M.A.

2000

This is to certify that the

thesis entitled

PEDIATRIC MENTAL ILLNESS: CORPORATIZED
MEDICINE AND VULNERABLE POPULATIONS

presented by

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has been accepted towards fulfillment
of the requirements for

M.A. degree in Health and Humanities

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Date 8/23/00

O-7639

MSU is an Affirmative Action/Equal Opportunity Institution

PEDIATRIC MENTAL ILLNESS: CORPORATIZED MEDICINE AND VULNERABLE POPULATIONS

By

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF ARTS

Department of Interdisciplinary Program in Health and Humanities

2000

ABSTRACT

PEDIATRIC MENTAL ILLNESS: CORPORATIZED MEDICINE AND VULNERABLE POPULATIONS

By

Ellen Paige Conser

Perspectives from bioethics, history of medicine, and health economics are applied to demonstrate the vulnerable status of mentally disturbed children. Moral philosophy and cultural history lay a foundation for a rights-based approach and social duty toward vulnerable populations. In the current context of scarce resources, corporatized healthcare, and emotionally-laden political discourse about just medical resource allocation, analysis of intergenerational obligations is pertinent. Principles from health economics are applied to show financial incentives' power within managed care, the consequences of which adversely impact not only individual child access to appropriate, quality care, but decisionmaking about whether to implement prevention programs potentially benefiting thousands of enrollees. The latter is particularly unfortunate, in light of promising findings about mental illness prevention programs' efficacy. Reform recommendations include strengthened roles for the federal government and schools, increased support for prevention and early intervention, adoption of a biopsychosocial perspective, and societal acceptance of allocative justice.

ACKNOWLEDGMENTS

My deepest appreciation extends to the following individuals, without whose unflagging assistance and encouragement this goal would never have been achieved: Dr. Mike Woolson, Dr. Gerald Osborn, Dr. Kurt Ackerman, and Dr. John Goddeeris.

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LIST OF ABBREVIATIONS

AFDC: Aid to Families with Dependent Children. Federal welfare legislation passed in 1935 (Woolston, 1991, p. 890).

CASSP: Child and Adolescent Service System Program. "[A] comprehensive approach to coordinating and delivering a far-reaching array of services from multiple agencies" (Satcher, 1999, p. 188). Widely-acclaimed, Congressionally-funded (1984) treatment model advocating an interagency, coordinated, individualized, culturally competent continuum of care, in which families are to be involved in treatment planning, and which favors less-restrictive treatment environments over inpatient placements where appropriate (see Burns & Hoagwood, 1998, p. 688; Knitzer, 1988, p. 64; Pumariega, 1997, p. 68;).

CBA: cost-benefit analysis

CEA: cost-effectiveness analysis

CMHCs: community mental health centers. President John F. Kennedy signed the CMHC Act in 1963 (see Christ, 1991, for more details).

EPSDT: Early Periodic Screening, Diagnosis, and Treatment Program. Federal legislation passed in 1967 mandating screening for a wide range of physical and mental illnesses.

FFS: fee-for-service

GNP: Gross National Product

MCOs: managed care organizations

MH/SA: mental health and/or substance abuse

MMHCs: managed mental health companies

PPOs: preferred provider organizations

QALYs: Quality-adjusted life years

SBHCs: school-based health centers

SED: serious emotional disturbance. In the literature, ‘severe’ alternates with ‘serious;’ ‘disorder,’ with ‘disturbance.’ Other variations abound, e.g., “behaviorally disordered, behaviorally handicapped” (Wassef, et al., 1998, p. 765). Psychiatric dictionaries and the DSM-IV fail to offer an ‘official’ interpretation of this acronym, although computerized health library database searching (e.g., PSYCINFO) yields best results with ‘serious emotional disturbance.’ Some child psychiatry texts describe SED as ‘serious emotional disturbance’ (e.g., see Wassef, et al., 1998, p. 764; Silver, 1988, p. 40).

Introduction[1]

My interest in mental illness and the U.S. mental health care system preceded my entrance into MSU's Interdisciplinary Program in Health & Humanities (IPHH). Coursework in IPHH lent conceptual structure to this passionate interest. Particularly intriguing aspects of mental illness include its lingering conceptual ambiguity, stigma, and power to wreak immense suffering. Mental illness lends itself well to analysis in the interdisciplinary context because of its multisector etiology, treatment, and social impact. Pediatric mental illness lends itself particularly well for these reasons, plus the fact that the most exciting emergent research findings about treatment, prevention, and early intervention indicate that providing a caring environment, not just medical care, is key. Other influences on my interest in mental health care include employment on a psychology research project. The current pertinence of the topics of health promotion for children, and intergenerational justice in health care resource allocation, was brought home in April, 2000, when I had the opportunity to attend a lecture by Joycelyn Elders, M.D. (Elders, 2000). Among her points were that 1) schools are the logical place for promoting children's health and preventing illness, and 2) there is a marked discrepancy between the number of children enrolled in Medicaid, and the percentage of Medicaid funds spent on children (versus the elderly). I had already written about these issues in the thesis prior to attending her lecture, so was excited to hear them reinforced by our ex-Surgeon General.

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[1] I particularly wish to thank Dr. Gerald Osborn for the advice and ideas he provided for this chapter, during a conversation January 20, 2000).

One contention in this thesis is that children with mental illnesses, living in the current era of uncertain access to quality medical care, represent a vulnerable group worthy of societal protection. The social tradition of heightened concern towards our most weak and vulnerable citizens has ancient roots. In the New Testament, Jesus Christ said, "[W]henever you refused to help one of these least important ones, you refused to help me" (Anonymous, 1966, p. 66). Political and religious leaders have drawn from this Biblical passage in making the following comments about society's responsibility to the weakest and most vulnerable citizens. Deriding a bill proposing welfare cuts as potentially harmful to children, Daniel Patrick Moynihan said, "the moral measure of our society is how we treat 'the least among us'"" (Moynihan, 1996, p. C7). The National Conference of Catholic Bishops (NCCB) joined Moynihan in urging the President to veto the bill, and reaffirmed this position in a message to Congress, stating, "We believe the moral measure of our society is how we care for 'the least of these.' We believe the poor and vulnerable have a priority claim on our consciences and our common resources. Decisions about social security and wages, budget priorities and surpluses, global economic and foreign policy ought to put the poor and vulnerable first" (Anonymous, 1999, p. 1). Elsewhere it asserted, "the nation should put poor children and families first. We believe the moral measure of our society is how our weakest members are faring" (Keeler, 1995, p. 1).

We will see in following chapters that the history of mental health care for children has been influenced by political and economic factors, as well as medical/scientific factors. Interestingly, the very definition of serious emotional disturbance (SED) is political and legal in its origins; moreover, the definition continues to defy consensus (Wassef, Morgan, Ramirez, & Collins, 1998, p. 764). Federal definitions were formulated in the 1970s, when legislation was passed to guarantee education for all children; SED was thus conceptualized and categorized as a handicap, potentially hindering learning (Wassef et al., 1998, p. 764). In 1970, the Joint Commission on Mental Health of Children offered a rather vague definition; in 1980, a National Institute for Mental Health (NIMH) task force offered a more detailed definition, focusing on SED's disabling aspects and the need to address individual service needs (Silver, 1988, p. 41). A later (1990s) definition, while still influenced by nonmedical factors, is more explicit than 1970s definitions:

> "...children and youth with the most severe disturbances of behavior and emotion...[C]ore components of SED [include]: persistent problems of behavioral self-control; poor family and peer relationships; and maladaptation in multiple areas of life (e.g., schooling, functional living skills). Practically, characteristics often associated with SED may include emotional instability, difficulty controlling anger, expressed belittlement of self, underachievement, problems of attention and impulsivity, social and emotional immaturity, poor or limited social skills, poor coping and adaptation skills, and irrational and erratic thinking processes. An erratic school history, possibly including repeated placements in multiple residential living centers, may also be associated with SED" (Wassef et al., 1998, p. 764).

One text about pediatric SED offers a more accessible, practical definition:

> "children and youth who have severe illnesses (usually psychoses or conduct disorders), which are of long duration (usually longer than one year), which cause such great disability that further psychological development is severely distorted or retarded, which require treatment by professionals of several disciplines, and which can tear an otherwise adequate family apart" (Looney, 1998, p. 238)

Diagnoses of SEDs made in schools using federal criteria may diverge from diagnoses made utilizing well-regarded diagnostic tools, such as the Diagnostic and c

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Statistical Manual of Mental Disorders (DSM) (Wassef et al., 1998, p. 765). More disturbing, the process through which children are diagnosed varies from state to state, even between school districts. (Wassef et al., 1998, p. 765).This lack of consensus exhibited in the definition of SED has hindered research, assessment of prevalence rates, and collection of other epidemiologic data (Silver, 1988, p. 42; Wassef et al., 1998, p. 765). It also has rendered the plight of this vulnerable group less understandable, and less visible, to Americans generally, a handicap in attracting political and fiscal support.

Nine to thirteen percent of all U.S. children suffer from serious emotional disturbances (Satcher, 1999, p. 179). The urgency of better meeting the needs of children with SED and mental illnesses generally is exemplified by the following finding of the first Surgeon General's Report on Mental Health, that "most children in need of mental health services do not get them...a high proportion [70%] of young people with a diagnosable mental disorder do not receive any mental health services at all" (Satcher, 1999, p. 180).

Mental disorder among children includes "serious deviations from expected cognitive, social, and emotional development," and "symptoms and behaviors [that] cause great distress and may lead to dysfunction of children, their family, and others in their social environment" (Satcher, 1999, p. 123). The U.S. Government provides the following definitions, while acknowledging the subjectivity and historical fluidity associated with defining these concepts.

> "'[M]ental health' and 'mental illness' are not polar opposites but may be thought of as points on a continuum. *Mental health* is a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. Mental health is indispensable to personal well-being, family and interpersonal relationships, and contribution to

> community or society...*Mental illness* is the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning...Alterations in thinking, mood, or behavior contribute to a host of problems-patient distress, impaired functioning, or heightened risk of death, pain, disability, or loss of freedom... '[M]ental health problems' [refer to] signs and symptoms of insufficient intensity or duration to meet the criteria for any mental disorder...[E]arly intervention is needed to address a mental health problem before it becomes a potentially life-threatening disorder" (Satcher, 1999, pp. 4-5; italics the author's).

When we examine mental health care, it is important to understand the concept of 'service sectors.' The phenomena of 'service sectors' is exemplified by the following quote:

> "[P]sychopathology in childhood arises from the complex, multilayered interactions of specific characteristics of the child (including biological, psychological, and genetic factors), his or her environment (including parent, sibling, and family relations, peer and neighborhood factors, school and community factors, and the larger socio-cultural context), and the specific manner in which these factors interact with and shape each other over the course of development" (Satcher, 1999, p. 127).

The very structure of the U.S. mental health care system, its "complex," "multifaceted," and "hybrid" nature, contributes to its problems, especially problems in gaining access to needed services (Satcher, 1999, p. 14). "[T]he U.S. mental health system...[comprises] the public and private sectors, general health and specialty mental health providers, and social services, housing, criminal justice, and educational agencies. These agencies do not always function in a coordinated manner" (Satcher, 1999, p. 14). "As a result, care may become organizationally fragmented, creating barriers to access. The system is also financed from many funding streams, adding to the complexity, given sometimes competing incentives between funding sources" (Satcher, 1999, p. 20).

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Specific to children is the following observation:

> "Children needing services are identified under the auspices of five distinct types of service sectors: schools, juvenile justice, child welfare, general health, and mental health agencies. These agencies are mostly publicly supported, each with different mandates...Many..arose historically for another purpose, only to recognize later that mental disorders cause, contribute to, or are effects of the problem being addressed. In the past, these sectors operated somewhat autonomously, with little ongoing interaction...Federal policies and managed care more recently [have] begun to forge their integration" (Satcher, 1999, p. 184).

Other important concepts include distributive and allocative justice, intergenerational equity, and rationing versus allocation of resources. These complex concepts will be defined and explored further in Chapter 2.

The topic of mental illness among children lends itself well to a Master's thesis project in medical humanities, for a number of reasons. Pediatric mental illness in general, and SED in specific, is characterized by its striking multicontextuality with respect to etiology, clinical presentation, treatment, and societal impact and implications. Today's most respected treatment models require the skills of a range of interdisciplinary providers, serving in a variety of social sectors. This is due to the fact that the complex challenge that is mental illness is borne not just by mental health providers but by schools, jails, social services, and the medical sector. An extensive search of the literature failed to uncover any work applying an interdisciplinary medical humanities analysis to the challenges posed by children with SED. Specific interdisciplinary tools used in this thesis include the history of medicine, health care economics, and philosophy of health care.

Allocative decisions about children's mental health care are currently often based on non-moral and nonmedical considerations, such as power and economic incentives, a

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instead of moral and clinical considerations, such as beneficence and outcome optimization. With respect to power, it is illuminating to examine why child advocacy movements have traditionally been ineffective in rendering major political reform. The answer seems to lie in their differences from traditional civil rights movements, to be described further below. The influence of economic incentives on allocative decisionmaking is examined in Chapter 1.

The next section shows how indicators of socioeconomic status (SES), such as race/ethnicity, family income, parental educational level, and parental marital status, influence (1) incidence and (2) recognition of pediatric mental disorders. These indicators also influence (3) the level of unmet need; (4) access to quality, appropriate care; and (5) the ability to advocate for that care. Emotionally disturbed children's historically-disadvantaged social backgrounds further constrain their already-limited civil rights.

Regarding (1), incidence, Newacheck (1989, p. 875) found that poorer youth, and those from families whose adults had less education, were significantly more likely to be disabled, the leading disabling condition being mental illness. Risk factors for pediatric mental illness include:

> "prenatal damage from exposure to alcohol, illegal drugs, and tobacco; low birth weight; difficult temperament or an inherited predisposition to a mental disorder; external risk factors such as poverty, deprivation, abuse and neglect; unsatisfactory relationships; parental mental health disorder; or exposure to traumatic events [e.g., acts of violence]...Dysfunctional aspects of family life [that can endanger a child's mental health include] severe parental discord, a parent's psychopathology or criminality, overcrowding, or large family size" (Satcher, 1999, pp. 129-130).

With respect to (2), recognition, parents or caregivers who are married and higher-educated are more likely to initiate discussion about children's problems, despite the fact that poor caregivers, and those ranking their own mental health low, are more likely to have a child diagnosed with a psychosocial problem (Horwitz, Leaf, & Leventhal, 1998, p. 370). Socioeconomic status (SES) influences parental helpseeking behavior (e.g., Riley et al., 1993, p. 779). "[R]ace and culture...affect the likelihood of care-seeking behavior" (Kelleher & Starfield, 1990, p. 118).

Black children are "less likely to be recognized as having a psychosocial problem" (Kelleher, et al., 1997, p. 1112). This may be attributable to communication barriers between doctor and parent, or stereotypical assumptions on the part of physicians. "[C]linicians may...view these symptoms as social or community problems. Racial and ethnic differences between clinicians and patients have previously been associated with psychiatric misdiagnoses" (Kelleher, et al., 1997, p. 1113); problems include both over- and under-diagnosis (Pumariega, 1997, p. 70).

Unmet need, (3), is related to

> "indicators of economic disadvantage, such as being on public assistance and not being covered by health insurance; opinions of the parents and children or adolescents that the latter had poor mental health; parental psychopathology; poor school grades and parent-reported access barriers such as...concern that the child would solve the problem unassisted, would refuse to attend mental health services, or would be hospitalized or taken away against the parent's will" (Flisher, et al., 1997, p. 1145).

Even among Medicaid-enrolled children, evidence suggests underuse of services, and clearly indicates unmet treatment need (Anglin, Naylor, & Kaplan, 1996, p. 325).

Regarding (4), access to appropriate, quality care, questions have been raised about the appropriateness of applying managed care approaches to the unique needs of mentally ill children. Specifically, access needs may be insufficiently met in plans designed with less vulnerable populations in mind.

> "[MCOs']...benefits restrictions [are] based on actuarial approaches...[and] selectively exclude poorer populations, who are higher users of services, and augment large pools of relatively healthy, minimally impaired populations from higher socioeconomic backgrounds, who are low users...If applied to child mental health services, the usual benefits-restriction approach in traditional behavioral managed care can potentially deprive poor, underserved, and more impaired children of timely, effective intervention and preventive services" (Pumariega, 1997, p. 68).

Socioeconomically disadvantaged families have less access to daily life resources like transportation (Flisher, et al., 1997, p. 1152). Benefits restriction strategies used by MCOs to control costs include locating services in out-of-the-way areas, thus disproportionately impair access to care for disadvantaged children (Frank, Koyanagi, & McGuire, 1997, p. 117). Deductibles and copayments disproportionately stifle utilization among the disadvantaged, and "prevent needy children from obtaining services" (Horwitz & Stein, 1990, p. 585). Experts say "participation in managed care may be deleterious to our most vulnerable children," because access to preventive and specialty services has decreased (Behrman, 1998), even among children covered by Medicaid. The CASSP principle of culturally-competent care is also at risk, as is the ideal of encouraging disadvantaged parents to become actively involved.

> "[T]here is room for concern about how MCOs will address the unique needs of diverse populations...outcomes for minority groups and low-income patients [in the Medical Outcomes Study] were worse for managed care patients than for FFS patients... It is possible that the additional administrative barriers that must be overcome to obtain specialty services in MCOs add one more set of hurdles for persons who already feel distant or foreign in the medical or mental health setting...[P]articular aspects of MCOs...may be particularly challenging or distasteful to minority families" (Scholle & Kelleher, 1998, pp. 677-8).

Access barriers reported by parents include "..being unsure where to go for help," and barriers related to "economic disadvantage," including being black (Flisher, et al., 1997, pp. 1151-52). Race/ethnicity influences utilization. "Significantly lower rates of services utilization" are documented; there is a "significant relationship between race and...service needs" (Pumariega, 1997, p. 70). "[T]he great majority of [Medicaid-enrolled youths with SEDs] are poor, underserved children of ethnic minority backgrounds" (Pumariega, 1997, p. 67). "[M]inority populations have traditionally been underserved by mental health, health, and human services, in terms of both the overall access to services as well as the cultural competence of the services available" (Pumariega, 1997, p. 67).

Medicaid-enrolled parents face not just financial but social barriers, such as family fragmentation, single parenthood, child-care limitations, and insufficient social support (Williams, Diehr, Drucker, & Richardson, 1979, p. 139). The poor are also less likely to own computers and have access to, or experience using, the Internet, an increasingly powerful health care resource, both for information and social support (Sanger, 1999).

The consequences of insufficient access are cost- and care-shifting to other social service sectors, often unequally impacting various populations for no apparent medical reason. "Culturally diverse children are underrepresented in mental health institutions and overrepresented in child welfare and juvenile justice settings and placements compared with nonminority youth, even when they are equally psychiatrically impaired" (Pumariega, 1997, p. 70). It is outrageous and irrational that, because of such access barriers, some children are more likely to receive care only after committing a crime and being incarcerated (M. Woolson, personal communication, May, 2000).

With respect to (5), being able to effectively advocate for care,

> "Being able to express needs articulately and persistently sometimes can make a critical difference in whether particular services and providers are approved. Unfortunately, parents of children with special needs, especially those with low and moderate incomes, often lack the skills to serve as their children's advocates" (Fox, Wicks, & Newacheck, 1993, p. 552).

Economically disadvantaged populations face a variety of barriers with regard to self-advocacy, for example, toward even-handed applications of policy to health coverage. Barriers include less education, and fewer economic resources to contribute to a cause. What is worrisome is how well disadvantaged populations and others can and should be expected to undertake the role of being "responsible," "proactive," and "informed" (e.g., see Mechanic, 1998, p. 82). Others expect consumers to be "constant[ly] vigilan[t]," "educated," and "active" (e.g., see Scholle & Kelleher, 1998, p. 680), precisely at a time when gaps in economic, educational, health and other indicators of social well-being between well-off and poorer Americans continue to widen.

After a preliminary choice of the thesis topic, initial research led to a number of surprises. One was that the concept of children's rights in the U.S. is a relatively novel concept, compared to other industrialized nations, particularly in Europe. European nations have an established record of respect for children's rights and welfare. A recent example is the furor in Great Britain about the legality of corporal punishment (e.g., spanking) toward children. Great Britain is one of the last nations in Europe to enact this sort of protection. Proposed Health Department legislation there criminalizes certain forms of corporal punishment (e.g., hitting a child on the head; spanking would still be allowed) (Miller, 2000, p. A4). While child advocates "welcomed [the proposal] as an important first step," and encourage any legislation that "is going to improve the human rights of children," some advocates say it "falls short of offering [children] full protection" (Miller, 2000, p. A4).

However, Britain is merely flowing with the European tide: "[s]everal European countries, including Sweden, Norway and Denmark" prohibit corporal punishment in both school and home settings (Miller, 2000, p. A4). Scandinavian countries are extremely child-friendly environments in this regard. In contrast, the US has no equally-explicit legislation about the limits of home discipline (Miller, 2000, p. A4).

Britain and other European countries are also noted for their strong contingent of home nurse visits to both ante- and postpartum mothers, and newborns. "Preventive interventions [including nurse home visits] have been shown to be effective in reducing the impact of risk factors for mental disorders and improving social and emotional development" (Satcher, 1999, pp. 134-136). Specific programs involving home-visiting nurses are discussed in the prevention section of Chapter 1.

Western European nations' child friendliness can be explained by exploring fundamental differences between European and American history and cultural values. European nations' rich history of shared collective experiences includes war, invasions, and serious threats to their governments. In contrast, America has never been invaded by a foreign power or had an unstable government. Shared collective experiences, for example London's Blitz during WWII, can effectively galvanize a community to action. During the Blitz bombings, children were sent out of the city as a protective measure. Bombing is indiscriminate; in affecting rich and poor alike, it can motivate a heterogeneous population to unite to a common cause. These phenomena spawned the prioritization of community exhibited in European nations today, and is reflected in their policies, such as those concerning children's rights. In contrast, America's rugged individualist citizenry, lacking such collective experiences, prioritizes individual autonomy. Unfortunately for the cause of achieving a moral healthcare system, this guarantees a constant tension between individual autonomy and just resource allocation. Western European nations' shared values, along with shared collective experience, combine with ethnic/racial homogeneity to cement a strong prioritization of community. Unfortunately, America's increasing heterogeneity may mean the goal of prioritization of community welfare is moving further out of reach (G. Osborn, personal communication, May, 2000).

The U.S. has received criticism for its treatment of children, exemplified by its failure to ratify the U.N. Convention on the Rights of the Child (UNCRC), unlike most other nations. Rights pertinent to children's health care covered by the Convention include the right to a basic standard of medical care (Article 24; see also Wringe, 1996, p. 20), and the right to education in order to reach one's highest potential (Articles 28-9). As inferred above, insufficiently treated mental illness can hinder learning. Philosopher Laurence Houlgate argues that justice requires society to meet the basic needs of children, saying "[a] need is basic if the harm caused to the person whose need is not met is serious or substantial" (Houlgate, 1980, p. 111). Because untreated or improperly treated emotional disorder contributes to "serious or substantial harm" to children (e.g., a markedly increased risk of lifelong problems, involving nearly all aspects of social and intellectual development and functioning), access to quality mental health care for children with mental illness seems clearly a basic need.

Arguments as to why America should devote resources to poverty and other problems amongst children are morally forceful in justifying or supporting a right to a basic standard of health care, or--more specifically--fairer and increased resource allocation toward quality mental health services for the most severely disturbed children. These arguments include encouraging people to care because children are "intrinsically valuable" (Richart & Bing, 1989b, p. 4). Alternatively, "[m]ore selfishly, the future of poor children can cut two ways: as a burden which drags the rest of the country down, or as a vital, energetic force which will help shape the America of the future" (Richart & Bing, 1989b, p. 4).

Some children's advocates see government as the natural enforcer of children's allocative rights to resources. "The President, Congress, and every federal, state, and local government entity continuously choose which ventures to support. Government is the final arbiter of who gets what resources as well as when and how to distribute these goods and services" (Richart & Bing, 1989b, p. 6). According to this view, parents alone—even 'good' parents—are incapable of raising children to their fullest developmental potential. Philosopher John Dewey said, "[w]hat the best and wisest parent wants for his child, that must the community want for all its children" (Richart & Bing, 1989b, p. 6). Yet still, "in America, parents bear the primary responsibility for meeting the needs of their own children" (Richart & Bing, 1989b, p. 6). Measured effectiveness is another reason to support government intervention. "A wealth of empirical evidence documents that government can 'transform the nation's capacity to improve outcomes for vulnerable children'" (Richart & Bing, 1989b, p. 7).

