for these people may be found in the development of an "ethical community," rooted in the philosophy of a mutuality of need and responsiveness to the needs of all individuals in our society.

THE PLACE OF A PERSON WITH AN INTELLECTUAL DISABILITY IN SOCIETY

Philosopher Martha Nussbaum (1997) has identified three capacities that are essential to the cultivation of humanity in today's world. The first is an ability to examine oneself and one's traditions critically. The second is an ability to see beyond some local region, group, or country. As Nussbaum suggested, "The world around us is inescapably international" (p. 10). To cultivate our humanity, we must try to understand the variety of ways different groups realize our common needs and aims. Finally, she suggested that the development of a "narrative imagination" or "the ability to think what it might be like to be in the shoes of a person different from oneself, to be an intelligent reader of that person's story, and to understand the emotions and wishes and desires that someone so placed might have" (pp. 10-11) is the quintessential quality for the purposes of this discussion. It is only in recent years that we have come to recognize that to appreciate the essence of an intellectual disability, we must try to identify with the lives as they are lived by people with an intellectual disability.

Historically, society's continued denial of humanity toward persons with intellectual disability, as well as society's seeing such persons as a disposable commodity, challenges us. We move from a century that started with pride in scientific rationality and the triumph of logic over superstition to a century in which we should, in Nussbaum's (1997) terms, "make all human beings part of our community of dialogue and concern, showing respect for the human wherever it occurs" (pp. 60-61).

While not gainsaying Clegg's (1998) argument that in looking at past events in present time, one should not simply organize a set of ideas into chronological order, it is useful to examine the way society has almost consistently demeaned the place of persons with an intellectual disability in society. There are, of course, a number of positive signs that may be a harbinger for the future emancipation of this group. However, as will be indicated, significant though these signs may be, they were still quite tenuous within the overall social, cultural, political, and economic milieu at the beginning of the twenty-first century.

A categorization of historical eras suggested by Cliff Judge (1987), an early Australian leader in the field of intellectual disabilities, provides a useful framework in which to trace the evolution of community practices and attitudes toward this population. Judge has appropriately warned, however, that it is difficult to distinguish categorically one particular period in history from any other as a complex set of customs, social attitudes, and political imperatives define the

character of an era. For example, infanticidal practices that were once found acceptable in an earlier period of history are still practiced in some communities today. Although we currently believe that community attitudes toward people with significant disabilities are more accommodating of diversity, religious prejudices, ethnic persecution, and discriminatory practices against minority groups are still manifested in all continents of the world. People with disabilities are more often than not a part of these minority groups.

A Prescientific Era

Infanticide, a practice that dates back to antiquity, typifies the fact that it is only in recent times that children have been seen to have a distinct place in society. The outlawing of child slavery and abuse and the principle that children are not mere chattels of their parents are relatively recent phenomena that are still not being applied in all countries. For instance, in many countries, including India and China, male babies are preferred for a variety of reasons. One example is that in some countries, males are seen as better agricultural workers. The practice of providing dowries for females, which can impoverish a family, is suggested as a reason for the preference for males.²

In the case of children with intellectual disability, however, there is an added and more insidious reason that Stainton (1998) has described as the oppression of people labeled as having an intellectual disability. Stainton has argued that

the central idea in their oppression lies at the heart of the idea of modernity, that is, the association of reason and value and this accounts for the pervasiveness and consistency of oppression . . . in modern societies. (P. 115)

Unlike other disabilities, especially physical and sensory, Stainton has posited that a distinctive and consistent characteristic of intellectual disability is the phenomenon of *otherness*,³ which led to the practice of infanticide in classical Greece and the keeping of intellectually disabled people as slaves and fools by the nobility in ancient Rome (Stainton 1994).

In answering the question as to what lies at the heart of this *otherness* and its consistent and potent source of oppression for this population, Stainton's (1998) thesis is that

intellectual disability strikes at the very heart of classical and modern ideas of value and humanness. Shakespeare at his most Aristotelian sums up this central plank in the modernist project: "What a piece of work is man! How noble in reason! How infinite in faculty! . . . the paragon of animals" [*Hamlet*, II.ii]. (P. 115)

The notion that a defect of the human mind can be equated with subhuman species is found in the natural philosophy and the social and ethical writings of both Plato and Aristotle. For Plato, low intelligence was something to do with the nature of slave mentality (Goodey 1992), and Aristotle maintained that

the deliberative faculty is not present at all in the slave; in a female it is present but ineffective, in a child present but underdeveloped. (*Politics*, lxii, cited in Stainton 1998:116)

The eugenics movement, so often typified as a phenomenon of the late nineteenth and early twentieth centuries, can be seen to have had its foundations in the classical era. For instance, there is a road sign near Sparta that reads, "The law giver of Sparta threw deformed and invalid children for the good development of the human race" (Judge 1987:4).

The principle that persons with an intellectual disability were considered less than human and, more important, were ascribed as being possessed by the devil had strong foundations in

religious beliefs of the Christian era. For instance, Martin Luther saw demonic forces underlying mental disorders:

Idiots⁴ are men in whom devils have established themselves, and all the physicians who heal these infirmities as though they proceeded from natural causes are ignorant block-heads, who know nothing about the power of the demon. (Cited in Judge 1987:4)

Superstitions concerning the origins of mental disorders became entwined with the origins of medicine. The writings of Hippocrates (460-359 B.C.) and Galen (131-200 A.D.) had profound effects on medical thinking for centuries. For instance, Galen is reported as saying that idiotic patients had large and outstanding ears (Judge 1987:7). In the sixteenth century, the pseudoscience of palmistry gained popularity. Palmists maintained that the shape, size, and marking of a person's hand and palm provided indications of a person's intellectual ability and character. Phrenology, another pseudoscience, gained popularity in the eighteenth century through the work of Franz Joseph Gall (1758-1828).

The movement went from a long period of superstition and the belief that intellectual disability had its origins in demonic and satanic forces (somewhat akin to witchcraft, with "treatments" such as exorcism and ritual burning) to the pseudoscientific era, which resulted in a search for a cure. Remedies such as purification with water treatment, bloodletting, the ingestion of "bitters" (quinine), multivitamin and cell therapy, movement training, and faith healing have been prescribed and are still being prescribed in parts of the world. It is this search for curative treatments that gave rise to the "medical model" of intervention for people with an intellectual disability.

"Moral training," which became advocated for "moral imbeciles," can be seen as related to exorcism, as mental disorders after the Middle Ages were seen as something quite distinct from the body. The thesis that the mind is basically distinct from the body can be traced to Cartesian philosophy. Descartes's view, suggested by Edwards (1998), was that "the self can be identified with the mind or soul, and is only contingently related to the body" (p. 47). In this view, "the self is encased, housed or trapped within a body; the mental and physical realms, are clearly demarcated; and the body is an object different from inanimate objects only by virtue of the degree of complexity and its organization" (Edwards 1998:49).

The Age of Enlightenment

In the seventeenth century, John Locke (1623-1704) set the philosophical groundwork for the "Age of Enlightenment" and heralded the then radical belief in the value of education, which countered the deeply held religious view of "man" having to bear the ineradicable stain of original sin. The prevailing view was that education could do very little to ameliorate the human condition without "the previous impression of God's saving grace" (Spellman 1988:2). Despite this new optimism, Locke's writings still reflected the widely held view that persons with intellectual disability do not attain the same level of personhood as those of higher intelligence. For instance, in his analysis of what constitutes "personal identity," Locke emphasized the role that "continuity of consciousness" plays in the identity of self and the identity of a person (Gibson 1968). Locke, too, drew comparisons between animal and "idiot" intellect (cf. Locke [1690] 1959:II.11.12-13 and II.9.14). For Locke, "a 'person' was a 'thinking' intelligent Being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different terms and places" (cited in Lowe 1995:103). Thus, the defining characteristics of personhood, for Locke, were rationality and consciousness, including self-consciousness.

Goodey (1992) has cited contemporary writers whose views also highlight the permanence of the concept that persons with intellectual disabilities are less than human. For example, Gilbert Ryle's (1949) *The Concept of Mind* gives as its definition of *specifically human behavior* "behaviour which is unachieved by animals, idiots and infants" (Goodey 1992:28). From

antiquity, then, there has been a pervasiveness of the concept of the separateness of those labeled “intellectually disabled” from full personhood. The optimism that the Age of Enlightenment brought for many did not include those with intellectual disability.

An Abandonment Era

Just as the practice of infanticide typified the denial of personhood for children, especially those who were deemed never likely to attain this status because of their disability, the practice of abandonment became more common with the advent of the Industrial Revolution. For children with an intellectual disability, this era saw the emergence of a number of sensationalized cases of “feral children”⁵—children who, when abandoned, did not die from exposure but were either cared for by animals or were able to care for themselves. Malson (1972) documented 53 such cases between 1344 and 1961. While the authenticity of many of these reports is open to question, the immense publicity surrounding such events spawned the morbid curiosity of the public that was always eager to observe “deviant” examples of humanity, typified by displays of such people in sideshow alleys.

