

# Perspectives

## Christmas in Purgatory: A Retrospective Look

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It has now been 40 years since the publication of Blatt and Kaplan's (1966) *Christmas in Purgatory*, a photographic exposé of institutions. In this article I review this landmark work in the context of some of the major events in the field of mental retardation in the era immediately following its publication. The growing dissatisfaction with abusive and dehumanizing conditions at institutions soon led to the emergence of new concepts and philosophies as well as law suits that eventually challenged the very existence of institutions.

"There is hell on earth," wrote Burton Blatt (Blatt & Kaplan 1966), "and in America there is a special inferno. We were visitors there during Christmas, 1965" (p. v). Blatt, then a professor at Boston University, had followed the controversy surrounding Senator Robert Kennedy's unannounced visits to New York's Willowbrook and Rome State Schools in fall 1965. Kennedy publicly denounced conditions at the institutions. In response, public officials and supporters of Governor Nelson Rockefeller accused Kennedy of painting a misleading picture of conditions at the institutions based on superficial tours. Blatt was aware that Kennedy had accurately portrayed the nature of conditions found at institutions.

With the aid of a friend, photographer Fred Kaplan, Blatt decided to expose institutional conditions on his own. He arranged for visits to four large state institutions in the Northeast at which Kaplan secretly took pictures of conditions on "back wards" with a camera secured to his belt. Blatt and Kaplan then visited Connecticut's Seaside Regional Center, a small, relatively new facility, where Kaplan openly took pictures of brightly lit wards, well-dressed residents, decorated dormitories, and education programs.

*Christmas in Purgatory* depicted horribly overcrowded wards, naked and half-clothed residents, and barren rooms. The second part of the book showed the relatively positive scenes from Seaside. The back cover of *Christmas in Purgatory* included

testimonials to its importance from Senator Edward Kennedy, Michigan Governor George Romney, and Minnesota Governor Karl Rolvaag.

One year later in 1967, Blatt, together with Senior Editor Charles Mangel, published a version of the exposé in *Look Magazine*, "The Tragedy and Hope of Retarded Children." The article began: "These children do not have to be locked up in human warehouses. Yet, to our shame, this is where we put them—in back wards, without compassion, without even basic care" (p. 96).

In 1967, Blatt was invited to give a keynote address at a special session of the Massachusetts Legislature convened at one of the state schools. He reviewed his findings as described in *Christmas in Purgatory* and urged the Commonwealth to develop a "network of small, community-centered residential facilities" (Blatt, 1970, p. 258).

Blatt's *Christmas in Purgatory* and *Look* article not only received widespread public and media exposure, but captured professional attention as well. In 1968, Blatt published an article based on *Christmas in Purgatory* in *Mental Retardation*, a journal of the American Association on Mental Deficiency—AAMD (now the American Association on Mental Retardation). In 1974, Blatt received the Humanitarian Award from AAMD and was elected to serve as its president in 1976.

When he first exposed the institutions, Blatt advocated for institutional reform. By the mid-1970s, if not earlier, he had given up hope that institutions could be reformed. In 1979, Blatt, with two junior colleagues, published a follow-up photographic exposé, *The Family Papers: A Return to Purgatory* (Blatt, Ozolins, & McNally, 1979), based on visits to the original institutions, other institutions, and community settings. The institutions were smaller and cleaner and the residents were better dressed, but the pictures in *The Family Papers* depicted idleness, loneliness, and neglect. In the introduction Blatt et al. wrote, "As you will see, everything has changed during the last decade. As you

will see, nothing has changed” (p. vi.). The authors concluded the book by stating that “We must evacuate the institutions for the mentally retarded” (p. 143).

The field of mental retardation was ripe for the publication of *Christmas in Purgatory*. During the 1960s and 1970s, new concepts and philosophies were emerging that challenged the legitimacy of institutions. From the 1800s until the latter half of the 1900s, the field of mental retardation was dominated by physicians and psychologists. What is now the American Association on Mental Retardation was established in 1876 as the Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons. Concepts and philosophies in the field reflected medical and psychological perspectives: medical causes, medical and psychological treatment, psychological testing, and psychometrics.

In the 1960s, sociological concepts started to become more prominent in the fields of mental retardation (Trent, 1994). By the end of the decade, a clearly formulated philosophy informed by a sociological understanding of mental retardation emerged.