My own most passionate feelings about this issue are represented by the following quote:

> "[G]overnment is the most important actor in most aspects of life important to Americans. The federal government, for example, has made crucial financial commitments to bail out the City of New York as well as the Chrysler and Lockheed Corporations. State governments often provide important tax incentives to companies that wish to relocate. Just as government intervention in, and support for, the lives of corporations is appropriate, it is equally appropriate in the lives of children. Since bold economic interests enjoy massive government support, the advocate has every right to ask: Why should the so-called social issues be excluded from government assistance?" (Richart & Bing, 1989b, p. 6)

The issue of individual rights in general, and children's rights specifically, is relevant to the thesis topic, particularly when we think about what sort of duty, if any, society has to provide some form of universal health benefit. Children's rights seem to be a special case, different in many ways from human rights in general. Individual and children's rights have historically been conceptualized in widely divergent ways, and the argument laid forth here represents but one. Human rights, in the context of right to health care, also lie squarely in the realm of modern academic discourse about moral dilemmas pertinent to bioethics and medical humanities.

The conceptually opposed notions of (1) children having equal moral status with adults, and (2) children as vulnerable and needing protection, have been somewhat mediated by the best interests principle. However, from a global perspective, it is not clear which culture's conception of 'best interest' should prevail (Freeman, 1997, p. 8). Nor do children themselves typically have a voice in formulating conceptions of best interest (John, 1996, p. 7). In real-world use, the best interests principle falls short of meaning "what's good for the child," instead being interpreted as a way to balance children's versus adults' interests. Often, the latter takes precedence (Houlgate, 1980, p. 107).

Some note a phenomenon of "depoliticisation of children," or, the "mistaken belief that problems related to them are non-controversial and lie outside the political agenda" (John, 1996, p. 9). What is required to alleviate children's plight, therefore, is nothing short of a "political re-awakening" (John, 1996, pp. 9-10).

In this thesis, I will be making certain rights-based assumptions about society's obligations toward the care of mentally ill children. This assumption, of a rights-based approach to the issue at hand, is not without its philosophical criticism and detractors. Such critics include Robert Nozick. Nozick, for example, asserts that there are "only three ways in which the right of access to resources may be gained," 'just acquisition,' 'just transfer,' and 'compensation for previous injustices' (Nozick, Anarchy, State, and Utopia [1974], as quoted in Wringe, 1996, p. 21). By way of another example, Colin Wringe has summed up a traditional philosophical assumption, that "...need, even extreme need, has not been regarded as sufficient to justify a right" (John, 1996, p. 6). My discordance with these scholars relates to my perception that there exist fundamental, irreconcilable differences between rights-based approaches and natural law. A rights-based approach offers a dual benefit: while cohering with the popular assertion that children have intrinsic value, it simultaneously holds positive utilitarian value and appeal.

Commentators on children's right to medical care highlight the moral relevance of children's relative inability to provide for themselves, through work or otherwise (thus ruling out a right to health care resources through Nozick's 'just transfer' pathway; see Wringe, 1996, pp. 21-2). A more promising route toward justifying such access seems to be Nozick's 'compensation for previous injustices;' namely, children's powerlessness and inadequate or unequal historical access to health care resources. It is also particularly interesting, and I believe relevant, to think about and compare the right to health care of various age groups (e.g., young versus old), in the context of finite and scarce resources. Chapter 2 pursues this dilemma, intergenerational equity in medical resource allocation, in greater depth.

Pope John Paul II placed ethical constraints on the use of power in achieving social goals when he said, "...power is responsibility: it is service, not privilege. Its exercise is morally justifiable when it is used for the good of all, when it is sensitive to the needs of the poor and defenseless" (Anonymous, 1999, p. 1). Legal recognition of children's impaired competence has enabled more powerful adults to decide to which resources and rights children are deserving (see Freeman, 1997). This phenomena sets children apart from other minorities, such as women and African-Americans, who have succeeded at changing their social status from one characterized by paternalism and weakness, to one of competence and autonomy (see Freeman, 1997, p. 10).

The work of philosopher Colin Wringe on the topic of children's rights is illuminating. Wringe's argument is essentially as follows. Until recently, it was a given assumption that children could not safely hold rights of freedom, the ability to decide for oneself, because they lacked the capacity for rationality. Wringe believes this notion was consciously amplified as "an excuse for adult over-protectiveness..." (Wringe, 1996, pp. 19-20). But the right to health care is typically categorized as a welfare right, not a right of freedom, and Wringe argues that welfare rights cannot be denied by appealing to children's irrationality or incompetence. Even irrational people suffer from a lack of needed basic resources. Welfare rights are particularly pertinent to children, who are characterized by their powerlessness and inability to provide for themselves. However, any social duty to provide access to medical resources would be a "duty of imperfect obligation," not a "duty of perfect obligation;" it must compete with other social needs, and need not be immediately, preferentially fulfilled. The reason for this is that, traditionally, even heart-wrenching need is not enough to justify a right to resources (see Wringe, 1996).

Relative to other civil rights movements, children's advocates have been historically unable to coalesce into a formal, well-populated reform movement. Rather, child advocacy efforts have largely been characterized by fragmentation, isolation, and piecemeal efforts. The conclusions of child advocates David Richart and Stephen Bing best approximate my own interpretations of the impact of political disenfranchisement on children and attending to their social needs. Richart and Bing note that child advocates are at a political disadvantage, because they cannot assert that everyone is directly affected by the problem (as can, for example, consumer advocates). The daily lives of most middle- and upper-class people are untouched by the plight of disadvantaged children (Richart & Bing, 1989b, p. 28). And the cliché holds that what is out of sight is out of mind. Children lack the benefits, political clout, and exposure of an AARP; nor do they have any broadly-organized political constituency. "Never in the history of American politics has there been a constituency so popular but with so little political clout" (U.S. Sen. Christopher Dodd, in Richart & Bing, 1989a, p. 29). Society has traditionally attempted to address those healthcare issues disproportionately affecting politically-powered constituencies (G. Osborn, personal communication, May, 2000).

The 2000 stir over seniors' spending for prescription pharmaceuticals is a recent example.

Richart and Bing identify seven critical differences between traditional civil rights movements and the children's rights 'movement,' differences that tend to cripple efforts to formalize and politically empower the latter.

1) The capacity to invest oneself in a cause is motivated by highly personal feelings of "alienation, uneasiness, or injustice," feelings which adult advocates lack. Adults also suffer "adult amnesia," forgetting what it is like to be a child.
2) This lack of feeling personally invested hinders efforts to recruit large numbers of people to child advocacy causes.
3) Self-empowerment activities undertaken by other civil rights movements are impossible for children and their oft-socioeconomically disenfranchised parents. Such activities include campaign volunteering, giving donations, and voting. This renders children unable to seize power by refusing others' assistance, closing a major pathway to gaining social status.
4) Children's advocates tend not to employ confrontational, visible protest tactics (public demonstrations, violence).
5) Child advocacy is not a grassroots movement: Adults themselves do not benefit, but rather "act as agents or representatives" for potential beneficiaries.
6) Children are less parochialistic and more idealistic than adults, who prefer to take less risk.
7) Child advocacy is poorly funded compared to other public interest groups (elder advocacy, environmental preservation).

Chapter 1 spotlights the pertinence of the rapid evolution of America's health care system, offers background on significant advances in treatment and prevention for mental disorders, and examines the limitations of Western biomedicine and biomedical ethics in addressing the problem. Chapter 2 acknowledges the imminent health resource dilemma posed by abrupt demographic changes. It examines the economic reasons for this quite political crisis, and applies philosophical analysis to issues of just allocation of medical resources among different age groups, specifically children with chronic or severe disorders and the elderly. The List of Abbreviations contains a glossary of acronyms frequently applied to government/social program names and medical terms. These may be accompanied by brief definitions.

Chapter 1: Foundations of Corporatized Medicine; Pediatric Mental Health Care; and Prevention/Early Intervention

This section explores the buildup of a traditional mental health care system, dependent upon interdisciplinary provider relationships, parental participation, and community involvement. This system conceptually evolved from the perception that mental illness did not etiologically reside within the child, but instead resulted from family, community, and societal influences. Indeed, "from their earliest origins, mental health services for children have emphasized a community orientation" (Pumariega, 1997, p. 68). Just as causation was not thought to rest solely with the individual, neither was it perceived that prevention and treatment should focus on the individual child alone.

Unfortunately, 19th and 20th century reformers' expansive hopes for prevention were largely unmet. Only recently have scientifically rigorous outcome- and effectiveness-assessment methodologies become widespread, tools that may help make prevention and early intervention a reality. But in a state of ever-scarcer health care resources, it remains to be seen how well we can attend to both the needs of emotionally disturbed children, and apply such tools to help at-risk children. One issue policymakers will continue to face is how to meet two competing social obligations: caring for the severely ill, and investing in "prevention, early identification, and early intervention" (Friedman, 1986, p. 8).

This section also opens discussion of the tremendous impact of changes in payment schemes and financial incentives on care for mentally ill children. Critics of managed care concerned about mentally ill children point to its disruption of the traditional system of care and reduced access. Children are devoid of advantages or rights that adults take for granted (e.g., the vote; patient self-advocacy; decisionmaking competency). These powers become increasingly critical as government assumes the roles of health system reformers and regulators of managed care. By 'managed care,' it is meant that medicine is seen as a corporate-driven commodity, versus viewing medical care as an inherent human right. Mental health advocates are concerned that nontraditional providers and services will become or remain economically inaccessible to patients arguably most in need of and most likely to benefit from them, as these providers and treatment modalities are less likely to be included in insurance benefits. What may be the most frustrating to advocates is that managed care has wrought such changes in the way mental health care is delivered in America precisely at a time when pilot studies involving holistic efforts are showing promise in preventing or lessening the lifelong sequelae of mental illness. Managed care is directly pertinent to this thesis. Its techniques and financial incentives dominate our current health care system, and powerfully influence access to care for emotionally disturbed children.

One attribute of managed care spotlighted by critics is that decisionmaking about treatment no longer predominantly hinges on clinical issues but on nonmedical factors: cost, efficiency, and profit. However, the influence of nonmedical factors on mental health care for children is neither a result only of the spread of managed care, nor recent (e.g., Mechanic, 1998, p. 84). Since the early 20th century, when the first pediatric psychiatric inpatient units arrived, "...the choice of treatment settings has been determined more by politics and custom than by diagnostic need" (Woolston, 1991, p. 890). Nonmedical economic factors were added by managed care's spread to behavioral health care.

At the turn of the 20th century, "terms such as child psychiatry, mental health, and emotional disturbance had yet to be invented" (Rafferty, 1991, p. 1170). Child psychiatry became a specialty in 1960 (Rafferty, 1991, p. 1170); the American Academy of Child Psychiatry was founded in 1952 (Rafferty, 1991, p. 1170). However, at the beginning of the 20th century, pediatricians also assumed a role in mental health care. (Rosen, 1968, p. 301). Interdisciplinary cooperation was urged (1935): "Doctors [pediatricians] should be very careful about claiming control of 'the whole child'...It is not at all certain that the practicing physician can provide all this care himself" (Rosen, 1968, p. 301).

Preventive efforts targeted at children at risk for mental illness began in the 19th century. Despite the lack of a scientifically rigorous knowledge base, child welfare workers identified influences that even today are considered or suspected to be crucial in fostering healthy development.

The federal government took notice in 1909, offering the first of several White House Conferences on child welfare. This conference stressed the importance of a proper home environment and good mothering (Rosen, 1968, pp. 294-5). The federal government, through its Children's Bureau (established 1912) assumed a parental educative function, making available the latest research (Rosen, 1968, p. 296). Between 1918-28 physicians, public health workers, government officials, social workers, and teachers were all considered to play a role in promoting "mental hygiene" in the first years of life. While the White House conferences did not break new theoretical ground, federal endorsement facilitated public interest (Rosen, 1968, p. 297). Awareness grew in the influence of school environments. Public awareness grew assisted by increased media attention (Rosen, 1968, p. 298). Prevention centered around thwarting the development of "asocial habits" and growing healthy personalities (Rosen, 1968, p. 299). Child development research continued to expand in the 1920s; conceptual interest turned to fostering normal social development (Rosen, 1968, p. 299). Etiological interest shifted away from inheritance (Rosen, 1968, p. 300); the family continued to be most important. Prevention was key. Outreach included

> "...the services of child welfare workers in rural areas, homemaker services, day care, and foster family day care services...to help keep the family unit intact whenever possible, and to provide continuing supportive counsel to parents...Group discussions with parents...and with disturbed children were initiated...in order that these problems might be resolved before they reached crippling proportions" (Rosen, 1968, p. 302).

1940-50 witnessed child welfare workers' research on and application of new concepts in child mental health (Rosen, 1968, p. 303). Another White House Conference (1950) convened researchers of personality development to identify and disseminate information about factors contributing to healthy personality formation. The need was vocalized for improved provider training and mental health programs in schools (Rosen, 1968, p. 303).

Two events introduced "the modern era of community-based systems of care for children": 1) the publication of a book (Unclaimed Children, by Jane Knitzer [1982]), describing sequelae of a lack of a "community-based system of care," and 2) the resulting CASSP (Child and Adolescent Service System Program) (Pumariega, 1997, p. 68). CASSP, developed in the late 1980s, "...assisted all 50 states in developing an infrastructure for publicly funded community-based services" (Pumariega, 1997, p. 68). It advocates an interagency, coordinated, individualized continuum of care, in which families were to be involved with treatment planning, and which favored less restrictive environments over inpatient placement when appropriate (Pumariega, 1997, p. 68).

Early (1920s-30s) hospital units focused primarily on children with organic disorders. The later (1970s), explosive growth of psychiatric inpatient care is attributed not to growth in recognition of children's needs but "scientific, political, and fiscal factors" (Woolston, 1991, p. 890; see also Friedman, 1986, p. 9). Children have traditionally been treated within a variety of psychiatric and nonpsychiatric institutional settings, "...including juvenile detention, social welfare, and educational systems" (Woolston, 1991, p. 890). Institutional placement occurred to address various perceived social needs: housing, unacceptable behavior, and mental illness. Until the 1950s, severe childhood mental illness was perceived as rare; institutionalization was infrequent. The state of care for status offenders and mentally ill youths in the 1970s-80s directly contributed to calls for managed mental health care (Schowalter, 1998, p. 167). Many juvenile detention centers closed as a result of decriminalization of status offenses. Transinstitutionalization occurred, from criminal justice to the medical sector. Fee-for-service insurance policies dominated in the 1970s-80s and fulfilled a new perceived need for inpatient care. Payers resisted the spiraling costs of such intensive, for-profit care, paving the way for MMHCs' spread (Schowalter, 1998, p. 167). Woolston (1991, p. 892) also attributes the 1970s-80s rapid growth in admissions to

> "...diminished availability of juvenile detention and child welfare systems, increased funding provided by private insurance and Medicaid, as well as increased social instability due to divorce, moves, social disruption, and the relaxation of the statutory rights of minors."

Economic factors-not diagnosis-were primary determinants of length of stay (Woolston, 1991, p. 891).

In the mid 1970s, pediatric admissions trended from public to private hospitals. Rapid growth of construction of private, for-profit psychiatric hospitals drew insurance coverage 1) toward intensive treatment, and 2) away from a traditional, community-based system of care:

> "This increasing intensity of treatment provided in inpatient units has tended to cut off such services from their historically related programs provided by educational, juvenile detention, and social welfare agencies. The very same medical, financial, and political forces that have promoted the growth of these inpatient units have created artificially rigid boundaries with these other related treatments" (Woolston, 1991, p. 891; see also Schowalter, 1998, p. 167).

There is evidence suggesting that managed care is inexperienced or inept at dealing with pediatric mental illness, particularly severe disturbance. States observe poor coordination between managed behavioral health providers and social sectors, whose intimate involvement makes the pediatric mental health care system unique (American Psychiatric Association, 1997, pp. IV-V). There is concern that managed care is inadequately prepared to deal with the vastness and complexity of pediatric mental illness. Such concerns fuel calls for health care reform involving transfer to a universal, single-payer, comprehensive model. Managed care's "design and operating principles" conflict with the mission and goals of courts and social services (American Psychiatric Association, 1997, p. V). Moreover, managed care is unfamiliar with streamlined funding mechanisms developed between social sectors (American Psychiatric Association, 1997, p. V).

Managed care has led to cost reductions in inpatient and specialty care (e.g., Rothbard, 1999, p. 211). However, most studies examining the impact of managed care on cost and outcome for psychiatric treatment have been done on healthier, outpatient populations (Rothbard, 1999, p. 212). Findings of unaffected outcomes and lower costs do not extend to severely ill groups. As of 1996 only one study had examined this population, and found continued high utilization and higher costs than among non-HMO-enrolled controls (Rothbard, 1999, p. 212). Given the dearth of data and variety of MCO models, it is premature to draw conclusions about utilization and cost for mentally ill pediatric populations.

"Since the early 1990s, the most profound change in managed care in the USA has been the rapid [enrollment] of vulnerable 'public sector' populations into mandatory managed care programs" (Rothbard, 1999, p. 212). States' "experimentation" with such public sector (Medicaid) programs burgeoned in the 1980s (Rothbard, 1999, p. 212). Results of these experiments indicate "...minimal effect on reducing costs" (Rothbard, 1999, p. 213). There is little cost- or care-shifting to either the general medical sector or "community-based, publicly funded mental health programs" (Rothbard, 1999, p. 214). Utilization, cost, and access appear to be similar between FFS- and managed care-enrolled public sector populations. However, "[m]anaged care recipients [reported] more problems obtaining their care and were less satisfied with their health plan than were FFS enrollees [sic]" (Rothbard, 1999, p. 214). Moreover, compulsory enrollment of the more-disabled, more-expensive populations has just begun. Savings reductions have been measured with populations dominated by the "...least expensive subgroup in the Medicaid population with one quarter the annual costs of the disabled group" (Rothbard, 1999, pp. 212-214). Yet, "[t]he lack of evidence that market driven techniques will result in greater cost efficiency in health services for public sector populations, without sacrificing quality of care, has not stopped governments from forging ahead" (Rothbard, 1999, p. 215).

To understand the impact of managed care's spread on allocation of medical resources, it is useful to comprehend the economic forces fueling this trend. It is valid to ask how well managed care models will meet guidelines representing best practices in the care of SED youth (e.g., CASSP). Caseworkers labor to adhere to best practices, while facing increased role conflicts. Ethical challenges ensue when the obligation to coordinate care collides with the new role, 'cost manager.' Severely emotionally disturbed children qualify as a chronically ill population; commentators agree that chronically ill populations are at risk of suffering disproportionately more than healthier populations under market-driven managed care. Reasons for this will be explored. Children's advocates fear that savings from shifting chronically ill, Medicaid-eligible children to managed care will be shifted to more politically visible, powerful, and popular Medicaid population cohorts, such as the elderly or disabled. Such issues (managed care's inability to achieve highest-quality care, provider role conflicts, family behavior and attitudes, and fair allocation of resources) have all been covered in the bioethics literature. What is new is analyzing these issues' relation to the plight of mentally ill children.

What inspired the rapid evolution from FFS to capitated, or managed, care among state Medicaid programs? Main reasons were rapidly increasing costs and decreased federal reimbursements (Scholle & Kelleher, 1998, p. 660). The spread of managed care in the 1990s has wrought "shifts...in the allocation of mental health service dollars..." (Burns & Hoagwood, 1998, p. 688). An example is decrease in inpatient spending relative to outpatient (Burns & Hoagwood, 1998, p. 688). Similar trends are observed in studies of state Medicaid program waiver experiments targeting children's mental health.

Some effects of managed care's spread are worthy of cautious praise rather than concern: managed care's decreased resource allocation to inpatient care coheres with a principle of CASSP, namely, restrictiveness of care. "Services will be provided in the least restrictive setting" (Burns & Hoagwood, 1998, p. 688). CASSP-modeled systems of care improve access (Bickman, Summerfelt, & Noser, 1997, p. 1547). However, there is concern that other CASSP principles will be less adequately met with the spread of managed care, namely community treatment, cultural competence, and family involvement in planning (Burns & Hoagwood, 1998, p. 688). Managed care-led changes in caseworkers' roles, from care to cost management, are also observed.

> "Further study will be needed...to determine what is meant by *case management* in [state health care reforms]. In public sector systems of care, case management typically involves a care coordination role, often with supportive and clinical features. In managed care environments, case management often refers to a financial management [also referred to as 'cost management'] and oversight function" (Stroul, et al., 1997, p. 397; italics the authors'. See also Horwitz & Stein, 1990, pp. 581-586, and Fox, et al., 1993, p. 547).

The literature is pervaded by pinpoints of optimism concerning managed care's spread to chronically ill populations, only to be followed by worrisome caveats.

> "A competitive health care marketplace offers the possibility of cost containment, improved access, and greater quality. However, there is also the possibility of market failure. One group that could suffer in a competitive marketplace is children with chronic illnesses" (Neff & Anderson, 1995, p. 1869).

MCOs

> "...[offer] better protection than conventional plans against out-of-pocket expenses and [are] much more likely than [FFS] plans to cover ancillary therapies, home care, outpatient mental health care, and medical case management. In addition, few HMOs [maintain] exclusions for preexisting conditions. Other aspects of HMO policies, however...operate against the interests of families with chronically ill children" (Fox, et al., 1993, p. 546).

Others assert that managed care threatens continuity of care by restricting access to a variety of providers (e.g., see Deal & Shiono, 1998, p. 100; Kelleher, et al., 1997, p. 1113). One study found that continuity of care, which is related to "provider familiarity with patients," was the "strongest predictor of clinician recognition" of psychosocial problems (Kelleher, et al., 1997, p. 1109). Furthermore, one study, roughly measuring access through utilization rates, suggested that one reason why utilization was markedly higher in a prepaid group practice plan (PGP) than in a prepaid independent practice plan (IPP) was that the former offered access to a variety of providers, including non-physicians (Williams, et al., 1979, p. 147). Savings realized from reduction in inpatient spending may be shifted to profit or to other Medicaid patients, rather than towards better fulfilling CASSP model principles: "...the critical issues here are how to shift institutional funds into community services before they disappear in Medicaid block grants or managed care profits" (Burns & Hoagwood, 1998, p. 689).

This section introduces the problem of undertreatment for mentally ill children under capitation. It also describes provider incentives to undertreat and suggested solutions, including: government regulation, 'reinsurance,' and risk-adjusted capitation rates. For example, until methods for determining accurate capitation rates are developed, chronically ill populations are vulnerable to access and quality-of-care problems arising from provider incentives to undertreat.

"...[M]anaged care technology seems to be so powerful at controlling behavioral health care costs that the abundant worry today is undertreatment" (Frank, et al., 1997, p. 116). When one considers this problem, the words of a mid-1980s commentator seem naïve:

> "...if a system objective is to restrict residential placements only to youngsters with the most serious need, and to emphasize intensive but less restrictive options, then fiscal policies should promote this. One approach...would be to apply [an HMO] model to children's mental health so that in fact there are incentives for providers to be efficient and thrifty" (Friedman, 1986, p. 12).

Undertreatment and barriers to access are concerns for enrollees of plans failing to design capitation rates to account for enrollees' varied risk. 'High risk' refers to the threat that care for a particular enrollee will cost more than the capitation amount paid to the provider that is supposed to cover the cost of their care for a specified time.

> "[M]anaged care organizations have few incentives to enroll chronically ill or disabled children with higher-than-average expected costs. Without mechanisms in place that adequately adjust capitated rates to account for these higher-cost enrollees, managed care organizations may lose money, and children with the greatest health needs may be underserved (Deal & Shiono, 1998, p. 93).