The most celebrated case, however, was Victor, the so-called Wild Boy of Aveyron or, in French, *l'enfant sauvage*. Victor was found in the woods of Aveyron and subsequently became the protégé of the French physician Jean Itard. Itard's attempts to educate Victor were to have a significant impact on another French physician, Edouard Seguin, who worked under Itard's supervision. The sensationalism of the feral child phenomenon gave impetus to the ongoing nature-nurture debate or the heredity versus environment question, which was to have a profound impact on the way people with intellectual disabilities were viewed in the first half of the twentieth century. Itard's work, and later that of Seguin, produced a spirit of optimism concerning the educability of persons presumed to have intellectual disability.

An Institutionalization Era

The phase of institutionalizing persons with intellectual disability, the effects of which still permeate disability policies worldwide, can, in a sense, be traced to the development of homes for foundlings—children often born out of wedlock. One of the earliest reports of such a facility was a home founded by Archbishop Datheus in Milan in 787 A.D. The founder of the celebrated Catholic welfare society, St. Vincent de Paul (1581-1680) is credited as being one of the first to take in not only foundlings but also people with leprosy, mental illness, and intellectual disability in the Paris home that was to become the Hospice Bicêtre. This, together with the Hospice of the Salpêtrière, was the site where the great French reformers Pinel, Esquirol, Itard, Morel, Bourneville, and Seguin led the world in drawing attention to the special needs of people with intellectual disabilities.

Institutions exclusively for intellectually handicapped people, as we have come to know them more recently, however, grew out of the “back wards” of hospitals for people with mental illness. In many cases, the needs of people with intellectual disabilities in these facilities were not met with the same vigor as those needs of people with mental illness. For instance, it was not until recent times that it has become generally accepted that intellectually disabled people can also experience mental illnesses.⁶ Two major factors that contributed to the scandals exposed in the latter half of the twentieth century by figures such as Bank-Mikkelsen, Nirje, Blatt, and Wolfensberger were the “therapeutic” practices applied to either cure or contain behavior and the gross overcrowding that occurred as a result of the pressures of industrialization and urbanization and, more recently, the increased life span of the inmates.

Emerging Educational Influences

Seguin's influence on the role of education to ameliorate the effects of intellectual impairments cannot be underestimated (Talbot 1964). His belief in the efficacy of intensive sensory-motor activities as an aid to learning and his exposition of detailed step-by-step instructional procedures reflected the intense optimism that flourished in the 1850s and 1860s around new ideas about the educability of "idiots." While the Age of Enlightenment provided the basis for the modern-day educational systems, influenced by figures such as Johann Heinrich Pestalozzi (1746-1827), the apparent incurability of "mental deficiency" challenged the very foundations of the Enlightenment ethos. Radford (1994) clearly summed up the position as follows:

In an age that celebrated intelligence as much as beauty, perfection and rationality, the "idiot" was dull, flawed, defaced with stigmata and above all incurable. In the blunt terms of the philosopher John Locke: "where the 'lunatic' has lost his mind, the 'idiot' never had one." (P. 12)

However, in 1844, the Paris Academy of Science proclaimed that Seguin had solved the problem of "idiot education" (Baumeister 1970). In 1848, he moved to North America, where he was instrumental in the foundation of several institutions for people with intellectual disabilities. Together with five medical colleagues, in 1876 he established the Association of Medical Officers of American Institutions for Idiots and Feeble Minded Persons, renamed the American Association for the Study of the Feeble Minded in 1907 and then, in 1933, the American Association on Mental Deficiency. The influence of the medico-psychologists of the nineteenth century, including Seguin, Guggenbühl, and Howe, extended throughout much of the then Western world and continued into the early twentieth century.

Assessment and Classification

Educational approaches to training persons with an intellectual disability were influenced by the rising discipline of psychology, which was to eventually usurp the power role formerly held by the medical profession (Crocker 1999). Theories propounded by Francis Galton (1822-1911), William James (1842-1910), Arnold Gessell (1880-1961), Charles Spearman (1863-1945), Cyril Burt (1883-1971), and Jean Piaget (1896-1979) had a profound effect on the way people with intellectual disabilities were assessed and classified.

Frenchman Alfred Binet (1857-1911), however, is credited with being the founder of psychometrics, the measurement of intelligence. As discussed above, there had been earlier "scientific" attempts to diagnose or explain the phenomena of low intelligence—from Galen's reference to the association between idiocy and large ears to palmistry and phrenology. Other movements included polygenism, which emphasized that among the human races, there were separate biological species; craniometry, or the measurement of the skulls and its context; and the measurement of bodies to search for signs of apish morphology in groups that were deemed undesirable.

Binet, director of the psychology laboratory at the Sorbonne, eschewed his early attachment to craniometry and the work of his countryman, Paul Broca, in his development of a scale to identify those children whose lack of success in normal classrooms suggested their need for some form of special education. His first scale, published in 1905, consisted of a number of everyday problems of life involving processes of reasoning. The tasks were arranged in an ascending order of difficulty, with an age level assigned to each task, giving rise to the concept of mental age and, subsequently, the intelligence quotient (IQ).

Despite Binet's deep interest in the theoretical aspects of intelligence, his scale had a practical, empirical focus. He explicitly avoided imposing any theoretical interpretation to his scale and denied that it was a measure of "intelligence" (Gould 1981). Contrary to the later misuses of his and later scales as a means to label and limit, in the belief that measures of intelligence are

markers of permanent inborn limits, Binet devised his scale to identify those children whose poor performance identified them as needing special education. He had definite pedagogical suggestions as to how these children might be instructed. For instance, he suggested that prior to being taught the basic subjects, they needed “mental orthopedics.” These included exercises to develop motivation, attention, and cognition discipline. Like Seguin, Binet’s pedagogy was a harbinger for instructional techniques developed by learning theorists in the latter part of the twentieth century. He certainly believed that intelligence could be augmented by good education and was not necessarily an immutable and inborn quantity.

The Menace of the Feeble-minded

The publication in 1859 of Charles Darwin’s *Origin of Species* and its interpretation by his cousin Francis Galton, the attribution of the causes of intellectual disability to the sinful behavior of parents (promiscuity and or alcoholism—usually of the mother), the documentation of mongolism and cretinism, and the genetic discoveries of Gregor Mendel (1822-1884) gave rise to the science of eugenics. Interestingly, eugenics did not have its original roots in the study of the epidemiology of intellectual disability but in the study of the epidemiology of genius. However, Mendel’s formulation of inheritance laws concerning dominant and recessive conditions gave rise to oversimplified interpretations. For instance, the eugenics movements ascribed intellectual disability as a single heritable condition and not one that can be due to a variety of genetics and other causes.

Eugenics societies sprang up across much of the Western world, with pressure being placed on the families of the intellectually disabled to encourage them to neither marry nor procreate. Arbitrary rules were established to discourage the reproduction of deficient offspring. It is only in recent years that sterilization laws have been removed from the statutes of countries such as the United States, Canada, Sweden, and France. Genetic research from British scientist Lionel Penrose, who demonstrated that eugenic strategies could only have marginal effects in reducing the number of intellectually disabled people being born at any one time, played a role in the reversal of these policies, as did the work of Lancelot Hogben and J. B. S. Haldane.

A principal figure in the eugenics movement was H. H. Goddard, director of research at the Vineland Training School for Feeble-Minded Girls and Boys in New Jersey. Goddard popularized the use of the Binet scale in America, agreeing with Binet that the tests were most effective in identifying people just below the normal range. These were then referred to as “higher grade defectives,” whom Goddard christened “morons.” The classification of intellectual disability, or mental deficiency, as it was popularly known, became a popular debate in the early twentieth century. Three categories emerged: “idiots,” who did not develop speech and had mental ages below 3; “imbeciles,” who did not become literate and had mental ages between 3 and 7; and “high-grade defectives” or “morons,” as Goddard named them, who could be trained to function in society. While “idiots” and “imbeciles” could be categorized to the satisfaction of professionals, including medical practitioners and the newly developing discipline of psychologists, as having a true pathology, the third group constituted a gray area. They formed a bridge, suggested Gould (1981), between pathology and normality “and therefore threatened the taxonomic edifice” (p. 158).

While Binet had steadfastly refused to refer to his scores as “intelligence,” Goddard perceived them as measures of a single innate entity, which he called “intelligence.” Furthermore, he saw intelligence being completely dependent on heredity, and, more insidiously, he saw a direct link between intelligence and immorality. This was a popular eugenical theme that led to criminals, most alcoholics, prostitutes, and others living on the fringes of society to be lumped together as “morons” who were innately defectives. In linking immorality and stupidity, Goddard advocated either “colonization” or “sterilization,” with a preference for the former. In institutions, such as his own at Vineland, procreation could be controlled. He even advocated that such institutions could replace the present almshouses, prisons, and even the numbers in mental hospitals. “Such colonies,” he suggested, “would save an annual loss in property

and life, due to the actions of these irresponsible people, sufficient to nearly, or quite, offset the expense of the new plant" (Goddard 1912:105-6).