Labeling theory (Becker, 1963; Erikson, 1962; Memert, 1951) focused attention on social and cultural aspects of “deviance.” Together with Goffman’s *Asylums* (1963) and *Stigma* (1961), labeling theory had a strong influence on sociological and anthropological studies of mental retardation in the 1960s and early 1970s (Braginsky & Braginsky, 1971; Dexter 1964; Edgerton, 1967; Mercer, 1973).

In the latter part of the 1960s, leaders in the field of mental retardation began to translate sociological concepts into a philosophy of caring for people with mental retardation. In 1969, the President’s Committee on Mental Retardation (PCMR) published an influential book, *Changing Patterns in Residential Services for the Mentally Retarded* (Kugel & Wolfensberger, 1969). Established in 1962 by President John F. Kennedy, PCMR intended *Changing Patterns* to serve as a resource in formulating recommendations on residential care to the president and the nation (Kugel, 1969). The book included invited contributions from American and international leaders, including two chapters by Blatt (1969a, 1969b) based on *Christmas in Purgatory*.

*Changing Patterns* contained two chapters by Bengt Nirje, then executive director of the Swedish Association for Retarded Children. In the first

chapter, “A Scandinavian Visitor Looks at U.S. Institutions,” Nirje (1969a) described his observations during visits to institutions in several states and confirmed Blatt’s reports. His second chapter, “The Normalization Principle and Its Human Management Implications,” was more important.

The concept of *normalization* was developed in Scandinavia and incorporated into a 1959 Danish law governing services for people with mental retardation (Bank-Mikkelsen, 1969). Until Nirje’s *Changing Patterns* chapter, it had not been systematically stated and explained (Wolfensberger, 1972). Nirje (1969b) provided the following definition: “the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close to possible to the norms and patterns of the mainstream of society” (p. 181).

In the introduction to *Changing Patterns*, Kugel (1969) wrote regarding the normalization principle:

This construct has never been fully presented in the American mental retardation literature, but it is of such power and universality as to provide a potential basis for legal and service structures anywhere. Indeed, the editors of this book view the normalization principle as perhaps the single most important concept that has emerged in this compendium. (p. 10)

Various contributors to *Changing Patterns* approached mental retardation from the perspective of the sociology of deviance. Dybwad (1969), the past executive director of the Association for Retarded Children (now the Arc of the United States), described normalization as a sociological concept: “The normalization principle draws together a number of other lines of thought on social role, role perception, deviancy, and stigma that had their origin in sociology and social psychology” (p. 386). Wolfensberger’s (1969) history of the origin and nature of institutions started with a review of the “role perceptions” of retarded persons (e.g., as sick) and explained:

Social scientists in the recent past have elaborated a concept of great importance to the understanding of the behavior and management of retarded persons. The concept is that of “deviance.” A person can be defined as deviant if he is perceived as being significantly different from others in some overt aspect, and if this difference is negatively valued. An overt and negatively valued characteristic is called a “stigma.” (p. 65)

Dunn (1969), who had previously published an article questioning the effectiveness of special education (1968), used language to describe institutions that could have come from labeling theorists

in sociology in his contribution in *Changing Patterns*:

Frequently, they have been operated on the medical model which views mental retardation as a disease, and has an emphasis on labeling and determining etiology; and once one has viewed mental retardation as a disease and affixed the label to an individual, one has a built-in, self-fulfilling prophecy. (p. 214)

Three years after *Changing Patterns*, Wolfensberger (1972) published another influential and widely read book, *The Principle of Normalization in Human Services*. In this book, Wolfensberger elaborated on the dimensions of *normalization* and offered a reformulated definition, namely: “utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” (p. 28).

In 1974, Blatt, then the director of the Division of Special Education and Rehabilitation at Syracuse University, recruited Wolfensberger to Syracuse, where he established a training institute to promote normalization and later *social role valorization* (Wolfensberger, 1983, 1998), a refined version of the principle.

Throughout the 1970s and beyond, attacks on institutions escalated. In contrast to earlier decades, the exposés played out not only in the media, but in federal courts as well.

The first case to receive widespread national attention was *Wyatt v. Stickney* (1972) brought against the Partlow institution in Alabama. In the *Wyatt* case, federal district judge Frank Johnson, who had ordered Governor George Wallace to integrate the University of Alabama in the 1960s, characterized Partlow as a “warehousing institution” and commented on the “atrocities” that “occur daily” (*Wyatt v. Stickney* 1972, p. 10).