What is more, the problem of chronic illness among children is worsening, rendering this population "especially vulnerable" (Neff & Anderson, 1995, p. 1866). "During the 20th century the prevalence of chronic illness in children and the proportion of health care resources used to care for them have gradually increased;" rendering this group a target for cost curtailment (Neff & Anderson, 1995, p. 1866; see also Fowler & Anderson, 1996, p. 11). Costs can be over five times greater than for healthy children (Neff & Anderson, 1995, p. 1866). A JAMA article recommended two steps to address undertreatment: risk-adjusted capitation rates (or carve-outs for certain illnesses), and adequate access to qualified providers (Neff & Anderson, 1995). Other recommendations include 'procompetitive' government regulation, and 'reinsurance' (a risk pool which MCOs both pay and tap into for particularly costly conditions) (Fowler & Anderson, 1996, p. 14; see also van Barneveld, van Vliet, & van de Ven, 1996).

As recently as 1996, new methods by which capitation rates are risk-adjusted to reflect prior utilization--in order to predict future utilization--remained incomplete; existing methods continued to "[present] problems for children with special needs, as these risk adjustments [usually based on gender and age factors] do not differentiate chronically ill children from healthy children. Thus, these children remain vulnerable in a competitive marketplace" (Neff & Anderson, 1995, p. 1868; see also Fowler & Anderson, 1996, p. 16). "[C]urrent risk adjustment methods...still leave chronically ill children at risk of discrimination"; and fail to prevent MCOs from

> "compet[ing] on their ability to segment risk rather than on the basis of quality and efficiency...Research in the area of pediatric capitation adjustment is especially relevant for children with special health care needs" (Fowler & Anderson, 1996, pp. 11, 16).

The use of carve outs for mental health care has risen. 'Carving out' means MCOs "pay behavioral managed care organizations (BMCOs) an administrative fee for managing behavioral health services" (Scholle & Kelleher, 1998, p. 663). More recently, though, administrative fees are less preferred than capitation: "employers and insurers are contracting with BMCOs on a risk basis; that is, the BMCOs receive a fixed sum per capita annually to provide mental health and substance abuse services and, thus, have financial incentives to restrict utilization" (Scholle & Kelleher, 1998, p. 663). Carved out services for Medicaid eligibles can be a positive, in that they "may increase access for poor children in situations in which these services otherwise would have been denied" (Deal & Shiono, 1998, p. 101). However, it is essential for states to understand the needs of mentally ill children, and explicitly list these services in the Medicaid contracts they negotiate with MCOs. Otherwise, "fully capitated plans have an incentive to interpret their service provision obligations narrowly and to reduce costs by shifting the responsibility for these services to [FFS] providers" (Deal & Shiono, 1998, p. 101).

Partly because of the spread of managed care in Medicaid, a new, stronger social obligation has been placed on states to protect vulnerable citizens' interests, with respect to both health care and daily living needs, a problem particularly for the mentally ill.

> "[T]he new [managed care] environment establishes opportunities for state mental health authorities to become the watchguards of the privatized public safety net, helping to establish appropriate standards and norms... and carefully monitoring performance as it relates to...vulnerable subpopulations. Particularly important are the boundaries with primary medical care, social services, vocational rehabilitation, housing, and the criminal justice system...[A]ctive state involvement will be needed to bring together the constellation of services that many of the most vulnerable patients require" (Mechanic, 1998, p. 96).

The nuances of financial incentives vary with the type of health plan contracted for by states, and the proportion of risk assumed by providers, states, and health plans. Examples of Medicaid managed care plan types are: 'fully capitated health plans,' 'prepaid health plans,' and 'primary care case management (PCCM) programs' (Deal & Shiono, 1998). Fiscal incentives work against the grain of the growing knowledge base of what approaches reap the most benefit in treating mentally ill youth. Even treatment models adopted as state policy, and professionally accepted, are not being implemented as much as they should because of financial incentives, possibly leading to undertreatment.

> "A serious concern is that without adequate risk adjustment mechanisms, there may be built-in incentives in managed care systems to underserve those with serious disorders. Children with [SEDs] would be vulnerable to such incentives to underserve, particularly if capitation rates are inadequate" (Stroul, et al., 1997, p. 397).

One promising model for caring for these children is CASSP. The Child and Adolescent Service System Program model arose in the mid 1980s; it advocates promoting a coordinated, comprehensive, accessible 'system of care' in each state, through a number of principles: individualized care, family involvement, a community-based continuum of services, service provision in the least restrictive possible setting, and cultural competence. Its outpatient emphasis counters prior spending trends: "historically, the [fiscal incentives which are...likely to drive decisions about service provision] have been on the side of institutional use" (Burns & Hoagwood, 1998, p. 688). In the mid-1980s, 75% of spending on childhood mental health went to inpatient care; such financial incentives influenced treatment decisions more than the knowledge base of what is clinically effective (Burns & Hoagwood, 1998, p. 688). Not all problems implementing CASSP can be attributed to misguided financial incentives. Authors note the practical difficulties of seamlessly distributing resources to local, multisector entities: "The availability of alternatives to institutional care remain limited, partially because it is not feasible to shift institutional dollars into community-based resources or to blend funds across child agencies" (Burns & Hoagwood, 1998, p. 691).

One reason policymakers are leery of insurance parity for mental illness is the problem of moral hazard. 'Moral hazard' is an economic term used by the insurance industry to describe "the tendency for people to demand more services as the price they pay for services falls...[T]he dilemma of insurance is that it protects...against risk but creates incentives for overuse" (Frank, et al., 1997, p. 110). The moral hazard problem is "more serious [for mental health care] than it is in general medical care" (Frank, et al., 1997, p. 110).

Insurers respond to moral hazard by instituting higher cost sharing for mental health services than for general medical services (Frank, et al., 1997, p. 110). However, the RAND study referred to in this article did not accurately simulate real-world Medicaid managed care, because RAND's subject enrollment was randomized, not voluntary. Thus, RAND was not subject to the problem of selection bias, where "patients who voluntarily enroll in or disenroll from a prepaid health care system differ in health status from the general population" (West, Stuart, Duggin, & DeAngelis, 1996, p. 506; see also Neff & Anderson, 1995, p. 1867). Unfortunately, this study design issue also hindered interpretation and generalizability of results from the Ft. Bragg demonstration project, a study comparing systems of care to 'usual care' for SED children (Bickman, et al., 1997, p. 1543). Selection biases resulting from voluntary plan designs "may be economically favorable to...HMOs and may undermine the cost-containment goals of prepaid health care for Medicaid participants" (West, et al., 1996), as discussed below.

> 'Adverse selection' results from "imperfect information: the insurer cannot observe characteristics of individuals that affect the cost of coverage. However, these characteristics (e.g., the risk of illness) are assumed to be known to consumers who use this information to select their individual policies. Other things equal, those with greater risk will demand more coverage" (Feldman, Escribano, & Pellise, 1998, pp. 659-660).

Adverse selection is a problem especially for mental illness because of its chronicity and complexity. Adverse selection leads to insurers receiving insufficient premiums to profit from caring for people at higher risk. People with MH/SA problems may flock to plans that become perceived as "...the 'good mental health' plan;" these people are deemed " 'bad risks' because it is likely they will be relatively expensive to treat" (Frank, et al., 1997, p. 111). 'Good' plans then lose money or become at competitive disadvantage. Insurers are familiar with this phenomenon, and have a strong financial incentive to try to achieve 'favorable selection.' Favorable selection is an insurance term meaning efforts to counter the attraction of such chronically ill, 'bad risk' enrollees toward their plans (see Feldman, Finch, & Dowd, 1989, p. 381; Fowler & Anderson, 1996; and van Barneveld, et al., 1996, p. 133). While the individual MCO may benefit financially, the community does not: "[F]or society as a whole, cream skimming is a zero-sum game...any resources used in performing cream skimming can be seen as social welfare losses" (van Barneveld, et al., 1996, p. 135). Adverse and favorable selection, and cream skimming, are important economic concepts for consumers, advocates, providers, and policymakers to understand; only through comprehension of these terms' meanings can one appreciate financial incentives' influence in corporatized medicine. Stakeholders must grasp that financial incentives are much more than a nebulous academic thinking exercise: they directly impact access to quality mental healthcare services.

Favorable selection is achieved in many ways, such as limiting or restricting coverage or benefits (see Fowler & Anderson, 1996, p. 10). Such behavior by insurers is documented (Frank, et al., 1997, p. 111). "[P]ersons who join HMOs or PPOs [vs. FFS plans] have lower baseline use and costs, better self-reported health status and functional status, and fewer medical conditions and functional impairments" (Scholle & Kelleher, 1998, p. 671). Favorable selection may be due partly to continuity of care factors, e.g., "the unwillingness of persons with ongoing health problems to change health providers" (Scholle & Kelleher, 1998, p. 671).

Favorable selection for mental health care is suspected to behave differently, specifically in the long-term. "[O]ver time...persons with more severe conditions disenroll at higher rates;" "enrolled populations in managed care and FFS plans may not be significantly different with regard to mental health problems or use at enrollment, but may tend to diverge over time so that MCOs have fewer patients with significant mental health needs" (Scholle & Kelleher, 1998, p. 671). Were MCOs to hold enrollees' medical welfare as a primary goal, they would attempt to discourage such behavior, since studies find that

> "continuity [of care] improves the receipt of preventive services, decreases the likelihood of hospitalization, and may increase patient satisfaction...In an era of market-driven health care reform, many families are being forced to frequently change primary care providers because of employer-directed changes in health insurance on a frequent basis" (Kelleher, et al., 1997, p. 1113).

Policymakers and advocates need to understand such concepts. "A long-standing problem for policymakers has been to determine whether restricted benefits for mental health are there for a 'good reason' (moral hazard) or a 'bad reason' (adverse selection). There is ample evidence that both have been at work" (Frank, et al., 1997, p. 111). They should also care about adverse selection and profitability of insurance plans: lack of competitiveness "...may reduce the number of services provided or change the types of services offered, both of which may have negative effects on access to and quality of care;" should the plan go bankrupt, it may "...cease to provide services, also negatively affecting access to and quality of care" (Zhang, Lancaster, Clardy, & Smith, 1999, p. 189; see also van Barneveld, et al., 1996, p. 135).

Certain patient populations are at particular risk for harm:

> "insurers may prefer not to contract with providers of care who have the best reputation of treating (certain) chronic illnesses, because this will attract nonpreferred risks. Thus, chronically ill people may find access to the best health care hindered...One possible outcome of inadequate risk adjustment is poor (access to the best) care and poor service for chronically ill people" (van Barneveld, et al., 1996, p. 135).

Benefits restriction is another method by which to counter adverse selection. It includes limiting access to specialists, or paying specialists unpalatable rates, to "try to discourage families of children with chronic illnesses from enrolling" (Neff & Anderson, 1995, p. 1867; see also Fox, et al., 1993). Benefits restriction can disproportionately serve as a barrier to chronically ill children: "several of the services that children with special needs might require, such as diagnostic procedures, laboratory services, and ancillary therapies, often would not be covered..." (Fox, et al., 1993, p. 548). More ethically problematic methods, particularly for populations less able to self-advocate, include "...administrative procedures that will discourage enrollment...making partial hospital care difficult to access, contracting with residential programs located in out-of-the-way or undesirable neighborhoods, and so on" (Frank, et al., 1997, p. 117).

Other administrative barriers include temporal gaps before coverage activates, a "lag period...of considerable importance to children with serious illnesses" (Horwitz & Stein, 1990, p. 583). Need for medical services is one of the most powerful predictors of overall pediatric utilization (Riley, et al., 1993, p. 767). Therefore, the need for such barriers, aimed at quashing inappropriate utilization, is less than for other groups. The disproportionate impact of administrative barriers on access for disadvantaged enrollees renders such barriers unfair.

One study of how adequately HMOs meet the needs of chronically ill children found that

> "[m]ost made services available only to individuals with conditions responsive to short-term therapy; some made them available only for acute conditions or only for nonorganic conditions. In these HMOs, children and adolescents with [SEDs] obviously would be unable to obtain treatment...Although access to mental health benefits was found to be relatively easy in the majority of HMOs, the amount of services covered often was too limited to allow adequate treatment of children with severe emotional or behavioral problems" (Fox, et al., 1993, p. 549).

A study of Medicaid enrollment found evidence of favorable selection; those choosing HMOs had histories of lower utilization than those opting for FFS Medicaid. Mental illness was one of four conditions studied (West, et al., 1996, pp. 503-4). These concerns are particularly pertinent for severely mentally ill youth, who are expensive to treat, often because they require continuing specialist care (see Horwitz & Stein, 1990, p. 584). "Services that are less likely to be needed by large numbers of children, but are often needed by children with chronic illnesses, are subject to [benefits] restrictions by both the indemnity insurers and HMOs" (Horwitz & Stein, 1990, p. 584). Proposed parity legislation claims to benefit the chronically ill partly because its goal is to "[limit] the consequences of adverse selection" (Frank, et al., 1997, p. 112), such as benefits curtailment, which can impact access to adequate care, particularly for the most at-risk, vulnerable populations who are disproportionately less able to aggressively seek and fight for the care they require.

Access to care, along with cost and utilization, is a "traditional outcome [measure]" (Stroul, et al., 1997, p. 397). Managed care techniques control access, reduce patient choice, and spread financial risk among stakeholders, in order to 'manage' costs (Behrman, 1998). Yet managed care arrangements also offer "...the potential to increase access...for Medicaid beneficiaries" (Deal & Shiono, 1998, p. 96), for example through applying cost savings toward increasing the number of individuals eligible through Medicaid by adjusting income rules (Cutler, McFarland, & Winthrop, 1998, p. 363).

As recently as 1998, commentators noted the dearth of research on access, outcomes, and utilization patterns with respect to managed care and children; the bulk of such work has instead been done with adults (Scholle & Kelleher, 1998, p. 664). Therefore, it is premature to offer policy recommendations, but worrisome patterns in children's mental health care are observed, especially with regard to access to appropriate care. Some conclude that "HMOs do not represent a more attractive option [for children with chronic conditions] as postulated in the literature" (Horwitz & Stein, 1990, p. 585).

Children's medical problems have become more complex at a time when society is becoming more aware of the barriers population subgroups face in accessing care. "During the last 2 [sic] decades, as the array of adolescent health problems has increased, the barriers adolescents face in accessing physical and mental health services have emerged in sharp focus" (Kaplan, Calonge, Guernsey, & Hanrahan, 1998, p. 25). With respect to general medical care, "insurance has been demonstrated to play a key role in determining the use of health services among populations of children and youth..." (Newacheck, 1989, p. 874). Insurance "can play a major role in determining access" (Newacheck, 1989, p. 877). While some assert that "[r]esearch has shown that managed care programs do not impede access," (Henley & Clifford, 1993, p. 211), the data on which these assertions are based are usually collected from adult populations. Insurance status affects youth access to a regular source of care. "[U]ninsured adolescents nationally [in one study] had significantly lower mean numbers of physician visits in the preceding year than did insured adolescents and were less likely to have usual sources of routine care" (Anglin, et al., 1996, p. 324).

'Accessibility' is the "degree to which the health care delivery system inhibits or facilitates the ability of an individual to gain entry and to receive services (includes geographic, transportation, social, time, and financial considerations" (American Psychiatric Association, 1997, p. 67). Health services researcher David Mechanic describes 'access' in the managed care context:

> "A major concern of consumers of mental health services is that managed care will significantly limit their access to specialty mental health services. Whether this is true depends on the definition of *access*. Issues include whether persons can receive a mental health service and treatment, whether such services must be obtained through a gatekeeper, and the intensity of services received" (Mechanic, 1998, pp. 90-1; italics the author's).

Access is a particular problem for the poor (Williams, et al., 1979, p. 139). A relative lack of research on access for chronically-ill children has been noted (Shatin, Levin, Ireys, & Haller, 1998). "[D]isabled adolescents [mental illness is the leading cause of disability in adolescents] were twice as likely to be covered by public health plans (primarily Medicaid) and proportionately less likely to be covered by private plans" (Newacheck, 1989, p. 877).

As of 1998, insufficient research had been completed to draw conclusions on the impact of barriers to access to specialty care on severely disturbed youth (Scholle & Kelleher, 1998, p. 678). While "overall access to mental health services is likely to increase in MCOs" (Scholle & Kelleher, 1998, p. 678), SED youth are particularly vulnerable to barriers to specialty care because of their greater need for and use of specialty providers. But there are positive routes MCOs can take to both achieve the goal of cost curtailment in this high-utilization, high-cost subgroup, and maximize access. For example, some suggest "creat[ing] a specialty care network...All participating plans would have access to the specialty providers in the network and would contribute to the network based on their volume of patients. This would provide expert care for serious, complicated, and rare chronic illnesses, build on the benefits of regionalization, and minimize the duplication of services that add to health care costs" (Neff & Anderson, 1995, p. 1869). Unique medical aspects of chronic illness in children, as well as the existing organizational structure of their health care, facilitate creation of such networks:

> "Clearly, many of these issues apply equally well to adults with chronic illnesses. However, it may be possible to move forward more quickly on plans for children...for several reasons. First, children's specialty care is more regionalized...and the number of chronically ill children is considerably less...Second, it may be easier to develop carve-outs, risk adjusters, and quality assurance measures...because illnesses in children are more likely to involve single entities without the overlay of multiple chronic illnesses...often associated with the aging process" (Neff & Anderson, 1995, p. 1869).

"Children's mental health needs continue to be largely unmet..." (Flaherty, Wiest, & Warner, 1996, p. 341). A large number of children who have been recognized as needing mental health services do not receive them. The scope of the problem—and of the suffering—is larger than most Americans realize: "[A]lmost 20% of all children might benefit from some specialized mental health intervention" (Piotrkowski, Collins, Knitzer, & Robinson, 1994, p. 134). The U.S. Office of Technology Assessment announced that "12 to 15% of adolescents present emotional/behavioral problems at levels warranting intervention, but less than one third of these youth actually receive mental health services" (Flaherty, et al., 1996, p. 342).

One study defined 'unmet need' as youth for whom "psychopathology and associated functional impairment were present but no mental health services had been received in the previous six months" (Flisher, et al., 1997, p. 1145). Although 20% of youth exhibit psychopathology, "...only a small proportion of these receive mental health services... there is a considerable amount of unmet need..." (Flisher, et al., 1997, p. 1145). Between 11-22% suffer from diagnosable mental disorder. (Anglin, et al., 1996, p. 325; Flaherty, et al., 1996, p. 341; Kaplan, et al., 1998, p. 31; Kelleher & Starfield, 1990, p. 114). From 3-9% suffer from SEDs (Davis & Stoep, 1997, p. 402; Piotrkowski, et al., 1994, p. 134). These numbers are difficult to determine with precision because "[n]ational data on adolescents' use of mental health services are severely limited" (Anglin, et al., 1996, p. 325).

According to federal guidelines, a child suffering from serious emotional disorder (SED)

> "'exhibits one or more of the following characteristics with such frequency, intensity or duration as to require intervention: Seriously delayed social development...inappropriate behaviors (e.g., dangerously aggressive towards others, self-destructive, severely withdrawn, noncommunicative); a general pervasive mood of unhappiness or depression, or evidence of excessive anxiety or fears or who has received 'a professional diagnosis of serious emotional disturbance'" (Piotrkowski, et al., 1994, p. 134).

While retardation and autism may be included as SEDs, this thesis focuses on emotional disturbance.

"[N]eed for mental health services is defined to exist when: a) there is functional impairment, that is the level of functioning falls below, or threatens to fall below, some minimum specified level; and b) this is due to some potentially remediable or preventable cause, for example psychopathology for which there is effective and acceptable treatment" (Flisher, et al., 1997, p. 1145). Insufficient access is related to persistent, "very high rates of unmet need" among SED children (Burns & Hoagwood, 1998, p. 691). Despite an increase in utilization, as of 1995 "only one third of youth with serious emotional and behavioral disorders received professional mental health services and only one third of them received special education services" (Burns & Hoagwood, 1998, p. 691). "The majority of children in need receive insufficient or no mental health services" (Pumariega, 1997, p. 67). "Only 6% to 20% of youth who need mental health services receive them" (Davis & Stoep, 1997, p. 402). Others cite data indicating only about 25-33% of needy youth receive services (Anglin, et al., 1996, p. 325; Kaplan, et al., 1998, p. 31). Less than 5% of American youth receive any mental health care, which can make research difficult (Kelleher & Starfield, 1990, p. 114). Data disparities seem to be due to a lack of national utilization data. In some cases, mental illness is classed as a 'disability' for legal and social programming purposes. A mid-1980s study deemed over 6% disabled; "[t]he leading cause of disability was mental disorders" (nearly 1/3 of disabled youths) (Newacheck, 1989, pp. 872-875).

Further, rigid medical necessity criteria often reflect the needs of acutely ill populations more accurately than the chronically ill, particularly mentally ill, for whom other approaches have proven themselves.

> "The vast majority of [state Medicaid] reforms are using medical or clinical necessity criteria for accessing mental health services. Further study is necessary to determine...whether the use of these criteria is restricting access to specialized services for children with emotional disorders. The children's reform movements of the past decade [e.g., CASSP] have moved away from the rigidity of traditional medical necessity criteria to more flexible approaches. It remains to be seen the extent to which managed care systems will build upon these reforms or return to the use of more traditional types of criteria" (Stroul, et al., 1997, p. 397).

Relatedly,

> "few health plans are familiar with the 'accessory' services that persistently ill patients need such as transportation, skills training, supportive housing, vocational training, and so forth. [Study interviewees] worried that these essentials would be the first programs cut, as the HMOs lack experience with these programs and, because of this inexperience, may have difficulty viewing these services as medically necessary" (Cutler, et al., 1998, p. 379).

These concerns are reflected in enrollee perceptions. In one study, FFS patients perceived fewer administrative barriers to access, while MCO patients were more likely than FFS patients to view access to specialty providers and range of provider choice as problems. Moreover, poor MCO plan enrollees were less satisfied with their care than comparatively poor FFS patients (Scholle & Kelleher, 1998, p. 674).

While access to primary care may improve under managed care, SED children disproportionately suffer from lack of access to specialists. Moreover, while MCOs may offer more alternative types of care, restrictions on number of visits and lifetime utilization, particularly for such interventions as psychotherapy and supervised living arrangements, are "likely to affect children with SED disproportionately" (Scholle & Kelleher, 1998, p. 676). "[T]he [Medicaid program's] rush into managed care may diminish access to needed services and particularly adversely affect high-risk children" (Stroul, et al., 1997, p. 387). Chronically ill children also are disproportionately affected by other, targeted, barriers to care: "services often needed by children with chronic conditions, such as...mental health services, most often have substantial additional restrictions" (Horwitz & Stein, 1990, p. 585). Although HMOs "have been proposed as a possible mechanism for providing...consistent, coordinated care for children with chronic conditions," this opportunity "may be more like a myth than a panacea" (Horwitz & Stein, 1990, p. 586). Some conclude that neither managed care nor FFS "can be strongly supported" in meeting their needs (Horwitz & Stein, 1990, p. 586).

The first step toward accessing appropriate care is identification of the disorder. Failure at this step contributes to unmet need. "[I]mprovements in communication around psychosocial issues are particularly important in this era of managed care because primary care physicians are becoming gatekeepers to more expensive services such as mental health interventions" (Horwitz, et al., 1998, p. 371)."[A]ccess may be facilitated by increasing parental knowledge of mental health services and enabling children and adolescents to initiate contact with services independently of their families" (Flisher, et al., 1997, p. 1145).

Improving youths' ability to independently seek services might include access to school health clinics. Such clinics are especially important since evaluators of programs for younger children document unmet need (Piotrkowski, et al., 1994, p. 134). One Head Start study found that teachers rated 23% as "[needing] mental health services;" yet only 2% were referred, and 25% of these did not receive services (Piotrkowski, et al., 1994, p. 134). The need is growing: "[a]necdotal information from Head Start directors indicate they are seeing increasing numbers of children exhibiting challenging, difficult behaviors (Piotrkowski, et al., 1994, pp. 134-5). The surveys also revealed evidence of insufficient access and barriers to care: "[m]ost respondents (88%) indicated that there were insufficient...resources in their communities, including lack of funding and affordable mental health professionals and barriers to services, such as waiting lists, poor transportation, and a lack of culturally competent providers"(Piotrkowski, et al., 1994, p.

135). For these reasons, there is agreement that "the mental health program is a weak link in Head Start's comprehensive services strategy"(Piotrkowski, et al., 1994, p. 133).

The school-based health center (SBHC) model, in contrast,

> "has several compelling features as a delivery system...: it reduces physical barriers to access, ...offers self-initiated confidential care, focuses on early identification..., provides an array of services that can be customized for the adolescent population, integrates health promotion into the school environment, and uses midlevel practitioners to reduce...costs" (Kaplan, et al., 1998, pp. 26-27).