The Reification of Intelligence

The ultimate reification of intelligence can be attributed to Lewis M. Terman (1877-1956), a professor at Stanford University, who revised Binet's 1911 scale and renamed it the "Stanford-Binet," which became the gold standard for nearly all IQ tests that followed. Terman followed Goddard in emphasizing the danger that "high-grade defectives" posed for society. His deep commitment to the value to society of mass intelligence testing is reflected in his comment that

it is safe to predict that in the near future intelligence tests will bring tens of thousands of these high grade defectives under the surveillance and protection of society. This will ultimately result in curtailing the reproduction of feeble-mindedness, and in the elimination of an enormous amount of crime, pauperism, and industrial inefficiency. (Terman 1916:6-7)

In addition to reinforcing the low expectations for cognitive development among those with low IQ scores, the work of Terman and his colleague Yerkes (1876-1956), together with that of Sir Cyril Burt (1883-1971) in the United Kingdom, supported the concept of a racial superiority.⁷ This was to have disastrous implications for African Americans and other indigenous populations who were also subjected to segregation and substandard educational and social opportunities in many parts of the world.

Results of Longitudinal Studies

Several longitudinal studies have soundly demolished the dire predictions made in the early half of the twentieth century. Notable are the works of Edgerton (1967), Edgerton and Bercovici (1976), and Edgerton, Bollinger, and Herr (1984). In his original study of 53 former patients of Pacific State Hospital in California, Edgerton's main thesis was that these persons' major motivation was to pass as ordinary people and to deny their institutional experience. However, to cope, most of them became dependent on "benefactors" who helped them to survive. Edgerton suggested that it was the *stigma* of intellectual handicap that was their biggest burden, which led them to don "a cloak of competence" to try to cover their incompetence. The management of this problem, maintained Edgerton, was the major issue for the deinstitutionalization movement that was to emerge in the 1960s.

As Clarke and Clarke (1985) observed, the prevalence of administratively defined intellectual disability peaks at the latter years of schooling, declining thereafter, almost entirely due to the eventual community adjustment for most of those with mild disabilities. However, those with more severe levels of intellectual impairment have tended to remain dependent on welfare agencies, this being the case at least until the mid-1980s. Work since then, however, has demonstrated, especially in vocational and supported living programs, that people with more severe levels of intellectual impairment do reach levels of semi-independence, which was formerly thought impossible (Parmenter 1993; Snell 1987; Wehman et al. 1988).

The effects of the assessment and classification on the field of intellectual disabilities can be viewed positively or negatively. Binet's original goal was to segregate and provide special education services for those who were identified as requiring assistance within the school environment. This initiative was to provide a basis for developing a parallel system of special education programs within the general provisions of education. However, the psychologists who followed Binet were to provide the foundations for the belief that people who fell below a certain level of IQ were ineducable. In many Western countries, it was not until well into the second half of the twentieth century that all children, regardless of disability, were deemed eligible for public education services. The pattern in developing countries has followed the same trajectory,

especially as universal education for nondisabled and disabled children alike remains problematic in many of those countries.

As social welfare programs have developed, assessment and classification have been seen as an essential element for eligibility for services. On the other hand, they have been seen as encouraging the labeling processes, which have traditionally been associated with negative attitudes toward all disabled people and people with intellectual disabilities in particular. Just as the early medical scientists concentrated on the etiology of intellectual disabilities, early psychologists also became, as Clark (1974) observed, “more concerned to classify than to remedy or treat, [so] relatively little work has been done to establish how much behavioural or cognitive change can be effected in difficult groups of subnormal subjects” (p. 435).

Population Explosion in the Institutions

The promises heralded by the innovative thinking of luminaries, such as Guggenbühl and Seguin in the nineteenth century, were not to be realized in the early twentieth century for a variety of reasons. The eugenics movement, of course, led to greater numbers of marginal members of society being incarcerated for the “protection” of society generally. The severe effects of the great economic depression in the 1920s and 1930s resulted in increasing numbers of families seeking institutional care for their intellectually handicapped children because they were unable to feed and clothe them. It was common practice for families to be advised on the birth of a disabled child to immediately seek institutional care as the best solution to the “problem.”

Thus, during this time, there was a burgeoning of institutional populations across the world. For instance, in the United States, institutional care increased continuously from the middle of the nineteenth century until 1967, when it peaked at 194,650 persons, or 95 per 100,000 of the general population (Lakin, Bruininks, and Sigford 1981). Rather than places of asylum and succor, institutions became veritable “hellholes.” Several commentators have described the appalling conditions evident in these institutions around the world at this time (Blatt 1981; Judge 1987). In parts of Eastern Europe, similar conditions are still to be found (Mutters 1999).

Advances in medical science, including the discovery of sulphonamides in 1935 and penicillin in 1944, had substantial effects on the morbidity and mortality of those with severe and profound levels of intellectual disability. Inmates of institutions were now kept alive in ways not previously possible. The irony is that this led to further pressures from overcrowding and extra demands on limited and, at times, ill-prepared staff. In 1965, in the United States, the average number of residents per institution peaked at 1,500 (Lakin et al. 1982). In 1962, the President’s Panel on Mental Retardation assessed the status of residential programming in the United States as follows:

The quality of care furnished by State institutions varies widely, but from the standpoint of well-qualified and adequate personnel and the availability and use of professional services and modern, progressive programs, the general level must be regarded as low. In large state institutions, the normal patterns of administration and care are compounded by overcrowding, staff shortages, and frequently by inadequate budgets. (President’s Panel on Mental Retardation 1962:137-38)

The history of the place in society of persons with an intellectual disability traced thus far portrays them as essentially being on the outside or, at the very maximum, on the fringes of society. Their humanity has often been denied, they have been seen as a threat and a danger to society, they have been oppressed and segregated, and despite some enlightened attempts to provide them adequate care and succor, the perception of their “otherness” continued well into the twentieth century. However, forces for change emerging in the latter half of the twentieth century would see a shift in society’s appreciation of the basic human needs of these fellow citizens.

FORCES FOR CHANGE

The Normalization Principle

Despite the enormous advances in scientific enquiry into intellectual disability in the latter half of the twentieth century, history may judge that the most significant event of the century, in the context of life changes for persons with such a disability, was the social impact of the normalization principle. In its original formulation by Swedish scholar Bengt Nirje, the principle addresses the most fundamental issue of concern—the basic humanity of people with an intellectual disability that had been historically denied them.

In this introduction to his collected papers, Nirje (1992) pointed out,

Two concerns have interacted in my papers . . . the problems inherent in the social situation of persons with intellectual impairments or disabilities, and the problems of establishing a coherent point of view of statements with regard to action, planning and legislation affecting their conditions of life. (P. 3)

Nirje's important contribution to the field was influenced by a number of converging factors. First, he was involved in a number of service organizations, including the Association for Persons with Intellectual Impairment (1962-1970). Nirje was the social welfare officer in the Swedish Red Cross Team, which provided support for Hungarian refugees in a former military camp in Austria (1956), and he was with the Folke Bernadotte Drive for cerebral palsy, which aimed to create better child-oriented environments instead of the former hospital institutions. Nirje (1992) commented on these experiences as follows:

Thus I had been close to the experiences of the alien, non-normal, demands-humiliations-uncertainties-fears for the future connected with life in a large collective, "mass managed," institutions—and to the efforts, strivings and deep human motivations for creating valid developmental opportunities in the society. (P. 4)

He was also closely involved at the national and international levels of policy and legal developments. In Sweden, in the early 1960s, Nirje collaborated with Karl Grunewold, inspector general of mental retardation services in Sweden, in helping to formulate the introduction in 1967 of the Act on Services and Provisions for Mentally Retarded Persons, which incorporated the ideology of normalization. Nirje admitted that one of the major inspirations for his later formulation of the principle was the pioneering work of Niels Erik Bank-Mikkelsen, the dynamic leader of the Danish state mental retardation services. Nirje recounted how he was deeply influenced by Bank-Mikkelsen's strong commitment to the legal rights of persons with intellectual disabilities and by his humanistic approach. Bank-Mikkelsen had been the driving force for the Danish law for mentally retarded citizens in 1959, the preamble to which included the words "to let the mentally retarded obtain an existence as close to normal as possible" (cited in Nirje 1992:6).

A further influence, alluded to by Nirje (1985), was his early training in the Uppsala School of Philosophy and by questions raised by Hägerström and Hedenius. Here he raised the issue that concepts of "rights" serve as a background to legislation. He asserted that human rights involve more than that which is actually covered by legislation. A final influence, suggested Nirje (1985), was Ruth Benedict's (1934) classic study *Patterns of Culture*. It was Benedict's treatise on how cultural patterns affect the development of the individual that stimulated Nirje to formulate the principle in terms of patterns of life for people with an intellectual disability. In his most recent formulation, Nirje (1992) has stated,

The normalization principle means that you act right when making available to all persons with intellectual or other impairments or disabilities pattern of life and conditions of every day living which are as close as possible to or **indeed the same** as the regular circumstances and ways of life of their communities. (P. 16)

Wolfensberger's Formulation

While Bank-Mikkelsen (1976) described normalization as the acceptance of persons with an intellectual disability of their handicap, offering them the same conditions as are offered to other citizens, a somewhat different formulation was proposed by Wolfensberger (1969, 1972) in the North American context. Basing his approach on the functionalist sociologist approach of Parsons (1951) and the interactionist approach of Goffman (1961, 1963), Wolfensberger emphasized using normative means to establish normative behaviors. Drawing heavily on the sociology of deviance, Wolfensberger (1972) suggested that “a (potentially) deviant person should be enabled to emit behaviours and an appearance appropriate (normative) within the culture for persons of similar characteristics” (p. 28).