Willowbrook State School in Staten Island, New York, was the next state institution to be cast into the public spotlight (Rothman & Rothman, 1984). Following a series of articles in the *Staten Island Advance* describing substandard conditions at Willowbrook, reporter Geraldo Rivera made an unannounced visit to Willowbrook on January 6, 1972. Footage depicting overcrowded and dehumanizing conditions were shown on that evening’s 6:00 news. National and local media then covered the story, and the *New York Times* declared Willowbrook a “tragedy” and “disgrace” in an editorial (Rothman & Rothman, 1984, p. 45). Approximately 2 months after Rivera’s initial exposé, parents of Willowbrook residents filed suit against the

institution in federal court. The case was assigned to District Judge Orin Judd. Like Judge Johnson in the *Wyatt* case, Judd was appalled by conditions at the institution and concluded that Willowbrook failed to protect the safety of residents and that conditions resulted in deterioration, rather than improvement (*New York State Association for Retarded Children, Inc. v. Rockefeller*, 1973).

Both the *Wyatt* and Willowbrook cases resulted in significant deinstitutionalization, and both institutions were eventually closed. However, the Pennhurst case in Pennsylvania was the first major case filed with the explicit aim of closing the institution. The attorneys for the plaintiffs in this case found a receptive judge in Raymond Broderick, who found that Pennhurst shared the many inadequacies and abuses of other institutions. He went further, however, in ruling that the institution was inconsistent with the principle of normalization:

Since the early 1960’s [sic] there has been a distinct humanistic renaissance, replete with the acceptance of the theory of normalization for the habilitation of the retarded. . . . The basic tenet of normalization is that a person responds according to the way he or she is treated. . . . The environment at Pennhurst is not conducive to normalization. (*Halderman v. Pennhurst*, 1997, pp. 24–25)

Pennhurst closed in 1988.

The reform efforts of the 1960s and 1970s occupy a central place in the history of mental retardation. The works of the leading reformers are not only mentioned in histories, but continue to be read today. The American Association on Mental Retardation published monographs in 1999 based on Blatt’s writings (Taylor & Blatt, 1999) and Dybwad’s speeches (Allard, Howard, Vorderer, & Wells, 1999). Wolfensberger continues to publish widely in the field of mental retardation, and in recent years, two edited volumes of his work have been published (Gaventa & Coulter, 2001; Race, 2003).

The reform efforts of Blatt, Dybwad, Wolfensberger, and others came in the tumultuous era of the 1960s and 1970s—an era characterized by public protests, challenges to the legitimacy of institutions of all kinds, the involvement of federal courts in what had traditionally been regarded as state affairs, and the increased role of the federal government in funding social programs. The early to mid-1970s was a period of unprecedented federal involvement in funding facilities for people with mental retardation, prohibiting discrimination against people with disabilities by recipients of fed-

eral funds, and ensuring the right to public education of children with disabilities.

Blatt and his colleagues offered new insights into the nature of settings for people with mental retardation as well as new concepts and innovations. Yet, it would be incorrect to conclude that their primary contributions were intellectual in nature. To the contrary, as Herr (1999) and Sarason (1999) noted, Blatt's major contributions were moral and ethical. He sought not only to create a more effective field and competent profession, he sought to inspire and motivate others to be better human beings.

In his remarks at the memorial service for Burton Blatt in 1986 and his foreword to the edited book of Blatt's writings by Taylor and Blatt (1999), Sarason told the following story. Blatt approached the Kennedy Foundation to fund the printing and distribution of *Christmas in Purgatory* so that it could be sent to public officials and policymakers across the country. The Foundation agreed to provide the funding, but only if Blatt would name the institutions at which the horrific conditions were found. According to Sarason (1999), Robert and Edward Kennedy wanted Blatt to name the institutions, which almost certainly included institutions in New York and Massachusetts. Blatt had promised administrators that he would never reveal the institutions' names. He also believed that if he named the institutions, people would conclude that the widespread problem of human abuse and dehumanization were confined to those specific institutions as opposed to representing the general problem of how America cared for people with mental retardation. Blatt turned down the funding; he acted on principle.

We need leaders like Burton Blatt today.

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