SBHCs do improve access (Anglin, et al., 1996, p. 318). "Schools can offer a matchless route for reaching young people...whose access to care may be limited, but whose future health depends on early and consistent service...they are available to all children in the community" (Henley & Clifford, 1993, p. 216). Another benefit is that children can more quickly access SBHCs than they can special education; treatment in SBHCs may avert the need for special education, and its stigma (Flaherty, et al., 1996, p. 344). This may represent savings, not cost shifting, since referrals to special education drop once access to MH/SA providers in school improves (Flaherty, et al., 1996, p. 348). A study comparing inner city high school, HMO-enrolled adolescents with access to SBHCs, to adolescents with no such access (covered by the same HMO), found that the former were over ten times more likely to make a MH/SA visit; moreover, speaking to prevention and early intervention, they were more often screened for high-risk behaviors (Kaplan, et al., 1998, p. 25).

A study of SBHCs in over 10 states illustrated the magnitude of need and demand exhibited by youth: "mental health concerns were the second most frequent reason for visits to the health clinic...behind acute illness/accidents" (Flaherty, et al., 1996, p. 345). Other SBHCs ranked MH/SA at the top of the list in terms of type of service utilized

(Flaherty, et al., 1996, p. 346). One study of over 3800 youth served at 3 SBHCs found that "the most common diagnostic category was emotional problems" (Anglin, et al., 1996, p. 321). Concerning vulnerable or at-risk populations, "the availability of an SBHC attracts a harder-to-reach segment of the population into preventive health care" (Kaplan, et al., 1998, p. 30; see also Flaherty, et al., 1996). Benefits include extending MH/SA care to underserved urban and rural areas (Flaherty, et al., 1996, p. 347). SBHCs clearly fill an unmet need for access to MH/SA care. One program found that "80% of youth presenting noteworthy behavioral/emotional problems upon referral...had *no* prior mental health involvement" (Flaherty, et al., 1996, p. 349; italics the authors'). The difference in utilization of MH/SA services in particular was "striking;" over 96% of mental health visits were by youth with SBHC access (Kaplan, et al., 1998, p. 25). Mental health and substance abuse often coexist in youth; over half of youth having visits with SA providers also had visits with MH providers in this study (Kaplan, et al., 1998, p. 25).

Most children (about 70%) are essentially healthy; 20% have "minor chronic problems," and most of the remaining 10% "have one or more severe chronic illnesses" (Neff & Anderson, 1995, p. 1866). One study found that "[e]ven among the high utilizers...80% received [an excellent] rating of their health" (mothers' reports) (Riley, et al., 1993, p. 773). But the Kaplan et al. study (1998, p. 31), which agrees with other findings, found that nearly 30% of diagnoses were for emotional problems. Those concerned about cost control should note that compared with youth with no SBHC access, youth with SBHC access had "significantly lower" rates of utilization of after-hours emergency care (Kaplan, et al., 1998, pp. 29, 32). The authors suggest:

> "This is a potential opportunity for managed care to improve the comprehensiveness and quality of care provided to adolescents while

> reducing costs, and it may prompt discussion of formal relationships with SBHC programs" (Kaplan, et al., 1998, p. 32).

Schools considering SBHCs should be aware of the connection between academic achievement and mental health status, thus the need to address both. "The relationship between scholastic progress and mental health is reflected in the associations of unmet need with low school grades...efforts to address either unmet psychiatric need or unsatisfactory scholastic progress that ignore the other are...likely to be of compromised efficacy" (Flisher, et al., 1997, p. 1153). Access barriers include barriers to initially accessing care, or barriers to completing the full recommended course of treatment. Successful SBHCs offer a continuum of services: "increased access to [MH/SA] services seems to meet an important unmet need in this population" (Kaplan, et al., 1998, p. 32; see also Flaherty, et al., 1996). They also improve socioeconomically disadvantaged students' access to care (Anglin, et al., 1996, p. 325).

It is uncertain whether MCOs can be convinced to view these efforts as worthy of investment, and help continue the increase in number of SBHCs that began in the 1990s (Flaherty, et al., 1996, p. 351). "...[S]chools cannot accomplish the needed changes alone. They must coordinate with other child-serving agencies, such as child welfare, mental health, and juvenile justice to pool resources and knowledge to address the question of...what preventive measures can be taken" (Davis & Stoep, 1997, p. 422). Excitement about SBHCs' effectiveness in bolstering access is tempered with awareness that funding depends on tenuous, temporary resources: school budgets, grants, and hard-pressed local agencies.

> "This gap leaves health insurance entities and public health funds as the most logical and perhaps only viable funding sources...Given the competitive health economic environment, insurance payers are not

> looking for additional areas in which to spend purchasers' dollars; yet, an increasing number of adolescents served by SBHCs are insured by managed care. The proliferation of SBHCs has coincided with the growth in managed care" (Kaplan, et al., 1998, pp. 27-8).

Another concern related to unmet need and access is the fact that children exhibiting 'externalizing' behaviors (e.g., those affecting conduct; "...annoying habits..., learning difficulties, behavior problems, disciplinary issues.., family difficulties...[and] behaviors that [are] upsetting to adults" [Horwitz, et al., 1998, p. 371]) are more likely to be noticed, diagnosed, and treated than those with 'internalizing' disorders such as depression (see Flaherty, et al., 1996, p. 349; Riley, et al., 1993, p. 779). Medicaid utilization data bear this out: one study revealed that the top three diagnoses normally have behavioral implications (Zhang, et al., 1999, p. 190). Others note such trends: "...those receiving services were not representative of all youth with mental disorders" (Flisher, et al., 1997, p. 1146). Clinicians are more apt to recognize psychosocial problems in "older children and males" (Kelleher, et al., 1997, p. 1113). "[S]pecial attention should be directed to younger patients, African Americans, and females" (Kelleher, et al., 1997, p. 1114).

A defining characteristic of the CASSP model's concept of community-based systems of care is "access to a comprehensive array of services" (Pumariega, 1997, p. 69). One CASSP-model demonstration (the Fort Bragg Demonstration Project), when compared to the traditional system of caring for children of military dependents (CHAMPUS), did demonstrate increased access (and higher satisfaction, and insignificantly different costs) (Pumariega, 1997, p. 70).

Those debating the merits of parity legislation recognize the importance of access. Of four definitions of 'parity' identified by Frank et al. (1997, pp. 115-6), one includes access as a key factor: under this conception, the mentally ill "would have the same access to necessary care as do persons afflicted with other illnesses." However, examination of state parity legislation reveals that "...few laws call for...equal access to appropriate care for mental illness" (Frank, et al., 1997, p. 116).

The new paradigm of managed care requires a more aggressive approach, and a more informed and educated stance, on the part of patients, consumers, and advocates in order to access appropriate care. Role changes and heightening of responsibilities are underway for patient advocates, purchasers, and government officials (Mechanic, 1998, pp. 82-3). Recent political activity and media interest has spotlighted holding MCOs accountable, through regulation, report cards, and lawsuits. Another commentator explicitly applies rationing terminology, raising the issue of its potentially disproportionate effects upon vulnerable populations. "[P]eople cite concerns about...rationing in [privatized] delivery systems, particularly because mentally ill Medicaid beneficiaries are poorly equipped to deal with denial of services" (Rothbard, 1999, p. 214).

The ability of families to effectively advocate is important because it influences access: "the availability and quality of services available to a child with special needs is likely to depend on the parents' ability to maneuver within the system" (Fox, Wicks et al 1993, 546). This includes keeping meticulous records. One survey found that many plans required such recordkeeping: parents were responsible for knowing when their annual copayment maximum had been reached, and alerting the HMO (Fox, et al., 1993, p. 551).

A critique of Tennessee's experimental Medicaid carve-out program (Chang, et al., 1998, p. 864) suggests that states can learn from Tennessee's 'failure' by, among other measures, structuring payment mechanisms to better serve the severely ill. Risk-adjusted capitation (shielding providers from adverse selection by adjusting the capitation rate to estimated future costs of insured patients) works better than using a single capitation rate for all enrollees, in part because it accounts for the fact that "the seriously and persistently mentally ill cannot effectively advocate for themselves" (Chang, et al., 1998, p. 868). This assertion is important because it explicitly acknowledges the linkage of vulnerability to impaired capacity to self-advocate; it also suggests that adjusting managed care payment techniques can better serve this population.

Risk has been traditionally adjusted by prior utilization data. However, commentators on Medicaid's transition into managed care are concerned, because "capitation rates derived from prior utilization data may...create...incentives to underserve certain populations of children..." (Stroul, et al., 1997, p. 396).

Many mentally ill youth are "multiproblem, multiagency children with limited family resources" (Pumariega, 1997, p. 70). Since they are often incapable of fulfilling roles as rational actors in treatment planning, parents or others must advocate for them. "For developmental reasons, ...children or adolescents may not be sufficiently knowledgeable or mature to appreciate some of the practical aspects identified by their parents, such as health insurance not covering the treatment, treatment taking too much time or being inconvenient and transportation problems" (Flisher, et al., 1997, p. 1153).

Some Medicaid programs incorporating capitation address such practical needs. Philadelphia's HealthPass program, a "hybrid between [an HMO] and a traditional Medicaid fiscal intermediary," offers services such as a 24-hour hotline, community-based services, media efforts, brochures and mailings", and access to a nurse who coordinates care (Henley & Clifford, 1993, pp. 214-5). Improvements in immunization rates, the outcome measure studied, resulted.

While managed care can help attain CASSP principles, such as reduced emphasis on inpatient care and greater involvement of family, concerns have been raised that—as the family's role evolves—these changes may go too far.

> "Involving family members can make them an unpaid part of the treatment team...But in depending more on families and communities, institutions must avoid shifting undue responsibility and burden to them...[M]anaged care may increase families' caretaking burdens" (Mechanic, 1998, p. 93).

Often, 'family' means 'mother' (Riley, et al., 1993, p. 781).

A fact that speaks both to intergenerational justice in resource allocation, and to the political power of well-organized constituencies, is this: Medicaid covers not only low-income individuals but the elderly, blind, and disabled. Medicaid is "...the major funding source for long-term care for the elderly and for health services provided to the blind and disabled" (Deal & Shiono, 1998, p. 94). Yet, "...women of childbearing age and children, who together account for 69% of Medicaid recipients, ...[incur] only 26% of program costs" (Deal & Shiono, 1998, p. 93). "Although [the latter] represent the majority of Medicaid recipients, other groups consume a far greater proportion of program expenditures" (Deal & Shiono, 1998, p. 96). And, raising issues of policy fairness, despite the relatively lower costs incurred by this group, "low-income women and children...have been the primary groups enrolled in Medicaid managed care" (Deal & Shiono, 1998, p. 93), a move primarily motivated towards nonclinical, cost-control goals. Indeed,

> "in states where reforms are directed toward subsets of the total Medicaid population, the Aid to Families with Dependent Children (AFDC) population is most likely to be affected, with the aged, blind, and disabled

> population being the least likely to be affected...12% of the reforms...involve only children and adolescents...[W]here there are special age-based reforms underway, they involve children and adolescents" (Stroul, et al., 1997, p. 390).

States look to managed care to rein in costs, yet illogically target one of the least costly Medicaid-eligible subgroups. Costs are spiraling not for them but for the elderly and disabled (Deal & Shiono, 1998, p. 96). Even leaving low-income women out of the equation, concentrating only on children, there is cause for fairness concerns. 20% of children benefited from Medicaid in 1995; almost 50% of Medicaid beneficiaries that year were children. However, since they are relatively low-cost, they accounted for only 15% of spending (Deal & Shiono, 1998, p. 96). "In contrast, while only 27% of enrollees were elderly, blind, or disabled, this group consumed nearly 75% of program resources" (Deal & Shiono, 1998, p. 96). "[M]others with dependent children...are the least expensive subgroup" (Rothbard, 1999, p. 214). Some compare their enrollment (often involuntary) into managed care plans to experimentation (see Rothbard, 1999, p. 212; Stroul, et al., 1997, p. 395), or taking advantage of this subgroup's disadvantaged and stigmatized socioeconomic status as 'undeserving:' unwed, poor, diverse, young. "[I]f there is a special age-based focus, this tends to be on children... This finding is encouraging in that children are not being left out of reforms, but it raises some concern that *children may be vulnerable as the target group for experimentation* with managed care approaches" (Stroul, et al., 1997, p. 395; italics mine). Although others apply such 'experimentation' language to the en masse, rapidly increasing enrollment of "vulnerable 'public sector' populations" into managed care (e.g., Rothbard, 1999, p. 212), the ethical challenges this raises about fairness, equal treatment, and allocative justice have not yet been methodically explored in the academic literature.

As recently as the mid-1980s, there was "...still relatively little effective advocacy on behalf of emotionally disturbed children," despite the emergence of formal organizations such as the Alliance for the Mentally Ill and the Association of Child Advocates (Friedman, 1986, p. 10). The historical emphasis has been advocacy on behalf of mentally ill adults. Formal efforts to prod parents to advocate came about in the mid-1980s. Commentators stressed government involvement in establishing relationships with advocacy groups, promoting CASSP objectives, and bringing about reform.

> "The role of the state in relation to the community remains a major issue ...[U]ntil states see their role as being the establishment of general policy, and the promotion of community-based systems of service, then the system will remain less effective than it should be. A community-based system in which major responsibility rests within the community has the best chance of effectively serving youngsters and their families, of achieving interagency coordination and collaboration, of generating constructive advocacy, of maximizing accountability, and of establishing a productive partnership between the public and private sectors" (Friedman, 1986, p. 11).

The Health Care Reform Tracking Project is "a national study designed to describe and analyze state health care reforms and their impact on children and adolescents with emotional disorders and their families" (Stroul, et al., 1997, p. 386). It found that 80% of states have mechanisms to assist in accessing care or appealing care denials, for example, "appeals and grievance processes, 800 numbers, hotline/helplines, client representatives, and ombudsmen" (Stroul, et al., 1997, p. 393). 80% of states also monitor access (Stroul, et al., 1997, p. 393).

In order to be effective advocates, parents need not only be involved in treatment planning but also have a voice in reform. Yet these seem not to be occurring: Health Care Reform Tracking Project data reveal that family involvement "seems peripheral...The fact that families are not more extensively involved in the reform process is discouraging" (Stroul, et al., 1997, p. 398).

The proliferation of regional or national MCOs is worrisome particularly for the CASSP principles of individualized, community-based care in which parents have a strong voice. "[T]he use of national MCOs for managing mental health and substance abuse care may complicate the help-seeking process... This may be particularly likely in instances where...treatment [is] determined through telephone contact with a manager at a national referral center using standardized referral processes and having limited knowledge of local resources" (Scholle & Kelleher, 1998, p. 676).

Payers are concerned that reforms will lead to inappropriate utilization of services, a trend exhibited among adults when financial disincentives (e.g., copayments) are experimentally removed. However, a study of utilization and access among youths found that those enrolled in an HMO, but also having access to an SBHC, "seem to use both systems of care appropriately" (Kaplan, et al., 1998, p. 32). Another study, while finding that SBHCs "seem to increase adolescents' use of comprehensive health care services," also found that such trends "do not seem to represent overuse; rather, they may signify the patterns of use that occur when adolescents have free access to needed services" (Anglin, et al., 1996, p. 329). What is more, utilization of costly emergency care can be lower for youths with SBHC access (Kaplan, et al., 1998, p. 32).

Like the treatment of pediatric mental illness, prevention and early intervention efforts are ideally multisector. Until recently, critics doubted the preventability of mental illness. As recently as the 1970s, prevention was a "fledgling...movement in mental health" (Faenza & McElhaney, 1997, p. 401). However, 1990s research has raised hope:

prevention and early intervention do work (e.g., Gans, Alexander, Chu, & Elster, 1995, p. 1226). They are particularly apropos for youth, since their most pressing problems "are more behavioral than biomedical" (Gans, et al., 1995, p. 1226). "The systematic, population-wide application of preventive measures...can markedly reduce morbidity from mental ill health among children in the Americas" (Eisenberg, 1992, p. 230).

There are many misconceptions or myths about the limits of prevention. Understanding prevention's multifactorial nature is difficult. The purposes of this section are to 1) provide examples of such misconceptions, 2) show that America's track record on this issue has been poor, and 3) describe potential reforms.

Critics argue that the majority of children are emotionally healthy; thus, prevention and early intervention rightly are a tiny blip on the radar screen of priorities for resource allocation, and bioethics analysis. Evidence from medical economics suggests otherwise, however, and gives moral urgency to this problem. Societal funding of prevention has the potential to lower insurance premiums for everyone, even healthy 'low risks,' potentially allowing more individuals to afford coverage (Feldman, et al., 1998, p. 668). Unfortunately, "this external effect has not been considered in cost-benefit analyses of disease prevention projects" (Feldman, et al., 1998, p. 668). Indeed, as described elsewhere, methods for evaluating health care interventions may not accurately do justice to prevention.

"The health care needs of children are different from those of adults" (England & Cole, 1995, p. 138). To understand why both treatment and prevention of pediatric mental illness requires other than a mere translation of interventions effective for adults, one must understand child development. "[T]he science of mental health in childhood and adolescence is a complex mix of the study of development and the study of discrete conditions" (Satcher, 1999, p. 124). Physicians often possess inadequate knowledge of child development, a hindrance that can lead to inappropriate treatment (Mechanic, 1999, p. 76).

To fight misconceptions, in studying prevention we need to consider the best possible unbiased data. An understanding of child development rebuts critics claiming that certain etiological findings are merely politically-based. However, early work on psychological development and social factors in causation of mental illness "was characterized by dogmatism, conjecture, and wild and irresponsible statements" (Mechanic, 1999, p. 73). Despite recent research data about risk factors, it remains "clear how little we really know," partly due to the great number of complex variables influencing development (Mechanic, 1999, pp. 73-4). For example, a variety of loving family practices are likely to result in a healthy child; even a chaotic environment is no certain predictor of pathology (Mechanic, 1999, p. 73). While blaming families is inappropriate, parental attributes make a difference, and are predictors in determining whether symptomatic children get treated (Mechanic, 1999, p. 75).

What makes thinking about these issues so difficult is that the developmental process normally renders children a 'moving target.' Growing children's behavior typically fluctuates wildly, depending on the stage of development; great ambiguity may surround attempts to determine whether a particular behavior is 'normal' or 'abnormal,' indicative of emotional disturbance, or just a trying time for parents. Moreover, the chasm between normal and abnormal development is one of degree, not one of kind (Satcher, 1999, p. 128).

Children are a product of more than genes, medical history, and temperament. "[P]sychopathology in childhood arises from the complex, multilayered interactions of specific characteristics of the child (including biological, psychological, and genetic factors), his or her environment (including parent, sibling, and family relations, peer and neighborhood factors, social and community factors, and the larger socio-cultural context), and the specific manner in which these factors interact with and shape each other over the course of development" (Satcher, 1999, p. 127). It follows that disordered environments can lead to pathology (Satcher, 1999, p. 128). These differences from adults present "unique opportunities for [early] intervention" and prevention (Satcher, 1999, p. 128).

"Perhaps the most important context for developing children is their caretaking environment" (Satcher, 1999, p. 128). Biological and environmental causative factors work together: their "influences...are difficult to tease apart;" this complicates research on causation and risk factors (Satcher, 1999, p. 131). Additional research on prevention and early intervention is urged in the first Surgeon General's report on mental health, "to address pronounced gaps in the...knowledge base" (Satcher, 1999, p. 454).

"[E]arly intervention...is the key to effective treatment" (England & Cole, 1995, p. 138).

> "[c]hildhood is an important time to prevent mental disorders...because many adult mental disorders have related antecedent problems in childhood. The field of prevention has now developed to the point that reduction of risk, prevention of onset, and early intervention are realistic possibilities...[P]revention does work" (Satcher, 1999, pp. 132-133).

Service sectors are beginning to acknowledge that "investment in prevention may be cost-effective" (Satcher, 1999, p. 133). From the mid 1960s to the mid 1980s, nontraditional medical sectors were at the forefront of successful preventive efforts in America, resulting in improved health status and long-term savings (Emanuel & Emanuel, 1997, p. 161).

Preventive efforts geared toward pediatric mental illness are already, in fact, widespread. "Despite widespread skepticism, effective prevention of *some* psychiatric disorders is not only possible but is,...in some countries, virtually complete" (Eisenberg, 1992, p. 231; italics the author's). Examples include the following. "[V]accination against measles prevents its neurobehavioral complications; safe sex practices and maternal screening prevent newborn infections such as syphilis and HIV, which also have neurobehavioral manifestations. Efforts to control alcohol use during pregnancy help prevent fetal alcohol syndrome" (Satcher, 1999, p. 133). Other examples, while not strictly psychiatric, include addressing dietary deficiencies (Eisenberg, 1992, pp. 231, 234). Prevention in specific areas, such as nutrition, vaccination, safe sex, and maternal health is much more effective now than in the past. However, merely providing educational information is insufficient. Preventive interventions and health promotion ideally occur in a caring environment. Creating an effective caretaking environment for children, partly through prenatal care and family planning, may be America's 'best shot' at preventing mental illness (G. Osborn, personal communication, May, 2000).

Examples of cost-effective preventive interventions for mental illness follow. A 1989 article (Burton, et al.) described a comprehensive mental health program for employees of a large bank. This intervention, a form of employee assistance program (EAP) prioritized prevention and early intervention. The intervention was demonstrated to be cost-effective: "[t]otal hospital days and average length of stay decreased by 43%

whereas total inpatient psychiatric hospital charges decreased by $309,518" (Burton, et al., 1989, p. 363). When considering the cost of the program, the total net savings on psychiatric care was 14.7%; yet the quality of care improved (Burton, et al., 1989, p. 366). From 1984 to 1988, mental health costs as a proportion of medical plan costs fell from almost 14% to about 12% (Burton & Conti, 1991, p. 312).

The above intervention involved adults. An example of a preventive intervention for children that has proven cost-effective is a neonatal screening program for several congenital metabolic disorders, including phenylketonuria (PKU) in Japan, begun in 1977 (Hisashige, 1994). Untreated PKU can result in retardation, a serious emotional disturbance. Early intervention involves straightforward dietary alterations. Costs for untreated individuals afflicted with retardation as a result of PKU include, e.g., institutionalization costs, foster care, and special education (Hisashige, 1994, p. 387). Cost-benefit analysis (CBA) revealed that the program was cost-beneficial (Hisashige, 1994, pp. 382, 387). A 1975 study showed that fetal heart rate monitoring during labor can prevent roughly ½ of cases of pediatric mental retardation that would have resulted if unmonitored; cost analysis revealed that spending $100,000 annually in maternal/fetal care could "prevent an anticipated long-term expenditure of almost $2 million" (Quilligan & Paul, 1975, pp. 96, 99).

Relatedly, a 1990 study (Porath, McNutt, Smiley, & Weigle, p. 31) performed CBA and cost-effectiveness analysis (CEA) on a program vaccination program for cytomegalovirus (CMV). Congenital infection with CMV is the leading cause of retardation in America. Routine immunization was found to be cost beneficial; such programs would save $2.5 million annually (net) (Porath, et al., 1990, p. 31). The discount rate used was 5%. A genetic screening program begun in Michigan in 1977 has prevented some cases of mental retardation, cost-effectively (Thoene, Higgins et al 1981, 335). The program screened for multiple genetic and metabolic factors that cause retardation. The program would need to prevent only three or four cases of retardation annually to generate a cost-effective return on the program investment (Thoene, Higgins, Krieger, Schmickel, & Weiss, 1981, p. 339).

The problem is lack of social will, not preventive interventions' efficacy (Faenza & McElhaney, 1997, p. 403). America has "[failed] to adopt prevention as a national mental health priority" (Faenza & McElhaney, 1997, p. 403). "[T]he greatest barrier to better child mental health is failure to muster the political will to apply what is known to the care of mothers and children in all sectors of society" (Eisenberg, 1992, p. 230). Reasons for this failure include historical neglect and under funding of mental health care, and stigma (Faenza & McElhaney, 1997, p. 407). After distributing resources toward treatment, yet still failing to "adequately provide services for large numbers of children...," few resources remain for prevention (Faenza & McElhaney, 1997, pp. 404-5). Political battles fester over what constitutes just resource allocation, e.g., between advocates for at-risk populations potentially benefiting from prevention, and mentally ill people needing treatment. Such ideological discord thwarts the cooperation needed to advocate for funding (Faenza & McElhaney, 1997, pp. 406-7). These battles illustrate the phenomenon that "[f]rom the standpoint of the community, in contrast to that of the individual, decisions about undertaking preventive measures require a weighing of competing social aims" (Eisenberg, 1992, p. 238). These battles have been analyzed with respect to other disorders in the bioethics literature, but have not focused on pediatric mental illness. Indeed, a goal of this thesis is to address that deficiency. Experts call this dilemma "one of the most important [human services issues] facing policy-makers in children's mental health" (Friedman, 1986, p. 8).