Wolfensberger's focus on the use of normative means to establish normative behavior was built on a different value base and conception of people from the Scandinavian approach, with quite different implications for the provision of services to support people with an intellectual disability (Perrin and Nirje 1985). Wolfensberger's reductionist approach emphasized the need for people with intellectual disability to adapt to the cultural norms of their community, in much the same way as advocated by Goffman (1963). Goffman defined the concept of “passing” as the ability of members of deviant groups to minimize their differences or signs of deviancy so they are able to “pass” undetected into society. Whereas Nirje's formulation emphasized freedom of choice and recognition of a person's integrity, in the context of the realities of life, Wolfensberger stressed the appearance of conformity and passing and the need for people to hide their deviancy. Ontologically and epistemologically, they are quite divergent conceptualizations, albeit sharing a common nomenclature.

However, it was Wolfensberger's formulation that was to have a major impact outside the Nordic region. It was his approach that was embraced by policy planners and service providers in much of the English-speaking world. The influence of his writings and public lectures was a seductive force in the deinstitutionalization movements, as governments legislated to provide support for community-based options. Of particular relevance was his development of instruments to quantitatively evaluate human services. These were appealing to government bureaucracies, which saw the need to set standards and benchmarks against which funded services for people with intellectual disabilities needed to comply (Wolfensberger and Glenn 1975; Wolfensberger and Thomas 1980).

Subsequently, Wolfensberger (1983, 2000) reformulated his approach to normalization by developing what he termed the *theory of social role valorization* (SRV), which was meant to subsume and replace the principle of normalization that he had earlier enunciated. The new formulation placed extreme importance on the concept of “deviant” groups obtaining valued roles in society.

There are a number of contradictions and paradoxes implicit in Wolfensberger's formulation. On one hand, he asserted that its “concepts and constructs [are] rooted primarily in sociology” (Wolfensberger 1969:296), yet the strong call for the person with the disability to become more competent and to acquire “valued roles” is more related to Wolfensberger's psychological training and the emerging influence of behaviorism in the 1960s and 1970s.

Clegg (1998) has argued that while normalization is often described as a philosophy, it “is no more than a set of principles which lack heuristic power . . . the power to develop and to connect with other ideas” (p. 89). It is the doctrinal nature of social role valorization that causes controversy. Wolfensberger appears, like other functionalist theorists, to conceptualize a largely homogeneous society with a set of values that are “given.” It is difficult to see in a pluralistic and diverse society how SRV can be generalizable to all nations of the world. It is a moot point as to whose values one accepts.

Wolfensberger's position on choice and self-determination is interesting. While he is not opposed to the concept of self-determination,⁸ he indicated that the right to choose may be in conflict with what is defined as appropriate, normalized behavior. One can appreciate that the rights of the individuals to choose certain actions must be balanced with principles such as responsible and informed behavior and duty of care, but there is still the question of who determines what is "appropriate, normalized behavior."

Clegg (1998) has suggested that ontologically, normalization has been overly narrow in perspective. She proposed that normalization has been derived from a value Taylor (1989) has termed "the affirmation of ordinary life." This idea can be traced to the Enlightenment but is nearly impossible to define. Drawing on Taylor's triaxial approach to moral ontology, respect, and dignity, as well as what gives meaning to life, Clegg pointed out that most normalization values cluster around the respect axis. This allows us, she suggested, to see both its strengths and limitations.

It may be useful to move beyond this unitary approach, to one that encompasses Taylor's (1989) other two areas of moral ontology—for instance, issues of rights and citizenship and aspects that give meaning to people's lives. Within the context of normalization, especially as promulgated by Wolfensberger, very little discussion is concerned with these areas. However, more recently, the issues surrounding rights and citizenship and a closer attention to examining the deeper personal aspects of the lives of people with an intellectual disability have become important areas of focus.

Undoubtedly, the normalization principle, in its variety of forms, has contributed much to the field in the context of the reform of the institutional era. It added a further dimension to other developments that were affecting the disability scene, such as the civil rights and independent living movements in North America. It also provided a strong belief system for the professional staff who was given the responsibility of effecting the radical change from institutional to community living. On the down side, however, it led in part to a rigid doctrinal dogmatism that eschewed critical thinking and analysis. It did not allow, in Taylor's (1989) terms, for different positions to be balanced against each other. Nor did it encourage, as Clegg (1998) suggested, the development of a "reflective researcher-practitioner" model among the various support personnel engaged in disability services. Paradoxically, the movement toward community-based services has increased, rather than diminished, the tendency to classify and administratively segregate (Simpson 1998). This is especially true in those countries where economic rationalist policies aim to reduce welfare budgets (Parmenter 1999a).

The Deinstitutionalization and Community Living Movement

The combination of philosophical and social forces, including the normalization principle, precipitated a paradigm shift, at least in the Western world, in the way services were provided to people with disabilities, including those with intellectual disabilities. Legislation was enacted that led to the gradual decline of a variety of segregationist policies in education, employment, and accommodation.

The average annual change in pace of deinstitutionalization in Scandinavian countries, the United Kingdom, and the United States in the last quarter of the twentieth century has averaged 3.8 percent compared to virtually no change (0.06 percent) among other European countries (Hatton, Emerson, and Kiernan 1995). In the Netherlands, there was an average annual increase of 0.41 percent. There is evidence, too, that while there has been a dramatic drop in the number of people who were institutionalized, there remain considerable numbers in government and private institutions in many parts of the world (Walsh 1997).

Mansell and Ericsson (1996) argued that the pace of deinstitutionalization was sustained in the 1980s because community services were no more expensive than institutional care. In a number of countries, including the United Kingdom, the United States, and Australia, access to

new central government funds certainly stimulated the trend toward community-based programs. However, it was noted that in Britain and the United States, owing to central government concerns about the growth in welfare expenditure, there are growing restrictions on access to central government funds. In Scandinavia, the trend toward decentralization is placing increasing demands on local community instrumentalities. There is, therefore, an inherent danger that an institutional legacy may live on, especially as the effective community integration of people with intellectual disability has yet to be fully realized in those countries that enthusiastically embraced deinstitutionalization. In this regard, Mansell and Ericsson (1996) have asserted,

Deinstitutionalization, then, is not just something that happened to people with intellectual disabilities and their families. It also happened to decision-makers and staff in services and to researchers. They have to shift their attention to new problems and issues in the community. . . . But they had also to recognize that institutions were the expression of beliefs in society and that their demise may leave those beliefs and the practices the underpin still to be tackled in the community. This is surely the greatest challenge for all societies: how to build and sustain social solidarity and mutual commitment among people with different needs, talents and aspirations, so that everyone may flourish and prosper. (Mansell and Ericsson 1996:252-53)

There are several challenges ahead in effecting real changes in the quality of the lives of people with intellectual disabilities and their families. Simply closing institutions does not address the factors that led to their development. We need to explore the contemporary social, economic, and political forces that are shaping social welfare policies. In particular, we need to examine the processes that lead to the effective inclusion of people with intellectual disabilities into a community that welcomes and sustains them.

The Contribution of Science

To do adequate justice to this topic, we require a much more detailed analysis than is possible in this chapter. The burgeoning of research efforts across all fields of scientific endeavor relevant to the field of intellectual disabilities, especially in the latter half of the twentieth century, is outstanding. Developments in the basic biomedical sciences and those in the social-behavioral field have made enormous contributions to our understanding of a broad range of issues, including prevention, etiology, health services, education, and community living and working.

It would not be too optimistic to suggest that current and anticipated developments in genetics and neuroscience research provide exciting windows of opportunity for doing good. However, they also provide enormous ethical challenges. Scientists, as Rioux (1997) has pointed out, come with prejudicial attitudes as to what constitutes science and the scientific method. Scientists, too, come with preconceived notions concerning the intrinsic value of persons with “inborn errors of metabolism.” The very language of “normality” sends covert messages that something must be “wrong” with these people.

In his preface to Penrose’s *The Biology of Mental Defect*, John Burdon Sanderson Haldane (1948), one of his most eminent colleagues in the field of biochemistry, observed that an intellectual approach to the study of biology and its importance to the etiology of intellectual disability was not enough. Apart from its practical aspects, Haldane suggested that the study of intellectual disability was of considerable philosophical importance. For instance, the question of why people are different and what determines their individuality is of the greatest interest. In this respect, Haldane’s observation that Penrose’s contribution to the study of human biology was as much a contribution to general culture, as it was to the study of incomplete human development, is apposite in the context of this discussion. It would appear that one of the most important challenges for science in this field in the next century is for it to be more integrated and

inclusionary within the broader scientific endeavors and with humanities, economics, and the social sciences.⁹ A greater synergy between these various sections of research and enquiry, together with a deeper involvement of the public sector in the development of research policies, may help reduce the ever-widening gap between research and practice that was a feature of this field in the last half of the twentieth century.