Economic boundaries, as well as scarce resources, dictate whether implementing a prevention program is the best choice for investing a given amount of money. For example, one study concluded, "[t]he cost-effectiveness of clinical interventions for various risk behaviors among adolescents is unknown. It appears that preventive interventions would have to eliminate 15% of adolescent morbidities overall to break even in economic terms" (Gans, et al., 1995, p. 1226).

Issues that need addressed before policymakers can make informed decisions include: prevalence and costs of pediatric mental illnesses, costs of prevention programs, and at what point interventions prove cost-effective (Gans, et al., 1995). What is the potential overall increase in the nation's mental health? Is a given intervention the best, most rational use of the money we already spend on health care? Policymakers will need to provide rational, ethical explanations of how they arrive at their decisions. Should America continue to spend a disproportionate amount of money on care during the last six months of life, instead of spending more on prenatal and early childhood care? Should all coronary artery bypass grafts for the oldest old (over 80) be funded? What combination of care constitutes the best value for our health care dollar? Consideration of such questions involves shifting our nation's spending emphasis, not necessarily bedside rationing. In view of our lack of a single-payer system, the overarching context of this argument is that we must maximize access to health care by making the most efficient use of expenditures (G. Osborn, personal communication, May, 2000).

Criticism of preventive efforts as premature was apropos in the past, especially in the 1950s, when treatment ideology, "rhetoric," and interest shifted from the hospital to the community and the continuum of care approach. Advocates "accepted as an article of faith (but with little persuasive evidence) that the population at risk could be identified, and that early detection and treatment was the key to...more effective use of fiscal resources" (Grob, 1991, p. 199). Federal recognition of the need to enlist multiple social sectors in any effective preventive effort began as early as 1962. Prior to passage of the Community Mental Health Centers (CMHC) Act (1963), one official asserted, "[w]e believe that primary efforts to prevent mental illness must start in childhood and depend on the work of many social institutions-for example, the family, the church, the school, and public and private health and welfare agencies" (Grob, 1991, p. 205).

The immense social, economic, and taxpayer burden of preventable, untreated, or inadequately treated mental illness should concern us all, and functions as moral ammunition for prevention and early intervention advocates. Moreover, prevention and early intervention can save money. "The rationale...is that early treatment will prevent not only current suffering, but perhaps also future MH/SA [mental health/substance abuse] expenditures" (Schowalter, 1998, p. 170). Early intervention shows potential to "decrease long-term cost" (Cutler, et al., 1998, p. 374). Increased resource allocation to prevention may also offset access problems aggravated by late 20th century de-emphasis of inpatient treatment (Cutler, et al., 1998, p. 376).

Radical changes in economic incentives seem warranted. We must work toward financial incentives that promote prevention and anticipatory health guidance. Such incentives should be economically and ethically defensible. An extant example of such incentives is found in the British National Health Service (NHS), in which primary care physicians receive bonuses for performing preventive procedures (G. Osborn, personal communication, May, 2000).

One effect of the spread of managed care is that "many health insurance programs fail to cover many services, especially preventive services...even when they are efficacious and cost-effective" (Emanuel & Dubler, 1995, p. 325). Moreover, "[f]inancial incentives in the current system encourage physicians to offer high-technology procedures rather than primary and preventive care" (Emanuel & Dubler, 1995, p. 326). Managed care's performance is admittedly mixed: "studies consistently demonstrate greater use of preventive tests and procedures among managed care enrollees" (Emanuel & Dubler, 1995, p. 326). Structural features of managed care, including its prepaid nature and capitation, have the potential in theory to promote preventive and holistic care (Armstead, Elstein, & Gorman, 1995, p. 29). Averting unnecessary psychiatric hospitalization would certainly reduce costs, and liberal coverage for enrollment in pilot or innovative programs such as those described below would likely improve access to multisector, multidisciplinary, coordinated care.

However, corporatized models of medical care do pose major limitations as well. Many mentally ill children are covered by Medicaid; and "[f]ew Medicaid beneficiaries remain with a single plan for an extended period of time" (Armstead, et al., 1995, p. 35). The difficulty of monitoring effectiveness and quality of prevention and early intervention efforts is heightened by rapid enrollment turnover. This dissuades managed care organizations [MCOs] from investing in prevention. "[T]he benefits of preventive services accrue only after years of expenditures...[prevention investments] make fiscal sense only if the [MCOs] expect patients to stay enrolled for years" (Emanuel & Emanuel, 1997, p. 170; see also Feldman, et al., 1989, p. 386; and Schowalter, 1998, p. 169). It must constantly be remembered that MCOs are driven by a corporate, competitive model, and are motivated to behave accordingly.

> "[A] stock may fall not only because of a company's loss, but also if its profits do not keep rising at an acceptable rate. This fact has kept the corporate fear and focus on 'now,' with little incentive" for long-term preventive efforts (Schowalter, 1998, p. 172).

Critics argue that such problems will work themselves out in the competitive health care marketplace, provided the marketplace is left alone to right itself (e.g., unfettered by government regulation). Demand for MCOs that are better at promoting prevention, they say, will encourage the other, 'bad' MCOs to improve or correct their policies. However, a flaw of this ideal corporate model is that it likely will take decades for this process to play out. This represents generations worth of unmet need and unnecessary suffering (G. Osborn, personal communication, May, 2000).

In the Recommendations section, a greater role for schools is urged. Such an approach will admittedly encounter hurdles. Commentators observe barriers and resistance to implementation of preventive techniques in the educational sector. These include 1) an inability to understand the concept of prevention due to its "diffuseness--effectiveness results from the absence of something occurring, rather than a product materializing before one's eyes;" 2) parochialistic thinking; 3) societal "preference for the status quo;" 4) failure to consult with implementers (teachers); and 5) schools' financial incentive to shift costs of such programs to other sectors (Meyers & Parsons, 1987, pp. 113, 141). Timing of implementation, background knowledge about the disorder, and design fidelity toward one target population also appear crucial in launching prevention interventions. In the past, programs have failed because they were prematurely launched, before an adequate knowledge base was constructed on the target illness. Insufficient information had been gathered on incidence, etiology, and diagnostic and research methods (Meyers & Parsons, 1987, pp. 112-113). To convince schools, known for their restricted budgets, to invest faith and funds in prevention, implementers must arrive prepared to demonstrate the potential cost-effectiveness and long term savings of the program (Meyers & Parsons, 1987, pp. 113, 144). "Investments in prevention...are ultimately political and social as well as economic and clinical issues" (Phillips & Holtgrave, 1997, p. 23). The data necessary to facilitate the welcomed, successful adoption of school-based preventive interventions has been gathered in the last decade and is referred to below.

Even with a national emphasis on prevention, it is bad policy to overpromise with regards to primary prevention. Secondary prevention and treatment should also be emphasized, especially for cases where primary prevention fails. Even the best possible knowledge base, data, or research methods will not eliminate mental illness caused by genetic or biological factors (G. Osborn, personal communication, May, 2000). No prevention or early intervention program can or should be expected to prevent all cases (e.g., see Faenza & McElhaney, 1997, p. 406; Gans, et al., 1995; and VandenBos & Miller, 1980, p. 142); nor can we expect them to be free of iatrogenic effects. "What is not possible now, or in the foreseeable future, is the prevention of *all* mental disorders" (Eisenberg, 1992, p. 231; italics the author's). Temporal factors unique to children add one more constraint. "[T]he window of opportunity is limited" (Piotrkowski, et al., 1994, p. 136).

Late 20th century bioethics, as well as managed care, appears guilty of insufficiently appreciating prevention's potential benefits. "Research and intervention involving primary prevention (related to mental health and psychology) have grown dramatically in the past 10 years. However, little attention has been paid to ethical issues in primary prevention" (Trickett, 1992). Prevention and early intervention remain weak stepchildren of both medical care and economics, "under-researched and under-funded" (White, 1997, p. 151). Current economic methods place prevention programs "at a distinct disadvantage," relative to other healthcare spending (Ganiats, 1997, p. 12; see also Phillips & Holtgrave, 1997). This issue is explored further in Chapter 2.

A number of programs have sought to prevent mental illness or promote mental health. While the programs below are based in home, school, and clinical settings, others focus on additional social sectors frequented by mentally ill children, including criminal justice. For example, diversion programs, focusing on secondary prevention and targeted toward juvenile offenders, "have sought to avoid the ineffective and potentially harmful effects of legal processing...by changing the names, location, focus, and procedures used" (VandenBos & Miller, 1980, p. 135). They can be cheaper than regular legal processing, and exhibit "treatment effects [which] extend beyond the individuals" (VandenBos & Miller, 1980, p. 135). Results of one intervention included "significant psychological changes...in self-esteem[,]...impulse control[,]...[and] attitude;" "significantly higher level [functioning] than the control group;" "better work histories;" "better interpersonal relations;" and "less likelihood of later legal difficulties" (VandenBos & Miller, 1980, p. 135).

What is noteworthy about the programs below is the degree of innovation and creativity built into their designs. These programs flow against the prevailing tide of the Western biomedical model of health care. Both fee-for-service and managed care payment schema have traditionally adhered to this model. To a great extent, bioethics has also adopted this acute-care model, at the expense of sufficient analysis of challenges posed by disease prevention, health promotion, and cooperation between medicine and other sectors in public health. Failings of the biomedical model are explored later. First, innovative, effective prevention programs will be introduced.

Certain features are common to many of these programs, contribute to their effectiveness, and provide guidance for policy and funding. Such features include holistic interventions, address of multisector needs, attention to risk factors beyond the individual, a longitudinal focus, addressing problems as early as possible, interdisciplinary providers, and large-scale or multi-state operations. Many of these features unite to promote an effective "caring" or "caretaking" environment (G. Osborn, personal communication, May, 2000).

Project Head Start

Introduced in 1965, Head Start "is probably this country's best known prevention program," despite its original intent, early intervention (Satcher, 1999, p. 133). It is countrywide, but there is "considerable program variation across localities" (Satcher, 1999, p. 133). Its goal is to promote social and cognitive functioning of poor preschool children; its successes include "lower[ed] enrollment in special education and...enhanc[ed] rates of high school graduation" (Satcher, 1999, p. 134). However, the reliability of research findings about Head Start's effectiveness is hindered by an absence of "national randomized controlled trial[s] to evaluate the program as originally designed" (Satcher, 1999, p. 133). Its original design is temporally longitudinal (eight weeks' duration), and holistically oriented, "includ[ing] a center-based component and a home visit by community aides, focusing on social, health, and education services" (Satcher, 1999, p. 133). Head Start offers long-term benefits pertinent to mental health promotion: "better peer relations" and "less antisocial behavior" among them (Satcher, 1999, p. 134). Over 15 million children have been served (Satcher, 1999, p. 133).

Despite these successes, Head Start has borne its share of criticism. Its mental health component has been called "a weak link in [the program's] comprehensive services strategy;" observed problems include insufficient resources and barriers to service access (Piotrkowski, et al., 1994, p. 135). "For too long, mental health has been Head Start's stepchild. Head Start can fulfill its full promise by, once again, becoming a laboratory for innovative practices in mental health" (Piotrkowski, et al., 1994, p. 138). In fairness, though, the lack of both controlled studies and sufficient long-term outcome data makes it difficult to evaluate the practical import of these observations.

Cost-benefit analysis of a program with similar goals as Head Start (the Perry Preschool program) found that

> "the economic return from providing early education to children in poverty far exceeds the costs...the estimated economic benefits of preschool education are quite large relative to its costs. In fact, the estimated rate of return on preschool education exceeds the average rate of return on investments in the stock market over the past 30 years" (Barnett, 1998, pp. 204, 206).

Elmira (NY) Prenatal/Early Infancy Project (Elmira PEIP)

This program is "an excellent example of a preventive intervention that targeted an at-risk population to prevent the onset of a series of health, social, and mental health problems" (Satcher, 1999, p. 134). Its attention to the child's environment and sources of social support (mothers) represents a holistic departure from the traditional acute-care biomedical model. It was also longitudinal: birth to age two. The intervention consisted of "parent education [frequent nurse home visits], enhancement of the women's informal support systems, and linkage with community services [including free transportation]" (Satcher, 1999, p. 135). Children were developmentally screened annually, and there was a noteworthy follow-up period (fifteen years). Unlike Head Start, its design was randomized and controlled. Its effects were "positive and enduring;" mothers exhibited fewer abusive, neglectful behaviors, and were "more involved with their children" (Satcher, 1999, p. 135). Children exhibited "fewer coping problems" (Satcher, 1999, p. 135). But perhaps most exciting were the 15-year follow-up findings:

> "[W]omen who were visited by nurses during pregnancy and infancy had significantly fewer subsequent pregnancies, less use of welfare, fewer verified reports of abuse and neglect, fewer behavioral impairments due to use of alcohol and other drugs, and fewer arrests. Their children, now adolescents, reported fewer instances of running away, fewer arrests, fewer convictions and violations of probation, fewer lifetime sex partners, fewer cigarettes smoked per day, and fewer days having consumed alcohol in the last 6 months. The parents...reported that their children had fewer behavioral problems related to use of alcohol and other drugs" (Satcher, 1999, p. 135).

This program is also noteworthy in its fidelity to the concept that the earlier preventive efforts are begun, the better. "The most logical place to start is at birth, possibly even before, with psychologically informed management of ante- and post-natal care" (White, 1997, p. 151).

Economically, Elmira PEIP provides much greater benefit to the higher-risk subsample of families, than lower-risk families. In the case of the former, government savings were significantly higher than government costs of the program ($24,000 versus

$6,000 per family) (Karoly, Greenwood, & Everingham, 1998). For lower-risk families, the government loses money. These numbers did not include non-government (societal) benefits such as costs of prevented crimes or higher beneficiary income. The authors estimate that adding in these societal benefits would raise overall savings by $6,000 per family. Net savings, in dollars per child, for the higher-risk families was $18,611 (Karoly, et al., 1998, p. 86). The authors guess that because children were only followed to age 15, thus benefits as adults were not counted, the savings figures underestimate the true savings to government (Karoly, et al., 1998, p. 87). Savings accumulate after only three years of enrollment in the program (Karoly, et al., 1998, p. 88).

The authors acknowledge the controversy of discounting and explain that their chosen rate (4%) fell within a range of commonly applied rates (Karoly, et al., 1998, p. 99). Because this program's benefits accrue over such a long time, even tiny alterations in the rate chosen significantly affect benefits and savings numbers. In other words, the program is sensitive to discount rate fluctuations. But even experimental manipulation of the rate within the commonly-used range does not affect the conclusion that both government and society reap net benefits (Karoly, et al., 1998 p. 99). Showing cost effectiveness of mental illness prevention/early intervention programs is extremely complex and difficult, due to the multicontextual nature of psychopathology (G. Osborn, personal communication, May, 2000). This clearly applies to the Elmira PEIP, PMHP, and Head Start cost effectiveness analyses that have been performed.

Primary Mental Health Project (PMHP)

PMHP, over forty years old (a rarity for any program [Hightower, 1997, p. 209]), is noteworthy in its site of operation: schools (Satcher, 1999, p. 135). While it is funded systematically in only seven states (Satcher, 1999, p. 135), it has experienced "significant growth" in the last two decades (Hightower, 1997, p. 208). Its clientele reflects its early-intervention focus: "less disturbed versus more disturbed children" (Hightower, 1997, p. 208). Its design explicitly acknowledges the interrelatedness of school achievement and emotional well-being, as well as the immense social cost of mental illness. "Children who fail to profit from the school experience are often at high risk for developing major mental disorders and many become chronic [tax] burdens to society...Far from vanishing, early problems tend to root and spread to many costly areas, including substance use, delinquency, and serious mental health problems" (Hightower, 1997, pp. 191, 210). Longitudinal (ten years), replicated research and follow-up reveals this to be true: "when ignored, children's early [school] adjustment problems [result] in long-term negative outcomes" (Hightower, 1997, p. 207).

PMHP's goals, therefore, are "early detection and prevention of...school adjustment problems" (Satcher, 1999, p. 135), and "[reduction of] adjustment difficulties as soon as possible" (Hightower, 1997, pp. 191-2). Its features include screening by inexpensive nonprofessionals. While the Surgeon General classifies this as a "successful mental health intervention," its main focus and area of success is academic achievement (Satcher, 1999, p. 136; Hightower, 1997, p. 192).

The program is cost-effective, and "has had a track record of demonstrated success...in a variety of settings [including urban, rural, multiracial and multiethnic schools]" (Hightower, 1997, pp. 193, 209). Moreover, it "exemplifies how prevention programs can root, evolve, and adapt" (Hightower, 1997, p. 209). At long-term follow-up, children "had significantly fewer problems" (Hightower, 1997, p. 208).

One program that has indirectly sought to prevent childhood mental illness, via primary prevention of child abuse and neglect, is the Hawaii Healthy Start Plan, incarnated at the federal level as Healthy Families, or the Hawaii Model. This intervention identifies high-risk children at birth; for the next five years, paraprofessionals coordinate a range of services for the children and their families (M. Woolson, personal communication, 1995).

The biomedical model is "a philosophic tradition in medical diagnosis" (Kessler, 1990, p. 141). There is a pervasive tradition within Western biomedicine of disease-specificity and ideological bias toward acute illness, not prevention. This section provides supporting arguments for this often-made assertion. The phenomena of a lack of a 'lifespan approach' is also explored. Examples of how the Western biomedical model's dominance harms patients are supplied. Arguments of critics are also considered.

The biomedical model attends well to acute illness, but not chronic illness and the multisector care the latter requires (Stroul, Pires, Armstrong, & Meyers, 1998, p. 121). Relatedly, the ideal of hospitalization to completely cure acute illness does not translate well to chronic illness like mental illness, which often requires addressing deficits of the child's environment (Woolston, 1991, p. 894). Limitations of the Western biomedical model, especially its rigid, inexorable reductionism, include the following. First is the Cartesian mind-body dualism, also called positivism (Cohen, 1993, p. 510). Second is a tendency to view patients as machines to be repaired ("mechanistic [or "Newtonian"] thinking" [Foss, 1994, p. 294]). Symptom information is elicited through history taking and physical examination (Armstrong, 1987, p. 1215), with the physician in an "observational mode," not a "relational [or "dialectical"] mode" (Cohen, 1993, p. 510;

Engel, 1992, p. 8). This encourages physicians to perceive as irrelevant contextual factors of a patient's existence, such as illness meaning, feelings and worries, lifestyle, and power relationships within a family and community (e.g., Fee, 1993, p. 1481; Lyman, 1989). It also promotes "failure of empathy" (Kessler, 1990, p. 140). Third, the cause of illness is "somatic or organic in etiology," not social (Lyman, 1989, p. 599). Fourth, the illness "is to be diagnosed by biomedical assessments...and treated and managed according to medical authority," (Lyman, 1989, p. 599). "Only the physician can have access to [the] truth;" patients are "subservient" (Armstrong, 1987, p. 1214). Fifth is the "reductionist doctrine:" "the reduction of illness to the 'lesion'" (Armstrong, 1987, p. 1214). Biological reductionism has elsewhere been defined as "explanations of phenomena occurring at several levels (e.g., social, psychological) that are sought at a single level (biology)" (Cohen, 1993, p. 510). For physicians strictly adherent to the biomedical model, "'science' and the scientific method have to do with the understanding and treatment of disease, not with the patient and patient care" (Engel, 1980, p. 538).

The biomedical model is also called the disease model; diseases are perceived as having "an existence independent of the patient" (Kessler, 1990, pp. 141-2). A "categorical approach" is taken; "[d]ifferent diseases represent the manifestation of different disease processes" (Kessler, 1990, p. 141). Strict fidelity to the biomedical model leads physicians to disregard patients' contextual life factors because "one conceptualizes the etiology and manifestations of mental disorders as entirely impersonal or alien, as not to be found in or relevant to the life history of the patient" (Kessler, 1990, p. 141). "[I]n no real sense is the patient seen as an author of his symptoms or at least as an important collaborator in their production" (Kessler, 1990, p. 144). This is in contradistinction to "dimensional" approaches, which view disease as "quantitative variations from normal [and] ...diagnoses...[as] mental constructs" (Kessler, 1990, p. 141). Biopsychosocial and other alternative models have been proposed to better account for the social construction of illness (Armstrong, 1987, p. 1213; Engel, 1980; see also Foss, 1994). Advocates of such models claim that increased attention to social aspects of disease need not detract from achieving scientific goals in medicine (Anderson, 1982, p. 243).

> "One [can] be scientific at the bedside after all!"... "Pure objectivity and total detachment of the investigator from his material no longer constitute inviolable criteria for what is to be accepted as science or scientific" (Engel, 1992, pp. 5-6).

Biopsychosocial models are not inconsistent with good science, scientific rigor, or even reductionism. Although reductionism has serious limitations, and in some senses we have taken it as far as we can conceptually, reductionism can be effective and useful in thinking about certain aspects of health care, such as applying knowledge of small-particle physics to oncology. The biopsychosocial model can thus help render outcomes of good science more efficacious in clinical care. We should maximize the strengths of reductionism, but not be limited by its flaws (G. Osborn, personal communication, May, 2000). Some claim that nothing short of "social and cultural revolution" is required to prompt a paradigm shift to a biopsychosocial model (Hewa & Hetherington, 1995, p. 137).

In biomedicine, illness is seen along a continuum from normal to abnormal (Kessler, 1990, p. 141). What is 'normal' is a problematic concept. Biomedicine defines "'normal'... in the statistical sense as referring to the usual or common" (Armstrong, 1987, p. 1215). Yet, careful analysis of physiological processes underway daily in any human being is likely to reveal "hundreds if not thousands of criteria by which any individual is in the 'abnormal' group" (Armstrong, 1987, p. 1215). We would hardly label such natural variations 'disease' (Armstrong, 1987, p. 1215). Abnormality (disease) results when individuals cannot function according to societal expectations or norms (Armstrong, 1987, p. 1215).

Components of the biomedical paradigm can harm those needing mental health care. The Cartesian mind-body dualism is thought to contribute to stigma (Satcher, 1999). Also, certain chronic, relapsing disorders poorly explained by medical science and with psychosocial components have been labeled psychosomatic (Helman, 1985). In this way physicians "psychologize" the illness, "shifting responsibility [and blame]...to patients' emotions, personality, or lifestyle," and away from the physician (Helman, 1985, pp. 1, 22). The biomedical model is powerful enough to mold patients' interpretations of the meaning of their illnesses (Helman, 1985, p. 21).

The biomedical model also contributes to improper diagnosis, for example of schizophrenia (Kessler, 1990, pp. 140, 146). "Employing only the biomedical model...often results in...'a strenuous and devoted attempt to force nature into conceptual boxes'" (Lyman, 1989, p. 600). The physician is encouraged to "find as quickly as possible the simplest explanation, preferably the diagnosis of a single disease, and to regard all else as complications, 'overlay,' or just plain irrelevant" (Engel, 1980, p. 538). Yet in the real world, "disease is a value-laden concept, not [an] objective, theoretical notion" (Daniels, 1989, p. 678). "[W]hat is health is context specific to the individual and to the community" (Rodd, 1989, p. 895).

Overreliance on the medical model can also result in poorer functional outcomes as a result of reduced caregiver expectations (Lyman, 1989, p. 599). Once someone is labeled 'mentally ill' (or 'Alzheimer's,' in the case of the cited article), caregivers are quick to accept "an oversimplified diagnosis and prognosis;" "even normal behavior is interpreted in terms of disease stages...The result may be a self-fulfilling prophecy of impairment." Granted, mental illness is not typically degenerative. However, these beliefs readily translate to caregivers for mentally ill persons.