The enormous pace of discovery of new knowledge has been a factor in the slowness of its application, but political, social, and economic commitment to this marginal population has not always been sufficient to maximize the benefits scientific advances have made. For instance, we have known since the early nineteenth century the causes of goiter and cretinism.¹⁰ Given the intense interest in the new science of human genetics and the demonstration that some cases of intellectual disability were largely genetically determined led, as indicated above, to exaggerated hopes of eugenical improvement. Penrose (1938), in his classical study, the Colchester Survey, demonstrated the multiple etiologies of the impairment. Not surprisingly, in the first half of the twentieth century, scientific efforts were directed mainly toward diagnosis of causes, assessment, and prevention, but very little effort was directed toward treatment. By 1963, Penrose reported that specific health interventions involving hormonal, dietary, and exercise treatments ameliorated the effects of specific impairments. Brain surgery for people with cerebral palsy and epilepsy was also reported in the early 1950s. Before this time, there was little emphasis on psychological and educational training, possibly with the exception for those described as “mild or borderline mental defectives.”

While biological and medical efforts were predominant, there was, at this time, a growing perception that people with an intellectual disability could profit from educational programs, albeit described as “training programs.” The language of the time was, in contemporary terms, patronizing and stereotypic. For instance, Penrose (1963) commented that “defectives are not naturally antisocial. They are naturally very friendly and are particularly susceptible to influence during the formative years” (p. 283). However, a closer examination of the work of trailblazers, such as Penrose, reveals a deep commitment to the essential humanity of this population and to their basic rights to exist as part of the human civilization. Penrose’s (1963) exhortation that as “subcultural mentality must inevitably result from normal genetical variation . . . the genes carried by the fertile scholastically retarded may be as valuable to the human race, in the long run, as those carried by people of high intellectual capacity” (p. 295). This is germane to the current debates concerning the ethics of the implications of the human genome project (Newell 1999; Roeher Institute 1999).

A contributing factor to the fragmentation of the research effort in this field was the relative isolation of scientists and their lack of awareness of each other’s work, especially across the major English-speaking countries of North America and the United Kingdom and Ireland. Although scientists in the Nordic and the Netherlands regions accessed English publications, there was little intellectual intercourse in this field across the Atlantic before the early 1960s. Language barriers also continue to be a problem for much of the Latin- and Germanic-based languages and large parts of Eastern Europe, Asia, the Middle East, and Africa, especially as English has become the major language of science.

*Formation of the International Association
for the Scientific Study of Mental Deficiency*

In an effort to improve the exchange of scientific knowledge, a meeting of scientists from Europe and the United States was held in London in 1960. The *Proceedings* (Richards, Clarke, and Shapiro 1962) of this conference portray the wide range of research interests across 11 aspects of intellectual disability. Of special significance was that 35 of the 97 presentations were from nonmedical disciplines, principally psychology and education. The steady growth of research on intellectual disability from these disciplines in the 1960s became even stronger in subsequent international conferences organized by the International Association for the Scientific Study of Mental Deficiency,¹¹ an association that formally came into being in 1964 as a sequel of the

London meeting. At the most recent Congress of the Association, held in Helsinki in 1996, the proportion of biomedical contributors was in the order of 30 percent, but the remaining 70 percent encompassed a much wider range of disciplines from the sociobehavioral sciences and a wider representation of countries (27 in 1960; 63 in 1996).

Shift in Definition of Mental Retardation

The decline of the dominance of the biomedical field was in large measure a result of the redefinition of mental retardation that included “impairment in adaptive behaviours” in addition to subaverage general intellectual functioning (Heber 1958:3). This new definition, linked with the optimism of new pedagogical techniques, supported the proposition that the effects of an intellectual disability could be reversed.¹² Interestingly, the educational initiatives of the psychologists of the 1960s and 1970s bore a remarkable similarity to those of the medico-psychologists of the nineteenth century. Simpson (1998) observed that the basic difference between the two periods was that, whereas the nineteenth-century reformers were establishing pedagogical institutions for “idiotic” children, their twentieth-century counterparts were using similar arguments to close them.

The predominant theoretical approach that the psychoeducational paradigm embraced toward the conceptualization of disability and to research and practice was one in which the disability was intrinsic to the person. This approach emphasized the utilitarian nature of programs and treatments that would make disabled people more functional for society. It was the person who must change to accommodate the needs of society; it was the person who must “pass” the test of society before his or her basic humanity was recognized and valued. A basic flaw in the psychomedical model of disability, on which many of the programs the normalization principle influenced, was its implicit assumption that there was a single set of norms appropriate for all groups (Jensen 1980). This problem was also inherent in contemporary attempts to measure quality of life (Parmenter 1996). It is suggested, therefore, that it is time to move beyond the normalization movement, as advocated by Wolfensberger, for it continues to support the objectifying and commoditization of persons with an intellectual disability. It has failed to recognize the intrinsic humanness of these people, despite their difficulties in conforming to a normative set of values that often fail to recognize the immense diversity of the human condition.¹³ Yet is it too idealistic to foresee a society that will accept Nirje’s (1985:67) view that integration is based on the recognition of a person’s integrity, which means “to be yourself among others—to be able and be allowed to be yourself among others”? Has society reached the stage where it has, as questioned by Goodey (1996), “the ability to include people with the severest learning disabilities, to the point of not noticing, or not being anxious about, the difference between Wittgenstein and them” (p. 96)?

Integration of Biological and Behavioral Sciences

This is not to deny the positive elements of contemporary scientific advances—for instance, the integration of psychobiological processes, especially in the neurosciences. Neuroscience, suggested Schroeder (1991), represents a fusion of several scientific disciplines—biophysics, biochemistry, physiology, anatomy, pharmacology, genetics, and psychology. It also focuses on understanding the relationships between brain and behavior. An excellent example of interdisciplinary research integration is the use of the results of morphometric studies of human cerebral cortex development to influence the direction of early language development programs for children at risk for language development delay. Huttenlocher’s (1990) studies of the immature cerebral cortex in humans have indicated that the growth of dendrites and synaptic connections occur during infancy and early childhood. Excess synaptic connections, however, are eliminated during later childhood years, but the abundant connections that occur during infancy may form the anatomical substrate for neural plasticity and for certain types of early learning.

This finding, Warren (1999) suggested, has profound implications for the timing of early language and cognitive development programs.

However, brain-imaging techniques, such as magnetic resonance imaging (MRI) and positron emission tomography (PET), together with chemical probes developed from the field of molecular biology, are providing powerful means for studying the complexities of the human nervous systems. The modern phrenologists are realizing the dreams of the phrenologists of an earlier era (Raichle 1999). While great advances have been made in the study of individual neurons and sensory organs, the full complexities of the human brain have remained out of reach. Other areas where the integration of the biomedical and behavioral sciences occur are in the study of behavioral phenotypes and the interaction of pharmacotherapy and behavioral therapy for people with learning and behavior handicaps.

Prevention

Modern science in this field has essentially addressed the question of how intellectual disability may be prevented. While this is a laudable objective in the eyes of many, it is not without its critics, especially as prevention raises a range of ethical and social issues. Examples of primary prevention¹⁴ include prenatal care, including adequate nutrition, vaccination for conditions such as rubella, newborn intensive care, and public education concerning the dangers of alcohol during pregnancy, together with education for responsible parenthood. Prevention of accidents leading to head injury and general trauma in childhood would also reduce the incidence of intellectual disability, especially in developing countries where the prevalence of intellectual and other developmental disabilities is the greatest. Teratogens, especially arising as a result of environmental degradation, also are an increasing cause of congenital defects (Guthrie 1986).

Advances in the study of genetics have resulted in both primary and secondary forms of prevention. The discovery of the Fragile X (fra (x)) syndrome represents one of the major advances in the understanding of inherited causes of intellectual disability. Work in the 1970s established that this X-linked syndrome is the most common form of hereditary intellectual disability. With the advent of methods for detecting fra (x) in blood and amniotic fluid cells, population screening and prenatal diagnosis of the syndrome have become common practice. With techniques to detect carriers of X-linked intellectual disability, genetic counseling of potential parents is now an accepted practice. Detection of fetuses with chromosomal aberrations presents parents with the decision of whether to terminate or continue the pregnancy.

For some time, there has been vigorous debate surrounding the bioethical issues that relate to the prevention of intellectual disability (Campbell 1999; Harper and Clarke 1997; International League of Societies for Persons with Mental Handicap 1994; Kuhse and Singer 1985; Meininger 1999; Roeher Institute 1999). For instance, the controversial Australian ethicists Kuhse and Singer (1985) have proposed the following in *Should the Baby Live*:

Decisions about severely handicapped infants should not be based on the idea that all human life is of equal value, nor on any other version of the principle of the sanctity of human life. . . . There is, therefore, no obligation to do everything possible to keep [them] alive in all circumstances. Instead, decisions to keep them alive—or not to do so—should take account of interests of the infant, the family, the “next child” and the community as a whole. (P. 172)

In discussing who has the authority to make this decision, Kuhse and Singer (1985) emphasized the role of the state, especially the economic costs to the state providing lifelong support for disabled infants, much in the same way health economists use the cost utility analysis concept of quality of adjusted life years (QUALYs) as a metric to decide cost-effective ways of using the health dollar (Parmenter 1996). They also argued that if parents decide that they do not wish to rear a disabled child, “there is no point in keeping handicapped children alive if, despite

their potential for a worthwhile life, they end up languishing miserably in totally inadequate institutions” (Kuhse and Singer 1985:190).