Another example of potential harm to patients is that it undermines the physician-patient relationship. Training in the biomedical model encourages physicians-to-be to "[turn] away from the patient and his experience of the illness" and can discourage listening (Kessler, 1990, pp. 143-4). Outcome is potentially threatened by failing to discover the individual's life context. "To be effective, the diagnosis and treatment of mental illness must be tailored to individual circumstances, while taking into account age, gender, race, and culture and other characteristics that shape a person's image and identity" (Satcher, 1999, p. 456). Grant (1991, p. 926) criticizes pediatric psychiatric training as: "overemphasi[zing]...individual deviance, disease, and psychopathology," and asserts that academic child psychiatrists should redirect education towards a more holistic, community-oriented, public health and preventive orientation. Moreover, empathy and compassion are not merely niceties or therapeutic 'frills,' they are necessary for accurate diagnosis and treatment, as well as truly scientific medicine. "The biomedical model encourages sympathy...but not empathy" (Kessler, 1990, p. 145).

The biomedical model averts focus away from weighty concerns in pediatric mental illness. "[T]he medicalization of hyperactivity in children shifts attention from the school and family situation of the child to an individual/physiological deviance designation" (Lyman, 1989, p. 599; see also Conrad & Schneider, 1980). It also encourages paternalistic thinking (Lyman, 1989, p. 602; see also Hummelvoll & da Silva, 1994, p. 10). "[T]he doctor knows best!" (Goodstein, 1975, p. 179). It tends to preserve the status quo, stifling social debate and health care reform (Lyman, 1989, p. 602). Commentators lament that many people needing mental health care do not get it. Stigma, misunderstanding, insufficient numbers of qualified providers in urban areas, and cost are cited as usual culprits. However, another barrier may be people's perception of the Western biomedical model. "It appears at least possible that the face of modern technological medicine...actively frightens off the most vulnerable consumers" (Little, 1981, p. 188). Lack of analysis of caregiving is also harmful. Rigid adherence to the biomedical model "overlooks the social construction" of mental illness, and ignores "the impact of treatment contexts and caregiving relationships on disease progression" (Lyman, 1989, p. 598).

Bioethics has also been criticized (from within) as myopically adhering to assumptions of the Western biomedical model. Early 1990s ethical analyses of dilemmas in managed mental health care were commonly "misfocused," "engag[ing] the issues at precisely the wrong level" (Boyle & Callahan, 1995, p. 20).

> "[E]arly complaints...arose from a moral analysis that assumed an idealized set of moral practices rooted in traditional patterns of medicine (such as Marcus Welby-type doctor/patient relationships, unlimited choices for all patients, and Cadillac care no matter the cost). The primary focus here was the individual patient and physician. This focus completely neglected the social fabric in which these individuals were embedded: issues of broader access to care or of standards for reasonable care" (Boyle & Callahan, 1995, p. 20).

Confinement of such analysis to the level of the physician/patient dyad oversimplifies what are really complex, multidimensional moral conflicts (Boyle & Callahan, 1995, p. 20). Moreover, such a narrow viewpoint ignores conflicts at other levels, for example "between a mental health services manager and all eligible enrollees in a [managed care] plan" (Boyle & Callahan, 1995, p. 20). It also discourages analysis of societal-level problems such as disparities in health status and access to care. "[P]hysicians predominantly worry only about the well-being of their personal patients" (Emanuel & Emanuel, 1997, p. 155). The psychiatric profession admittedly has a better record than other specialties at attending to these issues. "[Psychiatry has] been alone in addressing these issues for the past 20 years" (Pasnau, 1987, p. 147). Moreover, the biomedical model, combined with increased emphasis on economic models of accountability (medicine as commodity), "ignores or minimizes the importance of other domains of accountability. At best, there is a minimal role for public health, for equity of access..., and for community benefit" (Emanuel & Emanuel, 1997, p. 167).

"[T]he 'holistic' view of human life" represents "[t]he concept of the whole person" (Hewa & Hetherington, 1995, p. 135). Western biomedical model assumptions influence the structure of the "traditional mental health paradigm;" for example, bias toward treatment within the physician's office and treatment outside the home and community (Piotrkowski, et al., 1994, p. 136). This is worrisome since such "approaches may not be effective for those children with the most disturbing behaviors" (Piotrkowski, et al., 1994, p. 137). More recent treatment paradigms, such as CASSP, involving holistic, intersector approaches to care, have had to fight against the powerful biomedical model. Strictly medical sector management of mental illness also reduces the effectiveness of treatment and prevention. "[T]he goal of services must not be limited to symptom reduction but should strive for restoration of a meaningful and productive life" (Satcher, 1999, p. 455). "[T]here is a growing body of evidence indicating that social environments can have a profound impact on mental health" (Meyers & Parsons, 1987, p. 133). Indeed, one factor identified as critical to the effectiveness of certain prevention programs is "tailoring the system to the adolescent, not the adolescent to the system" (VandenBos & Miller, 1980, p. 145). This can mean addressing a youth's perceived need for help with "a boss, teacher, parent, or friend" (VandenBos & Miller, 1980, p. 145), assistance more effectively and cheaply provided outside the medical context.

It is paradoxical that traditional insurance "foolish[ly]" (Mechanic, 1999, p. 142) provides wider coverage for inpatient than outpatient services. After all, a main cause of furor over costs of psychiatric care was the explosion of private hospital construction, often targeting adolescents. Insurance structured this way has clearly impacted provider behavior, "provid[ing] strong incentives for hospital care that may not really be needed and encourag[ing] a medical approach to mental health problems" (Mechanic, 1999, p. 132). Parity legislation will not be a panacea if it merely extends coverage for this sort of insurance; such 'reform' will not address the "enormous sociomedical needs that require a thoughtful integration of traditional medical and other types of services" (Mechanic, 1999, p. 142).

The first Surgeon General's report on mental health claims that the current mental health care system is "rooted in a population-based public health model,"

> "characterized by concern for the health of a population...and by awareness of the linkage between public health and the...environment. Public health focuses not only on traditional areas of diagnosis, treatment, and etiology, but also on epidemiologic surveillance of the health of the

> population at large, health promotion, disease prevention, and access to and evaluation of services" (Satcher, 1999).

Adherence to this model is not as strong today as it may have been historically, partly due to political attempts by the psychiatric profession to gain legitimacy, and the increased power of third-party insurers in dictating what interventions are covered. The result has been preventable human suffering:

> "[M]any lives are wasted, children and adults die and are disabled, and communities fall apart for our failure to invest in a public health approach to many of the mental health and social problems that face Americans and their communities today" (Faenza & McElhaney, 1997, p. 407).

The psychiatric profession has combated repeated ideological assaults by other specialties that "psychiatry [is] not part of medicine, and that psychiatric practice rest[s] on superstition and myth" (Satcher, 1999). One reason for these attacks is that oftentimes, once a disorder's etiology and interventions are understood, 'ownership' is "transferred from the mental health field to another medical specialty" (Satcher, 1999; see also Pasnau, 1987, p. 150). A recent example is Alzheimer's disease (Lyman, 1989). One way to combat such assaults, and retain professional authority and economic status, is to encourage more rigid adherence to the biomedical model, de-emphasizing affinity with medical ethics (Youngner, 1997, pp. 309-311; see also Cohen, 1993). Psychiatry has a long history of better attending to "the whole patient" than other specialties; it also has had deeper community and family interactions, within a variety of social sectors (Pasnau, 1987, pp. 145-6).

Managed care also demonstrates biases toward acute interventions over both community-based interventions and prevention programs. Chronically ill people are particularly burdened by plans offering ample coverage and choice for short-term, acute office-based care, while placing greater restrictions on nontraditional, community-based, specialized, and long-term services that may best address the special needs of vulnerable populations with complex health histories (Fox, et al., 1993, p. 546; see also Pomerantz, 1999). "[S]everal of the services that children with special needs might require, such as diagnostic procedures, laboratory services, and ancillary therapies, often would not be covered in the hospital outpatient setting" (Fox, et al., 1993, p. 548). Home health benefits also have very strict eligibility criteria (Fox, et al., 1993, p. 550). Also, because so many of its dollars are devoted toward institutional care, Medicaid has had "limited opportunities to maximize the use of...funds to develop community mental health care" (Mechanic, 1999, p. 139).

Often, plans apply criteria that in practice deny service access to patients not "expected to improve significantly over a short period of treatment" (Fox, et al., 1993, p. 548). This "poses a particular obstacle to care for children with chronic illness or disabilities" (Fox, et al., 1993, p. 552). Sometimes this criterion combines with requirements that the provided service is "needed to restore lost function" (Fox, et al., 1993, p. 548). Admittedly, specialty care is not always needed; however, to curb expensive specialist use, it is imperative to provide for "adequate," "sustained" community services (Mechanic, 1999, p. 149). "[T]he current era of private and public managed care is at risk ethically if it focuses primarily on cost reductions and the effectiveness of short-term approaches...Many people suffer at a time when effective care is at hand" (Pomerantz, 1999, p. 5). Some note MCOs' newer disease management protocols for other chronic illnesses, and hope for the same for mental illnesses (Pomerantz, 1999, p. 5).

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Biomedicine's emphasis of acute care to the detriment of prevention carries over to economic methods by which costs and benefits of particular interventions are compared (Krahn & Gafni, 1993, p. 411). Critics of such methods claim that discount rates and other tools give preference to short-term acute treatment over longitudinal, preventive efforts. Chapter 2 analyzes this debate.

Biomedicine also fails to take a 'lifespan approach.' This deficiency is particularly harmful to mental health care. Mentally ill youth are suspected to benefit most from interventions that begin early and take a longitudinal perspective. The authors of Mental Health: A Report of the Surgeon General (1999) thought highly enough of the lifespan paradigm to structure the report by life stage, showing how etiology, treatment, prevention and other factors vary strikingly according to life stage.

> "Different stages of life are associated with vulnerability to distinct forms of mental and behavioral disorders but also with distinctive capacities for mental health" (Satcher, 1999).

Critics argue erroneously that the biomedical model has helped formulate better diagnostic criteria in mental health care, for example the Diagnostic and Statistical Manual (DSM) (Kessler, 1990, p. 147). Contrarily, the DSM embraces biopsychosocial medicine. While preserving the benefits of reductionism; it functions as a bridge between biomedicine and biopsychosocial approaches (G. Osborn, personal communication, May, 2000). Its multiaxial format has evolved away from a strict biomedical model, and is the model of an integrated psychosocial approach to diagnosis. It is the only medical diagnostic guide that attends to psychosocial stressors; psychiatry applies it to record such day-to-day life stressors in the patient's record, behavior from which other specialties would benefit by emulating. Its axes (Axis I-V) allow quantifiability of functioning and symptoms (e.g., social and occupational functioning, effects of stress and personality factors, and influence of physical illness), and enable categorization of specific, discrete disorders (G. Osborn, personal communication, May, 2000). Diagnostic tools of other specialties have yet to catch up with this model. The DSM illustrates the limitations of reductionism: there are no lab tests to diagnose mental illness. The DSM's phenomenologic approach to disease classification comfortably envelops social factors external to the individual. In so doing, it allows for a systematic accounting of the complexity of mental illness (G. Osborn, personal communication, May, 2000). In future, though, if diagnostic lab tests are developed, this does not mean we should devote less emphasis to care needs and fostering caretaking environments (G. Osborn, personal communication, May, 2000).

It has also been argued that physicians do not have time to explore the patient's life context (e.g., see Engel, 1980, p. 543). However, it has been mentioned that such efforts can provide meaningful clinical benefits.

To promote the best possible preventive services, and combat the limitations of Western biomedicine, we need some sort of overarching, national infrastructure. Policy promoting such an infrastructure should include, where possible, financial support of religious institutions that already are committed to social programs. Extant examples include Lutheran and Catholic social services. Such services often already have an infrastructure in place that would be helpful for providing preventive services (G. Osborn, personal communication, May, 2000).

Chapter 2: Socioeconomic and Demographic Trends; Intergenerational Resource Allocation; Value Judgments in Economics

Demographic trends are fomenting debate about just allocation of scarce medical resources. Aging populations require more, and more expensive medical care than younger cohorts. Technological advances accelerate this trend by lengthening lifespans.

The goal of this chapter is to explore intergenerational resource distribution from philosophical, historical, and economic perspectives. A case has been made that emotionally disturbed children represent a vulnerable population worthy of heightened protection. Recall that heightened concern toward the most weak is a longstanding moral tradition. All age groups should care about how vulnerable children are faring, for moral and economic reasons. Devotion of sufficient resources to children's needs is not merely an intrinsic good. Long-term social program sustainability requires maximization of youths' functional outcomes.

Despite advances in technological medicine, pediatric mental illness remains inadequately diagnosed and treated. The treatment system is underfunded, poorly coordinated, and often grants access on the basis of economic factors, not solely medical need. Prevention and early intervention are also poorly supported. The Western biomedical model, capitation, and bioethics poorly account for complex needs of mentally ill children. See Chapter 1 for additional evidence about these issues.

One purpose of this chapter is to forecast that if demographic trends continue, the welfare of vulnerable children will erode. Arguing that biases in medical resource allocation exist in favor of the elderly, to children's detriment, is premature. However, an argument is made that multiple phenomena are setting the stage for such biases. Such factors include children's low sociopolitical status, normative theories regarding resource allocation, and economists' choice of tools with which to evaluate health care programs. There exist promising findings about what works in child psychiatry, knowledge sufficient to enact reform. But as resources continue to be diverted toward wealthier, politically empowered, vocal cohorts, hopes for addressing shortfalls and putting knowledge into practice fade.

Some caveats are in order. This chapter is not a mere academic exercise. Political decisions are constantly made about social programs such as Medicaid. Medicaid, heavily relied upon by children with emotional disorders, was originally intended for those in poverty. Increasingly, however, it funds nursing home care. This is in the face of data showing that since the 1960s, poverty trends of children relative to elderly cohorts have reversed (Callahan, 1987, pp. 205, 219). The elderly used to be the group with the highest poverty rates; now, it is children (Callahan, 1987, pp. 205, 219). Despite this trend, Medicaid spending on elders' needs is increasing.

This chapter does not propose rationing elders' health care services in order to devote more resources to children. However, some philosophers do propose such reforms. In any event, serious proposals of rationing are premature for a health care system such as America's that lacks, for example, a global budget. In other nations, a fixed amount of money is devoted annually to health care. Savings realized in one branch of the system can be shifted to another branch experiencing deficit. Contrarily, "[t]he total resources that [America] devote[s] to health care is not a fixed pie such that more resources for children's health must mean less for the health of the elderly" (Goddeeris, personal communication, 1999). In corporate, competitive systems, savings realized in one area are just as likely to be shifted to profit or salaries as they are to improved services.

This attempt at exploring intergenerational resource allocation is somewhat novel and more explicit than prior attempts. However, it is not premature. Consideration of ethical dilemmas surrounding intergenerational resource allocation should occur now, to encourage a sense of objectivity in social discussions of potential solutions. This chapter does not aim to end the discussion and proffer explicit policy recommendations, but rather to inform rational public discourse about the extent and limits of duties generations have toward one another. It can be concluded, based on demographic trends and other data in this report, that the fairest approach would be intergenerational in nature (G. Osborn, personal communication, May, 2000).

Intergenerational Resource Allocation: Philosophical Theories

In an argument claiming that one age group's needs are insufficiently being met, partly due to claims by other groups, it is necessary to examine literature related to age-based allocation. This is particularly the case where the claim is made that the group in question represents a vulnerable population worthy of heightened societal protection.

Proposals to ration services for the elderly do not follow from children's unmet need. America's health care system does not function in such a way that a "fixed pie" of dollars is dedicated annually to health care spending. Therefore, any savings realized from rationing health care for one group would not guarantee heightened resource allocation to services for another. Critics argue, then, that devoting attention to intergenerational justice and resource allocation is premature. However, as mentioned above, one goal of this chapter is to inspire rational reflection upon these issues, before eruption of emotionally laden crises.

Children are comparatively healthy. Most are not mentally ill. Critics assert that unmet need is insufficiently documented to warrant contemplation of rationing, let alone rationing disproportionately impacting care for certain groups. Also, since the elderly are comparatively sicker, it makes sense that they consume more resources. A response to this is that in fact, unmet need is sufficiently documented to warrant concern and a sense of urgency (see Chapter 1). Unmet need, children's political invisibility, and continued spending trends on elder care are a recipe for socioeconomic disaster in the years to come. However, because interventions for mentally ill children do not involve exciting, dramatic technologies, and because children lack political clout, bioethics literature has been bereft of discussion about how to ensure that their needs are better met, in the face of the growing burden of elder care.

The reader should emerge from this section with understanding of the following points. First, philosophers recognize intergenerational justice and allocation of health care resources as emerging ethical dilemmas worthy of analysis and social discourse. Second, philosophical approaches toward justice between generations in resource allocation are multiple and conflicting. Commentators offer various arguments to justify their approaches. However, they frequently stop short of calling their allocation schema a solution, instead asserting that social debate and reforms must come first.

In the current context of resource scarcity and changing demographics, the proportionally greater and growing expenditures for the elderly represent a moral problem, one whose urgency is growing, and one which will be only be solved "by principle or by default" (Daniels, 1983, p. 491). This means that 'allocative' decisions between groups, or 'rationing' decisions within groups, will continue to be made for non-moral reasons, such as financial incentives (market-driven, laissez-faire, ability-to-pay), political influence, or haphazardly (by default). Alternatively, society can rationally deliberate the problem, change its expectations of medicine, and arrive at distributive schema more fairly representing health-related interests of all age groups (Daniels, 1983, p. 491; Daniels, 1985, p. 88). It is acknowledged by bioethicists that rationing currently occurs, in what Callahan calls a covert, piecemeal, unreasonable manner, or what Daniels and Wikler call an imprudent, irrational fashion (Callahan, 1987, pp. 127-131; Callahan, 1992, p. 221; Callahan, 1993, p. 25; Daniels, 1983, p. 496; see also Churchill, 1988; Jecker & Pearlman, 1989; Lewis & Charny, 1989, p. 28; Moody, 1978, p. 198; and Wikler, 1988, p. 71;).

This review is limited to work focusing on allocative justice *between* generations. Many articles consider ethical and clinical ramifications of age as a factor in decisionmaking with respect to the elderly alone (e.g., regarding highly expensive care such as dialysis [see Calkins, 1993; Grapsa & Oreopoulos, 1996] or transplantation [see Amrein, et al., 1990; Laske, Niederhauser, Carrel, von Segesser, & Turina, 1992], or marginally beneficial care). Conversely, other work concentrates on dilemmas posed by neonates. Such work was excluded for space limitations.

Prominent among those offering schema by which to justly allocate medical resources among age groups are Norman Daniels and Daniel Callahan. Callahan's account, drawing from a communitarian perspective, coheres best with my claim that mentally ill children are a vulnerable population, the medical needs of which society owes particular protection. However, not all advocates of allocative schema including age as a factor in what Callahan calls 'setting limits' rely on appeals to community: appeals to liberal individualist tradition are made by both proponents (e.g., Daniels) and opponents (e.g., Jecker).

Other literature augments or critiques Daniels' and Callahan's frameworks (e.g., Jecker, 1989; Minkler & Robertson, 1991). While this literature offers tools in thinking about the problem, its utility in arriving at solutions is limited, partly because it does not account for chronic illness in other than elder groups, and because such schema begin with 'ideal' assumptions about society, which poorly translate into the real world, with its injustices, uncertainties, and socioeconomic vagaries. This flaw is noted by others (Churchill, 1988; Jecker, 1989; Moody, 1988; Moody, 1991, p. 182; and Wikler, 1988, p. 58). Even creators of such schema stop short of claiming they have arrived at solutions: instead, they first require social deliberation, alteration in what society expects from medicine, and/or that pervasive social injustices be solved (e.g., see Callahan, 1987, 1990, 1992; Daniels, 1983, 1985, 1993; and Jecker, et al., 1989).

A number of themes, assumptions, and questions pervade this literature. For example, what is the best way to think about generational groups and their relationships and duties to one another? Are generations properly thought of as competing-what has been called a 'zero-sum game' (Callahan, 1987, p. 128; Moody, 1988, p. 53)-or are they interdependent, so that benefits of expenditures made on one age group overflow to others? Should the elderly be viewed as heterogeneous, or is it appropriate to view them as a homogenous group with similar values and needs (e.g., in asserting that elderly people 'normally' need and utilize more services than youths and adults)? Should deliberators view their own individual interests from a lifespan perspective, with an awareness that one will benefit from a resource-transfer scheme in old age, even when shouldering a burden while young? Or should they maintain the prevailing 'time-slice' perspective, in which one perceives a zero sum game between one's own age cohort and others, such as Baby Boomers versus the Oldest Old (Daniels, 1983, p. 495)? Assumptions include that the amount of medical resources is finite since other social sectors, such as defense and education, also rightfully draw from America's economic output.

Resource scarcity is not the only constraint. Demographic changes including increased lifespan, lower fertility, and larger proportional numbers of older persons compared to youth, both increase elderly's proportional medical needs and consumption, and increase the incidence and prevalence of chronic, incurable disease. The latter has also been fueled by unbounded technological innovation, which thwarts death caused by acute illness and injury, but is less successful in preventing and curing chronic conditions causing extensive suffering. Economic trends pointed to by advocates of age-based allocation schemes include an increased proportion of children in poverty (Callahan, 1987, p. 205; Callahan, 1990, p. 160), and stable or decreasing resources allocated to institutions contributing to the children's well-being, such as education and social services (Callahan, 1987, p. 262; Callahan, 1990, p. 160; Daniels, 1983, p. 490).

Another assumption is that intergenerational conflict (an 'age war') exists in America; some point to public surveys in refuting this, and in support of allocation schemes (Minkler & Robertson, 1991). Such schemes rely heavily on intergenerational goodwill (Moody, 1988, p. 41), belief in age groups' interdependence (Moody, 1988, p.

48), or the "moral economy" of generational reciprocity (Minkler & Robertson, 1991, p. 339) for sustainability. Critics of age-based allocation fear that today's elderly are scapegoated, and are really victims, wrongly blamed for unmet needs of other age cohorts (Minkler & Robertson, 1991, p. 328). In this view, social programs such as Social Security and Medicare require *more* resources, not fewer, to address gaps in coverage for long-term, nursing home, or home care (Jecker & Pearlman, 1989; Minkler & Robertson, 1991). Moreover, critics fear the worsening of 'ageist' stereotypes, should society entertain or enact such schema (Clark, 1985; Jecker & Pearlman, 1989, p. 1073; Minkler & Robertson, 1991).

This body of literature lacks unanimity on how to define or solve the problem. Indeed, analyzability of a problem does not imply its solvability. Some argue that solutions require nothing short of wholesale revision in social expectations of medicine, what we perceive its goals to be, such as cure-the goal presently dominating-or care (Callahan, 1992, p. 222). Another goal requiring re-thinking is the drive to meet each individual need: a 'flawed,' unachievable goal, since boundless technological innovation breeds continuous, unchecked upward revision of what constitutes 'need' (Callahan, 1992, p. 221). Society needs to re-think its definitions of health, disease, an 'adequate' lifespan, and a good death (Callahan, Setting Limits).

Dan Callahan in his 1987 book Setting Limits argues that in future we will need to use age as a criteria by which to allocate costly, marginally-beneficial, life-extending technologies. His policy goals include universal health care, avoiding premature death, and decreasing later life suffering by expanding services such as long-term care. He argues that the 'modernization' of old age, and attempts to avoid aging and death by asserting an unlimited claim on public resources, represent an "unjust burden on the young" (Callahan, 1993, p. 24). Modern medicine holds a "...philosophy of denying limits, particularly where aging and attempts to extend life are concerned" (Levey & Hill, 1989); we should seek a better balance between care and cure, length and quality of life.

A philosophy of setting limits seems un-American at present. By 'limits,' it is meant that when we inspect the practice of medicine, we see a great deal of futile care at the end of life. Even if a life totally devoid of illness were possible, there are still finite physiological limits on how long we can live. And even if we could thwart such limits (e.g., by manipulating genes related to aging), the idea of conscious control over aging is so socially disruptive that we as a society are simply not ready for it. Even in a state of perfect health for the foreseeable future, there is still a finite human lifespan; with this perspective in mind, we need to define and set limits on goals of the life cycle (G. Osborn, personal communication, May, 2000).