This position surely begs the question of the inevitability of institutional living being the only option, and, if it is, could not something be done about the conditions that exist in them? Kuhse and Singer (1985) would argue that they are taking a rationalist, realistic approach because in many countries, the state is either unwilling or unable to provide adequate options to institutional living for this population. The alternatives of foster care and adoption are also proving to be difficult options in contemporary society. Another disincentive for parents having to make choices is the inadequacy of support that the state may be willing or able to provide. Reinders (2000) has pointed out that the ethical debate on genetics has evolved almost totally within the medical paradigm, where the lives of people affected by genetic disorders always appear in a negative light. Within this paradigm, impairments or defects inevitably lead to a life of “suffering.”

The profound effects that the Human Genome Project will generally have on the future of medicine and its relevance to a range of causes of intellectual disability, in particular, place bioethical issues as one of the most important challenges this field will face in the twenty-first century. A full analysis of these issues is beyond the scope of the present discussion. Nevertheless, two points are worthy of note. First, in 1994, the International League of Societies for Persons with a Mental Handicap (now Inclusion International) published *Just Technology? From Principles to Practice in Bioethical Issues*, in which it was proposed that genetic research and its applications should be evaluated in terms of the following four principles:

- The principle of justice
- The principle of nondiscrimination
- The principle of diversity
- The principle of autonomy and informed decision making

These principles have informed Inclusion International’s contribution to the United Nations Educational, Scientific, and Cultural Organization’s (UNESCO’s) *Declaration on the Human Genome and Human Rights*, which was finalized in 1997. The essential element of the *Declaration* resides in the balance it strikes between safeguarding respect for human rights and fundamental freedoms and the need to ensure freedom of research.

Second, the scientists involved in the Human Genome Project are aware of a number of potential dangers inherent in their new discoveries, one example being that a functional variation in a human gene is patentable. Francis Collins, director of the USA National Human Genome Research Institute, has warned that it is imperative that the public project be completed quickly, before the private sector assembles and patents databases for the common functional variants of the human genome (Collins 1999). Raichle (1999) sounded a similar warning about the maps of human cortical function.

Advances in Technology

For those with severe intellectual impairments and high-support needs, advances in technology have made significant contributions to their mobility and their ability to communicate. Technology has facilitated communicative interactions at both school and community levels and has been instrumental in their successful inclusion into regular classes, further education, and employment (Glennen and DeCoste 1997; Hunt-Berg, Rankin, and Benkelman 1994). Instructional technology, based on the principles of applied behavior analysis, transformed the quality of special education and vocational training programs that supported the full-inclusion philosophies that emerged in the latter half of the twentieth century (Bellamy et al. 1988; Snell 1987). Advances in the application of nonaversive alternatives to dealing with problem behaviors have led to more humane and enlightened approaches to helping the small yet significant numbers of people with severe challenging behaviors (Meyer and Evans 1989).

Early Intervention

One of the most significant educational and technological advances that united families and professionals in the quest for a better lifestyle for people with intellectual disabilities was the development of early intervention programs. These programs, many of which commenced soon after the birth of the disabled child, offered an alternative to institutional care. They provided support and encouragement to parents whose preference was to keep their child within the family home. This support not only facilitated the child achieving much higher levels of functioning and participation, but it also provided a strong psychological foundation for the family to integrate the child into the normal activities of family and community life (Guralnick 1997; Turnbull and Turnbull 1986). While the positive results of early intervention programs have received strong support in the research literature, Clarke and Clarke (2000) have recently warned that “theories ascribing overwhelming, disproportionate and predetermined importances to the early years are clearly erroneous” (p. 105). They have argued that there is little support for the view that early childhood experiences are the most critical for the later development of children with an intellectual disability. For the effects of early intervention programs to be maintained, it is essential that effective educational strategies are also continued.

Changes in Nomenclature

There have been several changes in the way people with an intellectual disability have been named and categorized. Terms formerly used, such as *idiot*, *imbecile*, *feeble-minded*, *mentally subnormal*, *moron*, and *retard*, are now seen as highly pejorative and stigmatizing. Likewise, organizations have responded to community pressure to use more acceptable language. Examples are the American Association on Mental Retardation (formerly “Mental Deficiency”) and the International Association for the Scientific Study of Intellectual Disabilities (also formerly “Mental Deficiency”). Presently, there are committees in the United States examining replacements for the term *mental retardation*. A theory of names suggests that while names are only conventions, they are also important instruments in the construction of social reality (Stockholder 1994).

Summary of Scientific Endeavors

As indicated above, this commentary has not attempted to analyze the vast array of modern scientific endeavors across the various disciplines that contribute to the study of intellectual disabilities. What is of major significance is that as paradigms of disability have changed, so have new scientific paradigms emerged. An examination of the contents of the growing number of scholarly journals and handbooks on intellectual disability research published in the past quarter century reveals a growth in multiparadigmatic thinking and a less rigid way of conceptualizing the nature of reality.

There are promising signs of an integration of basic biological and behavioral research and evidence of a greater respect for, and understanding of, the role alternative paradigms play on the part of those engaged in basic research. However, the challenge for the scientific research community as we move further into the millennium is for a greater collaboration between researchers, policy planners, and the people most deeply affected—the persons with intellectual disability, their families, and caregivers. Successive international congresses of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) have repeatedly drawn attention to the slowness with which the service field applies the research findings into practice (Parmenter 1999b). In the field of intellectual disability, many interventions currently in use are of uncertain value and have never been adequately tested. One example of this is the use of facilitated communication (Calculator 1992). With the processes of deinstitutionalization, there has been a concomitant deprofessionalization of the field. Undoubtedly, the challenges of helping a person with intellectual disability live satisfactorily in the community are greater than those required for those who were placed in an institutional environment. However, many contemporary service systems with limited budgets are forced to employ relatively untrained per-

sonnel. This is not to suggest that we return to an era of professional dominance, isolation, and a disparity in power relationships between the professionals, people with disabilities, their families, and their caregivers. One of the basic skills the service sector lacks, in many cases, is an ability to work collaboratively across disciplines and with the consumers of the service.

Self-Advocacy by People with Disabilities

The worldwide growth of self-advocacy groups, albeit currently restricted to a number of Western industrialized countries, is a further and potentially vital force in intellectually disabled people achieving equal citizenship with their nondisabled peers (Dybwad 1996). The birth of the self-advocacy movement can be traced to a convention of people with disabilities held in Vancouver, Canada, in the early 1970s. A group known as People First was formally inaugurated in Oregon in the United States in 1973 by former residents of a state institution called Fairview Training Center.

Annual meetings of this group were held throughout the 1970s and 1980s, and the movement rapidly spread across the United States and provinces in Canada. As the movement extended to other countries, such as the United Kingdom, Scandinavia, and Australia, an international conference was held in the United States in Tacoma, Washington, followed by conferences in London, Toronto, and Anchorage, Alaska. In 1998, a self-advocacy conference was held in Lebanon, sponsored by the Committee for Arab Affairs of Inclusion International. The right of people with an intellectual disability to have a voice in how they would like to live their lives is becoming increasingly recognized. They are asserting their need to be consulted on a variety of policy and service issues, including involvement in the research agenda.

Activities in Developing Countries

While this chapter has essentially addressed issues within the context of Western industrialized countries, there are striking parallels in the emergence of attitudes, services, and policies in countries that are embracing the market economy. A major focus in assisting these countries to provide a more contemporary approach, based on a human rights perspective, is the work of Inclusion International. This organization is actively involved in supporting its member associations in Africa, South America, Eastern Europe, the Middle East, the India subcontinent, and parts of Asia. In many countries, poverty, poor public health provisions, population explosion, wars, and meager educational services exacerbate the conditions of life for persons with a disability. In most cases, raising the living standards of the total population is a prerequisite for improving the position of people with a disability. There is an urgent need for epidemiological data on the prevalence of intellectual disability in these countries to enable effective planning on a global scale to be accomplished. There are indications that the World Health Organization may sponsor this much-needed research.

Limitations of the Rights Discourse

Paralleling the development of the normalization principle in its variety of forms was the emergence, especially in the Western world, of policies based on the rights of individuals. This may be traced to the French initiative in 1789 in its proclamation of the *Declaration of the Rights of Man and the Citizen*. In 1964, Harvey Stevens, in his presidential address to the First Congress of International Association for the Scientific Study of Mental Deficiency (held in Montpellier, France), placed prime importance on the inalienable rights of the individual who is mentally deficient to the same dignity as fellow human beings. In 1971, the General Assembly of the United Nations (1971) issued the *Declaration of General and Specific Rights of the Men-*

tally Retarded. This provided a moral justification for legislation that was enacted by governments of several Western countries promising opportunities for people with intellectual disabilities to be a part of normal society. In 1975, the *Declaration on the Rights of Disabled People* (United Nations 1975) was proclaimed, followed by the proclamation of the decade 1983-1992 as the “Decade of Disabled Persons.” The most recent United Nations initiative in supporting the rights of disabled people was the adoption in 1993 of the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations 1993). In the preamble to the rules, a number of United Nations resolutions are cited as constituting their political and moral foundations.

In the eyes of the major international nongovernment advocacy organizations, the realization of rights of people with disabilities is the cardinal objective to be achieved. One cannot deny the rights of disabled people to have equal opportunities to access education, employment, the physical environment, and information and communication. There is also no denying the fact that special legislation enacted in most Western countries has underpinned the provision of a wide range of supports that has enabled the fuller participation of disabled people into regular community life. However, it is suggested that rights legislation is a necessary but not sufficient condition for people with intellectual disabilities enjoying the acceptance of the community.

Reinders (1999) has argued that the moral language of rights is neither sufficient nor necessary to ground moral responsibility for disabled people. He suggested that “to claim equal rights for the disabled makes sense only on the basis of commitments that draw on other moral sources than the sources that are intrinsic to the morality of rights” (p. 2). In the case of people with intellectual disability, Reinder’s essential argument is that the contemporary rights discourse is deficient in accounting for the moral features of caring practices—practices that are committed to the well-being of people who are dependent on the support of others. His concluding comments are quite apposite:

Without people who have sufficient moral character to care, rights can do little to sustain the mentally disabled and their families. People can be forced to comply, but they cannot be forced to care. (Reinders 1999:23)

Nirje (1985) also noted,

Laws and legislative work cannot provide total answers to problem solving and proper actions with regards to realization of human rights. These can only come into existence in the full cultural and human context. Such problems are not only practical, but also ethical. (P. 65)

As a universal approach, the rights movement runs into difficulties in cultures that do not have a social system that has a strong commitment to individualism, a phenomenon that is largely Western in origin. There are cultures that would emphasize the notion of a person’s obligations to the community or tribe more strongly than the reverse. It may be more profitable to envisage a society where the principle of mutual obligation transcends the principle of individual rights.

In the latter half of the twentieth century, there were remarkable forces for change in the way society viewed and supported people with intellectual disability. The normalization principle was a major catalyst for the deinstitutionalization movement that saw thousands of people in a number of Western countries move into community living and working programs. It is important to recognize the force of the word *program*, for in many cases professionals still exerted control over the lives of these people. Spectacular developments in science have also played an important role in the emancipation of this population, but along with these developments, there are critical moral and ethical issues to be resolved. People with intellectual disabilities also commenced to speak for themselves, discovering a sense of empowerment that challenged conventional attitudes and practices, including the attribution of impairment and disability that

had historically set them apart from the rest of society. The plight of people with intellectual disabilities in developing countries is becoming recognized. Much is yet to be achieved in relieving the life circumstances of people for whom the disability is an additional challenge. It is a moot point, however, whether reliance on a human rights approach will effect the greatest change in the lives of these people. The final section of this chapter will explore an approach that may see their transformation from the role of “otherness” to the achievement of the role of “citizenship” within the human family.

THE FUTURE

Throughout history, there has been a pervasive rejection of the full citizenship of people with intellectual disability, resulting in a variety of physical and psychological segregationist practices that culminated in their widespread institutionalization in the twentieth century. Movements such as normalization and human rights emerged as emancipatory forces in the last third of the twentieth century, but, as argued above, these catalysts for change are basically deficient in achieving the moral goal of full citizenship for this population. The future holds both threats and opportunities for the realization of full acceptance of persons with intellectual disability into a society that respects their “humanness” rather than their “otherness.” We must be cautious, too, in not allowing the “reformer’s zeal” to blind us from realities and to limit our thinking in the time warp of the deinstitutionalization era.

One of the threats at the research level is that many of the reform-oriented studies, especially in the area of community integration, are designed to answer questions posed by administrators and politicians—questions usually directed to whether reform programs are working. Insufficient interest is devoted to asking why situations are the way they are or how they can be understood from different perspectives; nor are current ideologies exposed to sufficient critical analysis.

In a sense, we are caught up in trying to solve yesterday’s problems while asking questions within the narrow confines of disability research. For instance, in studying the processes and outcomes of community integration, we have not addressed the situation of people with an intellectual disability in relation to the wider society in which they live. Also, many of the issues addressed that relate to prejudice and discrimination are indeed a part of ordinary psychosocial reality and of everyday life for all people.

The Dominance of Market Ideology and Globalization of the World Economies

Undoubtedly, the economic policies of the major industrialized nations in recent years have had an impact on the provision of services for disadvantaged groups. The redistribution of income and wealth both within and between countries has resulted in a growing gap between the rich and the poor. The neoclassical economic rationalist policies, driven in part by the globalized economy, is predicated on the principle of “utility maximization,” with individuals using their resources to achieve the highest level of satisfaction possible. The essential element is that people must be free to choose how they use their resources—in essence, economic reform means reducing interference by governments. In this process, strong countries can exploit the weak, while wealthy companies increase their wealth by shopping around the world for the cheapest labor. The materialization mantra is sapping the lifeblood of those elements that build social cohesion and a sense of mutual obligation toward one’s fellow citizens, especially those who are marginalized and relatively powerless.

Schalock (1999) has argued that human services organizations are being increasingly challenged to provide quality services within the context of two powerful, potentially conflicting

forces: person-centered values and economic-based restructured services. To justify expenditures that are measured objectively, one must demonstrate consumer outcomes. Rather than being collaboratively developed, value systems are imposed by authoritarian administrations. In much of the administratively dominated delivery systems, we are still witnessing the phenomenon Burton Blatt (1981) so eloquently exposed in his essay on the “bureaucratization of values,” in which terms become mere shibboleths, devoid of their original meanings. Human services are now being operated as business replete with a panoply of “business-speak” managerialistic jargon that tends to create a veneer of efficiency but is often devoid of the warmth of sound human relationships. This is not to deny that scarce resources must be applied efficiently to achieve quality outcomes. However, who is to determine the nature of the appropriate outcomes and the method of measurement? We have reached, in many ways, the “tyranny of quality” predicted by Goode (1991).

In his book, *Voltaire's Bastards*, John Ralston Saul (1992) has argued that Western civilization is without belief for the first time since the decline of the Roman Empire.¹⁵ Have we lost spirit and faith? Have we become more self-centered and self-indulgent? Have the richer and deeper meanings of life been leached out by the materialistic imperatives of the free market? While it may be inappropriate to look back romantically to the optimism and sense of excitement so evident in the 1960s and 1970s with the rapid growth of social policy initiatives in that period, one cannot help comparing that period with the barren social policy desert of the 1990s. There are encouraging signs, however, that a postmaterialist movement is emerging, as a reaction to the economic rationalist-driven policies of the 1980s and 1990s. People from both the industrialized and developing countries are challenging the current economic policies of governments, witnessed by the protests mounted against the World Trade Organization meeting in Seattle in 1999. Significant proportions of society are feeling alienated and isolated from the decision-making processes of governments. There is also a widespread belief that government policies are increasingly being driven by mega-transnational companies with little or no allegiance to national identities.

Environmental Degradation

In recent decades, the assault on the world's ecosystems has had and continues to have profound negative effects on the health of the world's population. The rapid growth in the production of new chemicals has increased the risk for birth defects. It is estimated that there are approximately 5 million chemicals to which our population has significant exposure. Of these, approximately 1,600 have been tested in animals for teratogenicity. About one-half of these agents have been shown to produce some form of teratogenicity (Shephard 1986). Occupational and environmental exposures to toxic solutions continue to contribute to birth defects worldwide. Lack of availability and, in some cases, lack of commitment to immunization programs such as those for rubella continue to be a major problem in the area of primary prevention. Rowitz's (1992) prediction that the human immunodeficiency virus (HIV) will become the most common infectious cause of developmental disability in the 1990s can be extended into the current century, given that the spread of this virus continues apace in large parts of Africa and Asia. Lead exposure and iron deficiency also continue to be significant causes of birth defects in both developed and developing countries. Effective nuclear waste disposal and the minimization of the risks of nuclear accidents will continue to be challenges.

Individualism

The rhetorical forces driving the free-market economy present a tantalizing and seductive similarity in their goals and processes to many of the contemporary goals for people with a dis-

ability, their caregivers, and their families. The concepts of freedom of choice, more control over one's life, release from government regulation, self-determination, and empowerment all appear to sit comfortably in both areas. The emphasis on individualism, however, presents quite a threat to a vulnerable population, such as those with intellectual disabilities. In our goal to encourage their independence, we have overlooked the essential fact that the vast majority of this population will, in many aspects of their daily lives, remain dependent on supports. Edwards (1997) has argued that the normative component of individualism compromises the integrity of intellectually disabled individuals and contributes further to their being ascribed a lower moral status than other humans. The individualistic view of the self militates against people with disabilities as dependence is viewed negatively. For example, Reinders (1999) pointed out that dependency for people with intellectual disability is the *conditio sine quo non* for their physical, mental, and spiritual well-being. The challenge, then, is for us to create environments where the interdependence of individuals is a central feature and where individuals perceive their identity and conceptualization of self in the context of a mutually dependent society.