That modern medicine denies limits is noted by others (e.g., Gleicher, 1991, pp. 2389-2390). Callahan's system would be "open and democratically achieved," (Callahan, 1993, p. 25), agreement at the community level, not covert as at present. To those arguing that such a schema threatens autonomy, Callahan responds that just resource distribution within a community requires limits on autonomy and individual claims. "[T]he old have a duty to the young not to make demands that will harm the young; and...the young...have some significant duties to sustain the welfare of the old" (Callahan, 1993, p. 26).

Opponents to age-based allocative schema claim that decisions should not be made on the part of the elderly as a group because of their heterogeneity (Callahan, 1987, p. 121; Callahan, 1993, p. 26). Callahan counters that this is not incompatible with using age as a criteria; with respect to two important factors ([1] they "consume a disproportionate share of resources," and [2] health care for them tends to be more expensive than for the young [Callahan, 1993, p. 26]), this can be viewed as a group problem. The attractiveness of age-based criteria are that they are "clear and visible"; they apply to everyone; and in helping people thwart premature death, society is both able to meet its obligation and avoid the ludicrous attempt to spend unbounded dollars on extending life expectancies (Callahan, 1993, p. 27). An added bonus is that establishment at the policy level avoids the vagaries and conflicts of interest of bedside rationing.

Norman Daniels' 'prudential lifespan approach' or diacharonic, life-course perspective advocating age-based rationing, is a 'person-centered' argument. The advantage of thinking about intergenerational resource allocation this way is that it enables acknowledgement of elder health care as a collective problem, one that each of us will face. It represents a shift away from the prevailing frame of reference for viewing the problem-a 'time slice' approach encouraging an 'us against them' mentality: currently-existing age cohorts competing for their share of the pie.

Looking instead out over our own lifespan, what allocation of resources or mix of spending and services, would rational individuals prefer, operating on the assumption of limited resources and one's inability to predict future medical needs? Daniels claims that we would want to maximize the chances of living a 'normal' lifespan. Toward this goal, one would opt for maximum access to life-extending services while young, while choosing less-expensive interventions that maximize quality of life after attaining older stages of life. Such a lifespan approach, deriving from Rawls' social contract, is already used for thinking about allocation of other social resources such as education (Clark, 1985, p. 123). Limitations of Daniels' approach include its assumption that "...more general principles of justice already solve problems of distribution between persons...answers to more basic questions of justice have been found already" (Jecker, 1989, p. 657).

Recall the introduction's contrast between Americans' 'rugged individualism,' and Western Europeans' shared, collective experiences and values. Recall also that the U.S. is one of only two nations that have failed to ratify the U.N. Convention on the Rights of the Child. The Convention spells out a basic right to both health care (e.g., Article 24) and education (Articles 28 and 29). Western European nations' prioritization of the community good has facilitated their understanding that there are solid, good reasons to invest in both early education and pediatric healthcare (G. Osborn, personal communication, May, 2000).

Jecker and Pearlman (1989) and others have categorized and critiqued arguments for and against age-based rationing. With respect to arguments supporting age-based rationing, Jecker and Pearlman. include 1) 'productivity' arguments, 2) 'person-centered' arguments, and 3)'equality' arguments. In seeking to maximize such a goal as productivity (or, financial savings of health expenditures, or return on investment in saving life-years), those marshalling productivity arguments claim that older persons compete unfavorably against the young: they are less productive, are more frequent users of high-end medical services, or have fewer life-years left to save (Jecker & Pearlman, 1989, pp. 1069-70). Productivity arguments are utilitarian in their effort to maximize social goals.

Callahan, Daniels, and Moody advocate age-based rationing by appealing to what Jecker and Pearlman call person-centered arguments: all individuals should be respected regardless of productivity level. Callahan argues that rationing health care to the elderly, with a mind towards assisting all to achieve a 'natural lifespan', is not inconsistent with respecting the old. Daniels, in rendering old age a part of all of us by calling for each individual to adopt a 'life-time' perspective, also promotes respect for individual elderly autonomy. Finally, Moody argues that restricting life-extending care to the elderly, while promoting palliative care, enables them to achieve better quality of life; it does not do so by disrespecting them (Jecker & Pearlman, 1989, p. 1071). The argument advanced in this thesis is a person-centered approach. Such an approach seems most persuasive in this context partly because it spotlights commonalities between the elderly and mentally ill children as vulnerable social groups. Advocates of person-centered arguments respect all persons whether or not they are employed or economically productive (Jecker & Pearlman, 1989, p. 1070). They prioritize quality of life, which is not inconsistent with respect for individuals (Jecker & Pearlman, 1989, p. 1071). For the elderly, this might be at the expense of quantity of life; for mentally ill children, it suggests we should emphasize quality treatment within a caring environment in cases where prevention or early intervention has failed or is too costly. These are critical uniting points in a modern industrial society that often grants respect, rewards, and individual social worth via economic productivity and independence. It often follows that such societies question the value of living as a disabled, chronically ill, incompetent, and/or dependent individual. One flaw of person-centered approaches is that they presume broader social needs (e.g., a just health care system) will be met when (e.g.) a longer lifespan or cure for mental illness is impossible.

Another category of arguments favoring age-based rationing is equality arguments. Adherents claim the impropriety of classifying ageism as equally morally objectionable as sexism or racism: while most people experience both youth and old age, they will not be members of all genders or ethnicities. Because of this, and facilitated by Daniels' 'life-time' perspective, "...differential treatment by age does not imply unequal treatment between persons over a lifetime..." (Jecker & Pearlman, 1989, p. 1071).

Jecker and Pearlman (1989, p. 1072) list the following arguments against age-based rationing: 'needs-based' arguments, arguments appealing to 'special duties', and arguments charging 'invidious discrimination'. Adherents of needs-based arguments emphasize the elderly's greater need for medical services, asserting that societal duty follows from this heightened, disproportionate need. Arguments appealing to 'special duties' invoke not elevated medical needs, but the communitarian-based notion of connection to the community as the foundation of a special social duty to provide medical care to older persons, not deny it. One assumption of such arguments is that individuals become more embedded (acquire more responsibilities) in a social network with age, such that the loss of an older person through death causes greater damage to "the social fabric" than does (e.g.) a neonatal death (Jecker & Pearlman, 1989, p. 1072).

Finally, arguments charging 'invidious discrimination' claim that rationing based on age is both conceptually supported by and will aggravate age bias and cultural prejudice against older people (Jecker & Pearlman, 1989, p. 1073). Some adherents of such arguments fear the slippery slope, that heightened cultural prejudices will lead to denied access to medical and other social goods. With this fear in mind, a person-centered approach seems most compelling because it promotes respect for all individuals, including those who for reasons of disability, age, or chronic illness are incapable of supporting or advocating for themselves. Such characteristics unite both mentally ill children and the elderly. Person-centered arguments for age-based rationing counter America's devaluation of all categories of dependent citizens. A person-centered argument advocating age-based rationing best adheres to my claims that mentally ill children's needs are insufficiently met and warrant rendering this group a vulnerable population owed special protection. Person-centered arguments have the added bonus of being among the most conceptually mature arguments favoring age-based rationing.

Intergenerational Resource Allocation: Historical Trends

A wealth of information illustrates significant sociodemographic shifts underway with respect to age distribution, lifespan, poverty, and other trends. Bioethicists have appropriated literature containing thirty years' worth of such data to illustrate the growing urgency of the problem of intergenerational medical resource allocation.

Since the 1960s, the economic fortunes of children have deteriorated, while those of the elderly have grown. In 1960, the elderly as a group were poorer than children (Callahan, 1987, p. 205). From 1970 to 1982, poverty among children rose from 37% less than that among the elderly, to 56% greater than among the elderly (Callahan, 1987, p. 205; Callahan, 1990, p. 160). By 1992, 20% of children lived in poverty; children were the poorest age group (Callahan, 1992, p. 219). That same year, the elderly were the "most affluent age group" (Callahan, 1992, p. 219). Yet from 1984 through 1987, federal expenditures targeted toward the elderly were six times greater than those toward children (Callahan, 1987, p. 205; Callahan, 1990, p. 160). Poverty has always been a greater challenge amongst minorities of all ages (Callahan, 1987, p. 205). In 1992, 50% of black children under 6 lived in families in poverty (Callahan, 1992, p. 219). Meanwhile, the income gap between haves and have-nots remains a problem: only three countries are more unequal than the U.S. in terms of distribution of income (Sardell, 1990, p. 290).

By 1980, health care benefits for the elderly were eight times greater per capita than for non-elderly; they were fifteen times greater per capita for the elderly than for children (Callahan, 1990, p. 160). Those aged 65 and over consumed a third of health care expenditures in the 1980s (Jecker & Pearlman, 1989, p. 1069). By 1990, 12% of the U.S. gross national product (GNP) was spent on medical care; an increasing portion of this was being spent on the elderly. Countering those claiming the amount spent on health care is an indicator of quality, Callahan (1987) wrote, "[t]hat the United States already devotes a larger portion of its GNP to health care...than other developed countries with excellent health-care systems is itself a good reason for politicians and health planners to believe that more money would not in itself guarantee any greatly improved level of health care" (p. 124). Note that this assertion, that spending more money does not necessarily improve quality, directly opposes age-based rationing opponents like Jecker, who urge that more resources, not fewer, be spent on the elderly in order to improve health care quality for them, specifically by closing gaps. In <u>Setting Limits</u> (1987), Dan Callahan forecasted: "[w]hereas in 1985 the elderly population of 11[%] consumed 29[%] of health-care expenditures, the expected 21[%] elderly population will consume 45[%] of such expenditures in 2040 (p. 120).

Given demographic shifts toward proportionally greater numbers of elderly, Medicaid spending trends are worrisome. Also worrisome are historical trends that powerful interest groups mold allocative decisionmaking in the form of federal legislation to their own interests. "Beginning in 1972, there was a shift within Medicaid away from spending on health services for nondisabled children as a higher proportion of Medicaid funds went to pay for services for aged, blind, and disabled SSI recipients;" between 1972 and 1987 the percentage of Medicaid expenditures on nondisabled children dropped (Sardell, 1990, p. 279). Further, "[a]lthough Medicaid is the major source of funding for children's health services, almost three-quarters of all Medicaid expenditures are spent on services for the aged, blind, and disabled" (Sardell, 1990, p. 279). Of course, it is likely that some emotionally disturbed children qualify as disabled, thus may be counted not under Medicaid children's expenditures, but instead grouped categorically with the 'aged' and 'blind.' Anecdotal and other evidence, however, suggests that even children exhibiting severe difficulties may be less able to win SSI disability coverage (M. Woolson, personal communication, May, 2000).

Legislation, such as the Omnibus Budget Reconciliation Act (OBRA, 1981) led to hundreds of thousands of families losing Medicaid coverage (Sardell, 1990, p. 279). During the late 1970s-early 1980s Medicaid spending per child fell 13%; federal spending for programs impacting child health and well-being fell 32%. In contrast, from 1985 to 1989, Medicare expenditures were projected to *rise* 60% (Callahan, 1987, p. 117). Medicare is a socially-maintained program funding health care for the elderly. Callahan (1987, p. 128) wrote "[w]hereas [Medicaid] was originally designed to provide general health care for the poor, its originally incidental inclusion of long-term care of the elderly has meant that as the latter's costs have risen, funds for the other poor have proportionately declined... *driven down* by the costs of long-term care" (Italics mine).

By 1987, 35% of Americans lacked health care insurance (Callahan, 1987, p. 215). In 1990, only half of children eligible for Medicaid were enrolled (Sardell, 1990, p. 283). Social factors help explain why Medicaid-eligible children are not enrolled, and include parental language and educational barriers. Governmental efforts have recently been initiated to make parents more aware (e.g., Pear, 1999), such as a nationwide toll-free number.

The journal *Morbidity and Mortality Weekly Report* surveyed over 185,000 adults to determine the relationship between age and having 'adequate insurance,' 'underinsurance,' or 'no insurance.' These data show a clear trend: the younger the person, the more likely he/she is to be un- or underinsured. In 1995-96 young adults were most likely of all age groups to be uninsured (Anonymous, 1998a, p. 531). The report recommended "more affordable private insurance, a national health insurance program, or allowing certain segments of the population to purchase Medicare"(Anonymous, 1998a, p. 532). While some posit that increased spending on health care fails to guarantee quality improvement, this report assumes that increased spending will improve access.

There is evidence that insurance status makes a difference in whether mentally ill children's treatment needs are met. For example, one study revealed that paradoxically, while youths with Medicaid were better able than uninsureds to access services, youths with private insurance accessed services at the same rate as uninsureds (Burns & Hoagwood, 1998, p. 693). "[P]rivate insurance, with its deductibles, co-payments, and historical caps, functioned as a barrier to service use even for very high need youth," a finding replicated in a national study (Burns & Hoagwood, 1998, p. 693).

Another MMWR report (Anonymous, 1998b) gives credence to the recommendation for national health insurance: "[t]he prevalence of adequate coverage was highest in Hawaii [87.9%], the only state to have nearly universal health-care coverage" (Anonymous, 1998b, p. 51). These findings agree with other data indicating that "...most persons who were uninsured were either uninsured or underinsured, possibly reflecting the inadequacy of employer-based health-care coverage" (Anonymous, 1998b, p. 53).

"Remarkable increases in the life expectancy of populations in economically developed nations have occurred in recent history...[m]ore remarkable is the increase in life expectancy at advanced ages..." (Manton, 1986, p. 672). Evidence from gerontology suggests that Callahan's schema might best balance the needs of the elderly with resolving the resource scarcity problem. Recall his proposals: better balancing care and cure, quality and quantity of life, by setting limits through emphasizing basic health care over a natural life span, while limiting life-sustaining technology. For example,

> "[a]t all ages the chronic conditions that produce the largest number of deaths (e.g., cancer, heart disease) generate only small amounts of the total chronic disability-even disability at high levels. The greatest amounts of disability are reported to be due to chronic degenerative conditions (e.g., senility, arthritis, and atherosclerosis)...Thus, to reduce the total amount of disability in the population by controlling chronic disease risks, it appears that one must intervene early in the degenerative process *before* the acute phases of the degenerative processes become manifest. Comparing disability levels in the 65-74 age group with those above age 85 shows that above age 85, the chronic degenerative conditions are even more important in causing disability." (Manton, 1986, p. 678)

Many chronic degenerative diseases are amenable to preventive interventions: the earlier, the better. Such interventions may not require high-technology, expensive, marginally effective procedures, but rather lifestyle modifications which can be effective at addressing multiple chronic conditions. For example, reduced fat in the diet can both reduce cholesterol levels that lead to atherosclerosis, and help reduce obesity, a risk factor for cancer, diabetes and other conditions. Callahan's schema prioritizes allocating resources towards interventions (e.g., prevention, early intervention) likely to reduce later life suffering. The urgency of addressing and preventing chronic, disabling illness and suffering among the elderly is growing: "...the numbers of disabled elderly adults can be expected to increase as the number of survivors to later ages increases due to mortality reduction" (Manton, 1986, p. 680). "Between 1965 and 1980, there was an increase in the life expectancy of those who reached age 65 from 14.6 to 16.4 years, with a projected increase by... 2000 to 19.1 years" (Callahan, 1987, p. 119).

"Between 1980 and 2040, a 41-percent general population increase is expected, but a 160-percent increase in those 65 or over" (Callahan, 1987, p. 119). Jecker and Pearlman (1989, 1069) stated that between 1900 and 1989, the number of persons over 65 rose eight times, while the *proportion* of persons over 65 rose three times; the number of people over 85 comprised the fastest growing age group—their numbers rose twenty-one times.

Logically, as the population of one age cohort grows, other cohorts remaining stable or falling, the proportion of medical expenditures on that cohort will grow, barring shifts in the manner in which, and to whom, health care is provided. Numbers bear this out. "In 1980, the 11 percent of our population over age 65 consumed...29 percent of the total American health-care expenditures... By 1984, the percentage had increased to 31 percent..." (Callahan, 1987, p. 119). These trends illustrate that intergenerational medical resource allocation is becoming an increasingly urgent moral and policy dilemma, a dilemma concerning issues of justice. The falling dependency ratio (ratio of young to old) is another trend that should be of concern to policymakers counting on the economic sustainability of intergenerational wealth transfer schemes. America's family size is dropping and is now barely 'replacement rate' (Callahan, 1992, p. 221). The number of offspring eventually translates into the number of workers available to support medical and other needs of elderly parents, and to maintain economic growth and competitiveness. Following this thinking, social spending on maternal and child health/nutrition services and education represents "an investment in the future American workforce" (Sardell, 1990, p. 287). In order for U.S. industry to compete internationally and avert "severe employment crisis," society should invest in 'human capital,' namely, educational reform to better facilitate learning, and "prevention through early intervention" (Sardell, 1990, p. 287).

Many people lack understanding of sustainability issues. The percent of GNP devoted to health care cannot continue to rise without deleteriously affecting other social sectors. Managed care, touted as a panacea in the 1970s-80s, did temporarily succeed at controlling costs. However, employers are reporting that premiums and copays are rising again (Meyer, 1998, p. 46). MCOs claim this is due to increased regulation and mandated services inspired by public backlash (Kahn, 1999; Matthews, 1998, p. A14; Meyer, 1998, p. 46). Economists claim that savings achieved by elimination of waste and fraud are finite, and will not curb the rising costs trend.

Even in the current era of spectacular economic growth, serious problems of access such as uninsurance and underinsurance fester, as do imperfections in allocative justice, such as income inequities, uneven geographical distribution of physicians, and delayed or inappropriate treatment for some life-threatening conditions for women and minorities. The cyclical nature of economic booms and busts is undeniable. Current economic conditions likely will not persist indefinitely; in economic downturn or recession, unemployment and underemployment rise. Because Americans' medical coverage remains linked to employment status (Anonymous, 1998b, p. 51), problems of under- and uninsurance are likely to cycle as well. This scenario can be aggravated by the ongoing erosion of social welfare programs. Poor and minority children are most likely to be adversely affected by such trends-and these children are most at risk of complex lifetime ramifications of mental illness. The argument in this thesis has been that emotionally disturbed children are particularly vulnerable; it is axiomatic that poor and minority children will be more greatly affected by such trends than privileged children.

Whatever reforms are proposed, sustainability must be a key ingredient. Regardless of how wealthy we are, we should be concerned about program sustainability; otherwise, we tacitly condone the magnification of already extreme discrepancies in income and health status among our citizenry. A possible solution, advocated by bioethicists including Callahan, is to shift funds from expensive, marginally-beneficial or futile life-sustaining medical treatment at the extreme end –and beginning- of life, toward preventive measures in childhood. Reviewing literature on age-based allocation can inspire discussion of how it might ethically be carried out. Proponents of public health interventions have encountered great difficulty in raising money from government and insurance companies. Their concerns resemble concerns of proponents of age-based rationing, specifically regarding moral commitment to rationing schemes. Society must be persuaded that such investments, which cause immediate financial hardship, are worthwhile long-term investments in human capital.

Moral commitment to funding prevention symbolizes commitment to future social welfare and sustainability of its institutions. Before America embarks on a high-tech, costly crusade to extend the limits of biological life, it should address the plight of millions of children who, because of untreated or inappropriately treated mental illnesses, 'fall through the cracks'- dropout, diversion to the criminal justice system, social and career impairment. It is shortsighted for insurers to claim that savings are achieved by denying early preventive treatment. Rather, economists have noted, the balloon is squeezed elsewhere: costs are shifted to other sectors (schools, prisons, social services). The private sector also loses economically, when premature death aggravated by such illnesses claims millions of productive life-years.

Recent trends in education spending indicate that society may be more amenable than ever to embrace preventive investment in human capital. Examples include reproductive services in high school clinics and disability accommodation. These examples, however, also show that powerful financial disincentives still exist with respect to how both education and health care are funded, disincentives rendering preventive interventions less palatable to payers.

Overcoming resistance by conservative interest groups, government invests in preventive medical and other services in some schools, including sex-education, distribution of contraceptives, programs for teen mothers, and day care for their children.

None of these contribute directly to the fundamental goals of education, namely to impart a defined mix of skills, competencies, and basic knowledge to create productive workers and citizens. Rather, the goal is clearly preventive, and benefits are long-term, not immediately realized-and not guaranteed.

One criticism of age-based rationing schemes is that it will be a struggle to convince individuals to commit goodwill and trust, for fear that their financial sacrifice will not be repaid in future if the system proves unsustainable. Similar reluctance makes individual school districts and MCOs wary of committing to preventive investment in human capital. A school district might invest additional dollars, above the amount for an average student, toward day care for a teen mother, only to see her transfer to another district-or drop out. Similarly, an MCO might spend additional dollars, above the amount for an average patient, on persuading a covered employee's child to refrain from starting smoking, and avert increased risk of costly, later-life disease. However, the MCO is unlikely to itself recoup the financial benefits of this investment, since it is highly unlikely that individuals will remain enrolled in the same MCO for life (Phillips & Holtgrave, 1997, p. 20). The MCO is aware that its competitors would benefit were this youngster to never smoke, thus never need expensive smoking-related disease treatments.

Such financial disincentives toward prevention are less of an issue in a cradle-to-grave, single payer system, for obvious reasons. It is reasonable to assume, therefore, that reforms toward a universal, comprehensive single payer health care system would face significantly fewer economic disincentives toward prevention and multisector public health measures than does the current system, with its multiple, competing payers.

Society has a moral as well as financial interest in making intergenerational resource allocation more just. This thesis identifies emotionally disturbed children as a vulnerable population group. The limited civil rights of children are aggravated by the fact that such patients are also often from historically-disadvantaged social backgrounds. Recall from the Introduction: "The moral measure of our society is how we treat the least among us" (Moynihan, 1996), and "We believe the moral measure of our society is how our weakest members are faring" (Keeler, 1995). This moral stance is espoused and endorsed by a wide variety of community leaders, religious and political.

> "[O]ur nation must restrain its spending to keep from further mortgaging our children's future...the weakest members of our society should not bear the greatest burdens. Poor families and children may not have powerful lobbies, but they have the greatest needs" (Keeler, 1995)

Intergenerational Resource Allocation: Economics Tools

The first part of this section explores commonly used economics tools such as cost-benefit analysis (CBA) and cost-effectiveness analysis (CEA). These tools, applied in health program evaluation, contain assumptions that may lead to future injustice in intergenerational resource allocation, particularly between preventive and curative interventions. Such tools, however, are "less susceptible to special interests, more likely to optimize the health of the target population, and most likely to optimize use of [limited] health care resources" (Ganiats, 1997, p. 12). CEA is a descendant of CBA (Redelmeier, Heller, & Weinstein, 1994, p. 301). Despite economics' grounding in an 'ideal' economy, it has been argued that CBA and CEA "...are needed only when market forces fail to allocate resources optimally, as in health care because of inadequate consumer information and distortions caused by insurance" (Redelmeier, et al., 1994, p. 302). The fact that psychosocial and other factors influence individuals' thinking about such tools, but are not accounted for in the ideal economy, raises questions about how accurately CEA, CBA, and discounting reflect real behavior and values, and fuels calls for improved discounting models (Ganiats, 1994, p. 298).

Economists define the "exponential discount model for time preference" as "...a mathematical formula for comparing different amounts of money at different points in time" (Redelmeier, et al., 1994, p. 301). Lipscomb (1989, p. S233) defines time preference:

> "...for a given quantity of an economic 'good' (defined as yielding pleasure), a person with a 'positive' time preference orientation—the typical assumption—will prefer current to future consumption. Likewise, for a given quantity of an economic 'bad' (defined as yielding displeasure), a positive time preference psychology will imply a preference for future over current consumption—a desire to postpone consumption."

Discounting is "a method of determining the present value of a future outcome" (Ganiats, 1997, p. 12), and "is based on a preference for the present over the future or, 'a bird in the hand is worth two in the bush'" (West, 1996, p. 240). The assumptions behind discounting are "1) most people would accept less money to receive it sooner; and 2) less money can be invested by society and allowed to grow...to yield the money required for future costs" (Krahn & Gafni, 1993, p. 404). "Opportunity cost of [a] health care program is the foregone returns from investment in another health program, in manufacturing, or education" (Krahn & Gafni, 1993, p. 404). The origins of discounting are anthropological and social and relate to fulfillment of basic needs within the environment (e.g., food) (West, 1996, p. 240). The conceptual distinction between individual and social discount rate is based on this difference in how much individual and social needs vary (West, 1996, p. 240).

Discounting also has philosophical origins. "Neoclassical economics" reflects modern thinking about discounting (West, 1996, p. 243). "The dominant current philosophy of...heavily discounting the future...rather than investing in real factories, employing real workers and producing real products, was not the philosophy of our forebears" (West, 1996, p. 244). Analysis of the history of discounting's use in evaluating health care programs yields an appreciation of the relation between discount rate and normative issues such as intergenerational resource allocation (Krahn & Gafni, 1993, p. 408). Today's neoclassical approach, which prioritizes the individual time preference rate over social values (expressed in the social discount rate), "is a relatively new concept...." (Krahn & Gafni, 1993, p. 408).

A.C. Pigou, an economic thinker, said, "The state should protect the interests of the future...against the effects of our irrational discounting and of our preference for ourselves over our descendants. It is the clear duty of Government..." (Krahn & Gafni, 1993, p. 409). Economic thought underwent a major shift in the mid 20th century:

> "[C]urrent economic thought grounds the notion of social welfare in the concept of utility, a subjective concept based on individual preference. This conceptual change...fundamentally altered the way economists thought about the social discount rate and the ancillary notion of intergenerational transfers. Only the preferences of the currently living generation were regarded as relevant to the determination of the [social discount rate]; the equal valuation of all individuals, regardless of the generation that they belonged to, was regarded as an anachronism" (Krahn & Gafni, 1993, p. 409).

Psychological, social, cognitive, clinical, and age factors relevant to time preference and beliefs about discounting are documented, and vary tremendously among individuals (e.g., Ganiats, 1994, p. 298; Ganiats, 1997, p. 13), among groups, and among disease states (Ganiats 1997, p. 16; Johannesson & Levin, 1991, p. 652). Psychological factors prompt people to value current over delayed benefits; such factors include uncertainty of the future, which inspires anxiety that one may not be able to collect future benefits (Redelmeier, et al., 1994, p. 302). Monetary risk-taking patterns and discount rates vary by age (Ganiats, 1994, p. 300). Evidence is insufficient to determine whether age factors influence the health discount rate; it "seems reasonable" Ganiats (1994). Clinical factors contributing to individual thought about discounting include the recognition that one is likely to suffer side effects today from deciding to take certain preventive drugs, but it is not certain that stroke or heart attack will be averted in future (Lipscomb, 1989, p. S234).

Rather than an economic discounting model, I chose an early investment model. The appeal of early investment is ancient wisdom; for example, see Aesop's fable, "The Ant and the Grasshopper." Most people agree that pain is involved in investing for the future, but most individuals also believe that such investment is wise. Of course, a 99-year old individual might find investment less attractive. Society must decide what interventions are rationally wisest to invest in, and should also make explicit what social goods will be discounted at each life stage (G. Osborn, personal communication, May, 2000).

The description of cost savings of the Elmira PEIP program (see Chapter 1) discussed that program's sensitivity to even small fluctuations in which discount rate is chosen for analysis. It may be the case that children's interests are best served by either minimizing the discount rate used, or eliminating its use altogether (J. Goddeeris, personal communication, May, 2000) in cost analyses that will help shape policy. Such choices would better promote the lifespan approach advocated in this thesis' argument.

With the help of complicated tables and figures, Welch (1991, p. 334) explains this phenomenon, concluding

> "higher discount rates tend to decrease the relative value given to the lives of children. In short, the choice of how much to discount future dollars becomes a choice of how much weight patient age will exert in CEA...[Discounting has a] potent effect...in favoring interventions for the elderly...[This phenomenon] has gone largely ignored."

Great controversy exists regarding discounting methodology (e.g., Ganiats, 1992, p. 551; Ganiats, 1997, p. 14; Johannesson, 1992, p. 359). Economists do recognize that health cannot be invested like money; it cannot be 'banked' for later use, and people must take good health as it comes to them—they cannot arrange to accept poor health today for good health tomorrow (Ganiats, 1997, p. 14; Redelmeier, et al., 1994, p. 302).

Analyses involving discounting come from additional perspectives: institutional, third-party payer, private for-profit insurer, corporate, government (Krahn & Gafni, 1993, p. 403). The choice of perspective dictates whose value judgments about resource distribution over time prevail (Krahn & Gafni, 1993, p. 412). Philosophers assert that health should "be on a higher level than dollars;" that directly comparing them cheapens life's worth (Ganiats, 1992, p. 551; see also Krahn & Gafni, 1993, p. 413).

Discounting may contribute to bias against preventive programs in favor of acute interventions whose benefits are realized sooner. Prevention programs are not always cost effective; this and the fact that their benefits lie in the future has put them at a comparative historical disadvantage to competing interventions (acute care, non-medical programs) for attraction of government funding (Anonymous, 1992, p. 148; Chapman & Elstein, 1995, p. 374; Lipscomb, 1996, p. DS121; Phillips & Holtgrave, 1997, p. 18). "[P]revention programs incur a bulk of their dollar costs today, but their...benefits occur in the future. Discounting these future benefits puts the program at a disadvantage" (Ganiats, 1992, p. 552). Prevention programs are also "held to a higher standard than treatment because [they] are expected to demonstrate cost savings" (Phillips & Holtgrave, 1997, p. 18). Recently (1997), only 3% of health expenditures were devoted to prevention (Phillips & Holtgrave, 1997, p. 18); in comparison, 15% of 1998 health expenditures were spent on dialysis alone (Gerson, 1999, p. A23). Cost analysis can both under- and overstate the net benefits of prevention (Phillips & Holtgrave, 1997, p. 18). Oftentimes, prevention clearly saves money; an example is regularly brushing one's teeth (G. Osborn, personal communication, May, 2000).

If an equal discount rate is not applied to both money and health, paradoxically, it might be most rational to never fund prevention programs, or to keep delaying them indefinitely (e.g., Ganiats, 1997, p. 12; Johannesson, 1992, p. 363; Johannesson & Levin, 1991, p. 651). Moreover, if the health discount rate is less than the monetary rate, "'no particular program should ever be implemented' because by postponing the program for one year the program will become more cost-effective" (Ganiats, 1994, p. 298). However, the prevention paradox is rarely seen because of powerful political influences (Redelmeier, et al., 1994, p. 302).

Bioethics, like economic theory, tends to prioritize the individual over the public health perspective. " 'Identified' lives saved by treatment in the present hold more influence than 'statistical' lives saved in the future by an equivalent investment in prevention; for example, the dramatic high-technology rescue of one premature baby demands our attention more than prenatal care for 500 women" (Phillips & Holtgrave, 1997, p. 20). One need only examine the prevalence of case-based, emotionally poignant analysis in the literature (and popular media) to see the truth in this assertion.

A majority of CEA discounting methods identified by Johannesson (1992) and others (Anonymous, 1992, p. 148; Johannesson & Levin, 1991, p. 651) exhibit mathematical biases against the young in favor of the old. This bias runs counter to economic theory. The theory and mathematics behind this are complex. Others raise such concerns, asking whether "...society should make allocation decisions...in a way that treats...cohorts equally—regardless of when in the future they come into existence?" (Lipscomb, 1989, p. S237). "It is...important to be aware of the distributional implications of different methods [of discounting] with regard to priorities between different age...groups" (Johannesson & Levin, 1991, p. 652).

To adopt a discounting method where the health outcome discount rate equals the monetary rate, means that we would be "...act[ing] as if there is a social consensus...Such a consensus...is basically a political judgment about intergenerational equity" (Lipscomb, 1989, p. S238). This is a "...problem of whether to accord all cohorts equal social standing in the cost-effectiveness calculus...a social judgment about equity and the nature of the social contract" (Lipscomb, 1989, p. S240). Selection of a social health outcome discount rate "...represents a global political decision about the relative weights current decision makers should attach to future population cohorts" (Lipscomb, 1989, p. S246).

The level of emotion attached to the issue of discounting in health policy analysis is clear.

> "Rather than use discount rates of 5% to 10%, why not use terms like shortsighted, living for the present, mortgaging your future and your

> children's future to more accurately portray the real issues? We in the United States are already reaping the 'rewards' of discounting the future in health, education, and the general well-being of society. As our society is in the process of collapse, people are living more for the present at the expense of the future" (Coren, 1992, p. 472).

West (1996, pp. 239, 244) writes,

> "Discounting inevitably encourages 'short termism' and hence biases public policy decision making...The most important natural resource (economic good?) is people, and people in the future are as valuable to society as people now...[eliminating discounting] for health care planning and other public policy decisions [is] better for the future of collective decision making and...society generally."

Some argue that "...selfish myopia [application of certain discounting methods] is not a rational basis for public policy—e.g., it would favour [sic] underinvestment in the long-term health for the poor...It almost certainly does not reflect the way people want governments to act on their behalf" (Anonymous, 1992, pp. 148-9).

Economists know that tools applying discounting to assess health programs' cost effectiveness are limited in resolving such normative questions (e.g., Watts, Jackson, & LoGerfo, 1979, p. 431). Some suggest the critical issue is not what the proper discount rate is, but rather being explicit as to what end CEA is being performed: toward a public health policy or a clinical policy (Ganiats, 1994, p. 299). Ganiats is also concerned about the emphasis on comparing the health discount rate to a monetary discount rate. The limiting factors of rationing in America are more often non-monetary, such as availability of ICU beds, organs, and equipment, whereas CEA applies dollars as a unit of analysis. Moreover, America has yet to limit dollars allocated to health care: the proportion of the GNP allocated to medical care continues to grow unbounded. To make CEA more relevant, one might adjust the method to calculate (for example) "dialysis machine per QALY" instead of the prevailing "dollars per QALY" (Ganiats, 1994, p. 299)

A consensus of sorts in recent literature is that cost and life-years should be discounted at equal rates (Johannesson, 1992, p. 359). However, GNP might influence the social monetary discount rate (Ganiats, 1994, p. 299).

There are a number of competing discounting models (Johannesson & Levin, 1991, p. 651; Lipscomb, 1989, pp. S234, S245). Each method for discounting life years or QALYs "yield[s] fundamentally different results;" whether a program is judged worthy of investment can vary radically depending on the method used (Lipscomb, 1989, pp. S234-6). Moreover, it is more difficult to compare CEA results across programs when economics lacks consistent use of a standardized method (Johannesson, 1992, p. 363).

Many suggest that discount rates be determined through political processes, although some (Lipscomb, 1996, p. DS121) are concerned that "...the practical problems of doing this would seem overwhelming...". Watts et al. (1979) state, "[M]ost of our social decisions are made with a heavy dose of political input. To the extent that [CBA and CEA] can help to make an open and informed process, perhaps this is the most satisfactory result." Krahn and Gafni (1993, p. 403) suggest a "consensus conference approach." This approach would create a targeted panel modeled on existing health care consensus and guidelines panels; its panel draws from both empirical and normative work, and exercises democratic deliberation through an open, public forum (Krahn & Gafni, 1993, p. 416). Chief advantages are openness, flexibility, and responsiveness to changing social values.

Ganiats (1992, p. 552) succinctly points out both the importance of discounting to health policy and allocation, and the need for further, corrective research on the topic:

> "Health policy and practice guideline formulation increasingly rely on cost-effectiveness research. This research, therefore, leads to a form of rationing...Rationing per se is not the problem, but some health policy research does lead to conclusions that we, as a society, may not choose to accept...[D]o we want to withhold funding from prevention programs because we discount future health benefits?...Do most people really prefer present health to future health? Does prognosis or age make a difference? Does the type of program (preventive versus curative) matter?...The paradox is likely caused by the relative youth of this field of research [see West 1996, 239] and begs for more research into discounting, preferences, and decision making."

Such research is imperative as "[e]conomic analyses are playing an increasingly important part in decisions about the allocation of limited resources between health care interventions" (Anonymous, 1992, p. 148; see also Phillips & Holtgrave, 1997, p. 19). "The choice of the rate of discount...is much more than a technical matter of interest only to economists and policy analysts. It embodies the values on which we make social choices..." (Krahn & Gafni, 1993, p. 405).

Chapter 3: Conclusions

Emotionally disturbed children are a vulnerable population. They are from disproportionately disadvantaged backgrounds. Indeed, some of the very risk factors for mental illness are hallmarks of social disadvantage or insufficient social support. Children are unable to advocate for themselves, vote, or monetarily contribute to causes benefiting themselves. They are unable to medically help themselves and are often considered incompetent to decide for themselves. Families, caregivers, and children face prolonged emotional and economic suffering as a result of the chronicity of these disorders. They suffer from stigmatized, misunderstood illnesses. Stigma remains a significant problem with respect to understanding of mental illness and its treatment. What is stigma? The following is a very personal account, provided by Mary Gullekson, Ph.D., sister of a man diagnosed as paranoid schizophrenic at age 12.

> "For me stigma means fear, resulting in lack of confidence. Stigma is loss, resulting in unresolved mourning issues. Stigma is not having access to resources, resulting in lack of useful coping skills. Stigma is being invisible or being reviled, resulting in conflicts regarding being seen. Stigma is lowered family esteem and intense shame, resulting in decreased self-worth. Stigma is secrecy, resulting in lack of understanding. Stigma is judgment, resulting in lack of spontaneity. Stigma is divisive, resulting in distrust of others. Stigma is anger, resulting in distance. Most importantly, stigma is hopelessness, resulting in helplessness. This all adds up to decreased potential, of self and for others" (Fink & Tasman, 1992, p. 11).

Not even the psychiatric profession is immune from stigma's taint: Paul Fink cites Gordon Allport's classic book, The Nature of Prejudice (1954): "man has a propensity to prejudice...we, 'almost instinctively,' form in-groups and out-groups...[P]sychiatry is the out-group of medicine" (Fink, 1983, p. 669). These observations remain pertinent nearly twenty years later.

The psychiatric knowledge base is built on a foundation of research data largely collected using adult subjects. Therefore, important questions remain unanswered regarding treatment appropriateness and effectiveness, cost effectiveness of treatment and prevention, and long-term outcomes for mentally ill children. We will not know what the best interventions are until such data is collected, from well-designed, controlled, longitudinal studies enrolling youth as subjects. Scattershot implementation of inadequately evaluated interventions is not completely wasteful, but it does not maximize the benefit from our health care dollar. Granted, it is true that "*medical necessity* and *appropriate treatment* [are] relatively slippery concepts given the uncertainties of knowledge of mental illness and the heterogeneity of patient populations" (Mechanic, 1999, p. 130; italics the author's). However, this does not negate the need to address research gaps, unnecessary suffering, and plentiful ethical dilemmas.

Fulfillment of youths' needs for quality health care, social services, and a healthy community in which to develop are increasingly threatened by demographic changes that are shifting political attention, and resource allocation, toward the elderly. This dilemma will become more aggravated by Americans' persisting recoil from death, and unwillingness and outright failure to debate and place limits on the application of costly, life-sustaining technologies. More recently, popular media spotlights every morsel of basic research offering even the slightest, remotest hope of extending the average lifespan beyond 100 years. Yet, these soundbites fail to consider the explosion of chronic illnesses that will inevitably result. For example, the number of hip fractures has recently skyrocketed. Suspected reasons for this are that people are living longer, are more sedentary thus have less muscle, and take multiple medications with the side effect of dizziness (Anonymous, 2000, p. 3A).

This drives home the assertion that no medical technology is a panacea. As medical science introduces ever more invasive, powerful, and complex interventions, unforeseen and unintended effects (both clinical and economic) will accrue. Americans persist in clamoring for exotic, dramatic and expensive interventions, while straightforward interventions geared at preventing pediatric mental illness go underfunded or unfunded. Transplantation, reproductive technologies, and gene therapy are spotlighted in the media, medical journals, and bioethics literature. Multisector treatment and preventive interventions for pediatric mental illness are not, despite having just as many unresolved, interesting questions and dilemmas.

The evolution of the medical professions, driven by ideological, political, and economic factors and incentives, has contributed to a dominant biomedical model poorly accounting for both chronic illness and the multisector needs of children with SEDs and their families. This model, reinforced and ideologically supported by both bioethics and third-party insurance payment structures, also fails to account for the stark, messy reality that it is not merely the individual child that is in desperate need of preventive or treatment interventions, but the family and sometimes the community as well.

The most logical level for reform is the federal level. Americans should be encouraged to view and accept the needs of emotionally disturbed youth as a federal government responsibility, morally buttressed by appealing to collective decency toward Americans of all ages (G. Osborn & J. Goddeeris, personal communication, May, 2000).

Ideally, under a deontological approach, collective social debate would inspire consensus about the policy components of 'collective decency.' For example, society might conclude that allocating a greater share of healthcare resources to emotionally disturbed youth is the proper way to achieve collective decency. However, partly because of the powerful political and nonmedical influences upon our healthcare system described above, it appears that this deontological approach, via social consensus, is not achievable at this time. A more workable alternative is a utilitarian approach incorporating a maximization principle, wherein economics tools like cost-effectiveness analysis are used to collect data that will guide policymakers in deciding which interventions make the best use of scarce, collective medical resources (G. Osborn, personal communication, May, 2000). In this way, the conclusions and recommendations offered in this thesis do not conflict with my initial assumptions about rights, and analyses of concepts of children's rights, put forth above (G. Osborn, personal communication, May, 2000). A choice need not be made between (1) better providing for mentally ill children's right to quality, appropriate, accessible healthcare, and (2) applying data from economics tools like cost-effectiveness analysis and cost-benefit analysis to policy formulation in resource allocation (J. Goddeeris, personal communication, May, 2000). Rather, (2) helps us most efficiently produce (1), maximizing the 'bang for our buck.'

Recommendations

Several goals stand out:

1) America's children would benefit from heightened nationwide promotion of prevention and early intervention programs with demonstrated effectiveness. Such promotion should be financial, political, and clinical in nature.

2) School-based health centers (SBHCs) represent an ideal site from which to launch prevention and early intervention efforts. SBHCs are the most practical sites to pursue the goal of maximizing children's access and helpseeking of mental health services. "Schools provide the ideal setting to implement primary prevention techniques" Meyers et al 1987, 147). Programmatically and symbolically, SBHCs also embrace the concept that mental illnesses are a multisector, not strictly medical, problem. Schools offer the potential to maximize convenience and promote a caring or caretaking environment; such an environment is the most obvious commonality in all demonstrably effective preventive interventions. Of course, SBHCs are but one example of an environment with the potential to foster prevention and early intervention.

3) Address research gaps by enrolling children in well-designed effectiveness and cost-effectiveness studies.

4) Promote social discussion about U.S. health care priorities, implications of extending average lifespans, and the limitations of high technology.

5) Promote physicians' and bioethicists' acceptance of the biopsychosocial model.

6) Government should assume a stronger role, partly because health care providers and children's advocates alone cannot enact reform. Federal involvement has the potential to improve access to prevention and early intervention. However, this does not negate the critical role parents must play. As discussed at the end of Chapter 1, government can take advantage of its existing infrastructure, to achieve the goal of implementing prevention policy over the lifespan. Of moral concern is its great potential to create equity in intergenerational resource allocation, as it sets and revises policy for America's nationwide public programs, like Medicaid and Medicare (G. Osborn, personal communication, May, 2000).

7) Stakeholders should embrace the lifespan perspective, and the prevention and health promotion efforts that logically follow.

8) Any explicit rationing should prioritize prevention services aimed at high-risk children, so as to do the most good for the most people.

Were my recommendations put into place, we would have a better chance of meeting our societal duties, such as meeting the welfare right of children to access to a basic standard of health care (see the Introduction). Such reforms would better serve the unmet needs of mentally ill children and other vulnerable groups. My recommendations do not conceptually conflict with my rights-based assumptions throughout the rest of this thesis.

Ideally, the federal government will assume a greater role. Federal government represents the only overarching nationwide structure that could shape such efforts, via (e.g.) insurance regulation or legislative changes. It is the only comprehensive infrastructure America has to shape policy (G. Osborn, personal communication, May, 2000). Mentally ill children across the country are not so different in clinical presentation, socioeconomic status, or etiology that they require fifty separate state approaches, with significant variations in coverage and organizational structure. A large number of mentally ill children are Medicaid-eligible; such interstate variability applies to Medicaid as well. "Even in cases where the federal government pays most of the cost, poor, low-tax states have been reluctant to make the necessary investment. The result is that the quality of one's benefits under the Medicaid program depends greatly on where one lives" (Mechanic, 1999, p. 139).

Nor can providers and advocates alone enact reform or significantly alter Americans' beliefs. "[S]ociety will probably not alter its priorities and decisions merely because mental health workers feel that current conditions may lead to poor mental health. These and similar battles, if they are to be fought at all, ***must be fought in the political realm***-a realm in which mental health workers have demonstrated no special ability" (Mechanic, 1999, p. 75; italics mine). David Mechanic forcefully argues for a greater federal role in mental health care:

> "While it is plausible that some states left on their own to use federal Medicaid funds could be more innovative and effective, the danger is that other states would draw back from health care commitments in the face of competing budgetary needs and ideological interest groups, increasing the range of program integrity among states. A nationally supervised program maintains a minimum decent standard for states that have a limited commitment to the disabled population, poor children, and the elderly. Civil rights offers a good analogy where, in the absence of federal standards, large disparities among states may have persisted" (Mechanic, 1999, p. 140).

Increased federal control would also improve children's access to effective prevention and treatment interventions. "All too frequently,...effective programs are simply unavailable in communities. It is essential to expand the supply of effective, evidence-based services throughout the Nation [sic]" (Satcher, 1999, p. 455). Political and corporate decisionmakers and stakeholders should work to recognize the limitations of their myopic, short-term perspectives toward investments in prevention and multisector, community interventions. Such recognition would encourage adoption of a lifespan perspective, toward health promotion and disease prevention.

> "Prevention programs, implemented correctly..., can not only survive, but also flourish in times of wealth as well as in times of downsizing. As American industry has discovered, short-term gains and outcomes are only a small part of determining long-term success. A long-term [e.g., lifespan] vision and plan based on solid research and forward thinking create products and services that people want and need. It is time that those involved with public policy decisions involving the development, evaluation, and dissemination of prevention programs (i.e., government at all levels), recognize the accrued benefits that can be had by investing more heavily in prevention" (Hightower, 1997, p. 210).

It has generally been argued throughout this report that capitation's spread has negatively affected quality of care for mentally ill children, partially through restricted access to specialists. However, critics point out the dearth of research data, particularly for pediatric populations, regarding the import of provider credentials with respect to outcomes. Some bioethicists argue that these sorts of questions about quality of care overshadow important moral questions, such as "What level of quality do we have a social or moral obligation to provide?" (Boyle & Callahan, 1995, p. 12).

Service priority should extend toward children exhibiting known risk factors, followed by those with mild illness, followed by the most severely ill youth. Moreover, "priorities in care go to...those interventions that have been proven most effective" (Mechanic, 1999, pp. 142-143). Prevention creates the most good for the most people; however, since we cannot prevent all mental illness, we must provide for a caring treatment environment for mentally ill individuals.

When there is rationing due to resource scarcity, ideally the worst off would be subject to less rigorous rationing mechanisms (Boyle & Callahan, 1995, p. 14). The spread of managed care, moreover, requires a heightened level of monitoring of service quality and access, "particularly in regard to subgroups of the population who are most vulnerable, either because of the nature and quality of their disorders or their social disadvantage" (Mechanic, 1999, p. 150).

Past experience with ineffective public demonstration projects geared at healthy development illustrates that a society that merely tries to "'invest' its way out of social problems" absolves parents of personal responsibility and encourages dependency (Samuelson, 1998, p. 45). "[W]hat people do for themselves matters more than what government tries to do for them;" financial supports for the poor are more appropriately viewed as "expressions of collective decency than 'investments'" (Samuelson, 1998, p. 45). However, such investments in quality of life ("collective decency") sometimes represent the most productive use of scarce resources (G. Osborn, personal communication, May, 2000).

While it is narrow-minded and often incorrect to blame parents for causing a child's mental illness, it may be rational (although not particularly useful) to blame them for individual choices and behaviors contributing to an at-risk environment. The most important 'investments' in children are from parents; "large federal programs...can't undo parental failure. Nor can they offset the ill effects of family breakdown. To think otherwise sanctions the behaviors that put children at risk" (Samuelson, 1998, p. 45). However, government has the potential to attenuate effects of poor parenting (G. Osborn, personal communication, May, 2000).

The dilemmas covered in this thesis should be important to all of us, whether we personally are touched by pediatric mental illness or not. Yet it remains the case that "[t]he fact that our national future depends on how each individual kid grows up has not made much of a dent" (Kochakian, 1998, p. 5).

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