Development of an Ethical Community

Where do the people with an intellectual disability stand in society as we move further into the new millennium? Is their position much changed from that of the previous two centuries? Have they been emancipated from the phenomenon of "otherness"? As they were before the institutional period, they are now more likely to physically be a part of society, no longer banished and segregated for their own protection and that of society. We have recognized for some time that the greatest post-deinstitutional period challenge was to help people with intellectual disability become part of a community rather than being merely physically located in it. We must also recognize that significant proportions of people with intellectual disability resided with their parents and were not placed in institutions. Many families kept their intellectually disabled sons and daughters in relative isolation from the community, fearful of negative attitudes and discrimination by neighbors and from a sense of shame because their children were perceived as less than perfectly normal human beings. On the other hand, there are families for whom the presence of a member with a disability has been an enriching experience.

How can we articulate a meaningful vision of community and social reality for this group? Paul Dokecki (1992) has argued that despite the significant movement away from dehumanizing paternalistic approaches to a greater emphasis on individual civil rights and personal autonomy, there remains a challenge for us to develop an ethical framework that will be sufficient to confront the ethical issues that will arise in the future for this population. The pervasive cult of perfectionism is still evident in present-day society nurtured by competitive individualism. We have, in many respects, maintained the power relationships so evident in the medical model of support by a power sharing with other professional groups. In this context, ethical decisions are made in a context in which professionals, deemed to be experts, make decisions. Radford (1994) has indicted the university through its authority of "science" for the rise of professionalism.

How can we foster an ethical community, as suggested by Dokecki (1992), in which the primary support roles are taken by family, friends, and extended support networks rather than by professionals? H. Rutherford Turnbull (1998) asserted that each member of a community must recognize that all are vulnerable in some aspects of our lives. As a first step, therefore, the ethical community must recognize a mutuality of need and a reciprocity of vulnerability. The ethical community would also recognize that all persons are fundamentally equal as human beings, and all persons are dependent on others in a metaphysically deep way (Edwards 1997). Dokecki's argument for the need of a concept such as "the ethical community" is strengthened by his reference to the work of Spiegelberg (1944, 1975) and Zaner (1988). Dokecki noted Spiegelberg's argument as follows:

A basic feature of being human, a feature that constitutes the basis of ethics, is that we are all subject to undeserved discriminations that produce inequalities at birth. An undeserved discrimination is an unequal lot in life, either privilege or handicap, which we inherit through no fault or desert of our own, in effect, through moral chance. (P. 44)

Zaner (1988) made a similar observation and has asserted that “fellowship then, not autonomy, is basic in human life” (pp. 300-1). The movement toward supporting families and focusing policy research on the family’s role in supporting their child with an intellectual disability is a promising sign that the development of the conception of an ethical community is not too idealistic to be seen as ever achievable (Dunst, Trivette, and Deal 1988; Knox et al 2000).

As we move from the era classified as modernism, epitomized by the penetration of market forces into every aspect of life and into a society characterized as “postmodern,”¹⁶ we need to recognize, as Toulmin (1990) has suggested, that the way ahead relies less on power and force and more on moral influence. Moral influence, it is suggested, rests in part on the strengthening of human relationships that produce a social rather than a physical capital. James Coleman (1988) has suggested that “social capital . . . comes about through changes in the relations among people that facilitate action” (p. 100). The development of social capital may prove to be an antidote to the social policy agenda of most nations that are contributing in large measure to social fragmentation and the growing sense of alienation on the part of marginalized groups. The social and economic changes in the 1970s and 1980s have effectively challenged the legitimacy of the welfare state model in which the top-down approach by governments ensured safety net provisions, especially in industrialized countries.

Mark Latham (1998), in *Civilising Global Capital*, has drawn on Amartya Sen’s (1992) concept of “social capability” that recognizes that personal well-being relies on more than the availability of material and social goods, for citizens must have the capacity to use these resources effectively. Social capability relies, suggested Latham, “on sound social relations: the recognition, mutual trust and respect between people that fosters a stronger sense of social participation and connectedness” (p. xxxix). In the context of support for persons with an intellectual disability and for other marginalized groups, the message for the millennium is clear. Although the latter half of the twentieth century saw tremendous advances in the physical emancipation of the intellectually disabled, we have some way to go before we see a more caring, mutually supportive, and ethical community where the aim is to promote the interrelatedness of community and human development values.

CONCLUSION

This chapter has addressed, from a historical perspective, the place in society of people with intellectual disability, from the prescientific era to present day. The key feature of the past 2,000 years has been society’s general banishment of the intellectually disabled to a status less than full humanness. The presence of an intact intellect has traditionally been seen as the *sine qua non* for the recognition of full citizenship.

In tracing the range of factors that have influenced the way we view people with intellectual disability and the way support services are provided, it is interesting to note the paradox that has recently arisen between the movements of physical integration and administrative segregation. As Simpson (1998) noted, “The possibility of conceptualizing the ‘intellectually disabled’ as comprising a discrete group, does not arise from the essence of such ‘disability’ nor the scientific study therefore, but from the precise discursive and technological conditions which sustain it” (p. 5).

Therefore, in addressing the future directions that ought to be taken in this field, it was argued that the concept of the development of an ethical community could provide a framework in which to meet the broader societal challenges that face the community generally. Latham (1998), in addressing issues completely outside the realm of disability, nevertheless has an im-

portant message in the context of these broader societal challenges for people with an intellectual disability as we move into the new millennium:

The greatest challenge . . . lies outside the realm of the State—that is, in rebuilding the foundations of mutual trust, recognition and support across the work of the non-state public sector. . . . In addressing the foundations of public mutuality, social democracy needs to give closer consideration to relationships between citizens. . . . During an era of social diversity and uncertainty, the need for new forms of commonality, in the interests shared across society, has become particularly acute. (Pp. xl-xli)

Can we meet this challenge and, in so doing, cultivate our humanity so that it includes all people?

NOTES

1. Throughout this chapter, the contemporary term *intellectual disability* will be used in preference to earlier terminology, such as *mental deficiency*, *mental retardation*, and *mental subnormality*. It also embraces the term *learning disability*, commonly used in the United Kingdom and Ireland.

2. Nussbaum (1997:187) noted that Nobel Prize winner economist/philosopher Amartya Sen estimated that the numbers of females in the world who are likely to have died because of their gender—whether through sex selection infanticide or through receiving nutrition and health care unequal to that given to males—to be in the order of 100 million.

3. This term was also used by Rynders (1987:2-3), who cited the allegations of “otherness” of persons with Down syndrome, such as Crookshank, who asserted in 1924 that Down syndrome represented a “regression to a non-human species (i.e., to an orangutan),” and Boyd and Fletcher in 1968, who asserted that someone with a disability such as Down syndrome is not even a person.

4. *Idiot* is a word derived from Greek, meaning a “private person.” It was historically used to denote an ignorant, uneducated person. Clarke and Clarke (1974) noted that it was a term used for a considerable period of time to refer to anyone who was mentally subnormal.

5. Renowned Swedish biologist Linnaeus, in his *Systema Naturae* (1735), classified the “wild man” or “the wild child” as *Homo Ferus*.

6. Tredgold (1937), however, recognized the need to study the psychopathology of those with “amentia.”

7. Mongolism, first described by Langdon Down in 1866, was a label based on the physical appearance of a particular clinical type, which together with the notion of “atavistic regression” implied that the Mongolian race was inferior (Clarke and Clarke 1974:13).

8. Self-determination is one of the ratings of the Program Analysis of Service Systems (Wolfensberger and Glenn 1975).

9. In a closing message to the 1989 Convocation of World Academics, which resulted in the publication of *Scientific Issues of the Next Century*, Claudio Martelli, deputy prime minister of the Italian government, observed that Professor Haldane, in his forecast of developments in his field of biochemistry from 1925 up until the 1990s, developed “a literary essay midway between epistemology, futurology, and experimental science” (Maltoni and Selikoff 1990:244). Haldane’s evocative title, *Daedalus, or Science in the Future*, might presage the need for a similar opus that encompasses the field of intellectual disability.

10. Swiss physician Coindet (1774-1848), in a lecture to the Swiss Society of Natural Sciences, recommended iodine preparations for the treatment of goiter in 1820. In 1846, Italians Prévost and Maffoni were the first to put forward the theory that goiter was due to iodine deficiency (Hetzel 1989).

11. Now known as the International Association for the Scientific Study of Intellectual Disabilities (IASSID).

12. This is reminiscent of the Paris Academy of Science proclamation that Seguin had solved the problem of “idiot education.” Harvey Stevens, the first president of IASSMD, commented that the new definition of mental retardation suggests that it is a reversible condition (Stevens 1964:1).

13. For a detailed critique of Wolfensberger’s approach to normalization, see Reinders (1997) and Simpson (1998).

14. For a comprehensive discussion of primary prevention, see the World Health Organization (1998).

15. Taylor (1989) argued that nineteenth- and twentieth-century cultures became confused about the meaning of life once religious certainties were displaced. The utilitarianism of Enlightenment thinking and the individual perspective of Romanticism could be seen as the harbingers for this shift in values.

16. Radford (1994) pointed out that some would regard postmodernity as a chimera, for we may only have moved into a more intensified version of modernity or “hypermodernity.”

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