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Service Delivery in an Institution

A case study

Abstract

The history of a large, private residential institution is presented as a prototype of changes in service delivery over the past 140 years. Three conceptual orientations are labeled as "healers", "guardians", and "fixers". New developments taking form at the institution portend future directions at other large, residential centres.

Résumé

L'historique d'une grande institution résidentielle privée est présentée comme prototype des changements survenus dans l'accessibilité des services au cours des 140 dernières années. Les orientations conceptuelles sont identifiées comme "guérisseurs", "gardiens", et "arrangeurs". Les développements récents dans l'institution laissent percevoir la direction future que prendront d'autres grands centres résidentiels.

The gradual evolution in thinking about the care, treatment, and disposition of people labeled mentally retarded over the past century and a half has been well-documented (Scheerenberger, 1983; Rosen, Clark, & Kivitz, 1976). Perusal of this sequence of philosophical and programmatic shifts suggests that change did not always represent progress, that not all current thinking is necessarily new or innovative, that the same problems and many of the same solutions existed throughout the history of the field, and that at all points of change there was controversy and resistance. For purposes of clarity, it is expedient to delineate phases of service delivery, recognizing that no phase was universally distinct from any other. At all times there were signs of imminent progress as well as residuals of older thinking.

It is often helpful to focus upon one discrete example of a class in order to illustrate what was generally true in a broader sense. So it is in the field of mental retardation where many large state and private residential institutions bore a remarkable resemblance to each other.

History of Elwyn over 140 Years

Elwyn, Inc., in southeastern Pennsylvania, is an interesting prototype for study. It was one of the first large residential facilities in the United States, established during a period of optimism and hope when the "movement" to educate the mentally afflicted spread from Europe. Indeed, Edouard Séguin was engaged to be superintendent several years after the facility was established as the Pennsylvania Training School for Idiotic and Feeble-minded Children.¹ It exists today as the oldest, private American facility in continuous operation for persons with mental retardation. Nationally recognized at its inception, it underwent the same rapid growth and experienced the same problems that characterized all the original special schools. By the turn of the century, it became primarily a custodial institution, depending largely upon state referrals, despite its private status. It stagnated for about a century, was revitalized during the 1960s, flourished and expanded in the 70s to become a network of institutional and community living arrangements and rehabilitation centres in four states, and later in Jerusalem, Israel. It suffered the anti-institutional onslaught of the 80s, and has somehow survived the recessionary trends of the early 90s, struggling today to define a meaningful role for itself. At Elwyn one can find the ashes of previous history as well as the tea leaves for discerning future developments.²

The history of Elwyn may be characterized into three eras in terms of philosophical orientation and objectives of its administrators. A fourth era, beginning in July, 1991, may well be underway. Risking oversimplification, we may identify the "Healer/Missionaries," the "Guardians," the "Fixers," and, perhaps now, the "Advocates."

Missionary zeal: the helpers

It should come as no surprise that the founding of Elwyn may represent the most optimistic and productive era. Inspired by the work of Samuel Gridley Howe, of South Boston, with a few children labeled "mentally deficient," Alfred Elwyn, a Philadelphia physician, organized a similar effort in Pennsylvania. Howe's principle teacher, James B. Richards, was enticed to establish a small private school in Philadelphia's Germantown section. The new venture opened its doors in 1852 and in 1854 it was incorporated as a privately licensed facility. In a few years, the school outgrew its rented space and sought a permanent home. Dorothea Lynde Dix, of Boston, a recognized advocate for the mentally afflicted, was enlisted to accompany the administrators to Harrisburg

to seek state funding. An allocation was secured, sufficient to purchase real estate and erect a building. Dix is said to have been instrumental in selecting a site 15 miles south of Philadelphia on the Baltimore pike, far enough away from city clutter to provide a safe, comfortable, country atmosphere for programs. The new facility began operations in 1859.

The original programs, inspired by Séguin's "physiological method" (Séguin, 1976a [original 1864]), were a mixture of sensory stimulation, motor activities, moral training, and physical exercise. Séguin's concepts had a strong learning-disability flavour. Muscles must be trained to obey the dictates of intellect; thus, sports and gymnastics assumed great significance. There was an emphasis on neurological and physiological bases for learning. Organs were trained to educate their functions and functions were practised to develop the organs (Séguin, 1976b, 1976c [originally published 1879, 1880]). Thus, sensation, motor activity, and cerebral functioning were viewed as interrelated. The enthusiasm and, perhaps somewhat unrealistic, aspirations of Richards are revealed in his description of his work with a young child:

Having often noticed that an experienced nurse would endeavor to arrest the attention of a new-born infant, not by showing some pretty toy, but by **talking to it as if it were an intelligent being**, I took this for my guide; and preparing myself for the task, laid upon the floor an hour each day, reading aloud to this imbecile boy, as if he understood me perfectly. This practice was perused for several weeks till, one day instead of lying on the floor, I sat in a chair. In a few moments, I saw by his making an effort to move, that he had missed me. As soon as I again placed myself by his side, he stopped fretting and appeared to be pleased. Here then, I had a 'fulcrum on which to rest my lever.' At the next lesson, instead of reading aloud, I read to myself. He noticed my silence, and slowly putting his hand to my mouth, attempted to open my lips. Upon reading aloud again, he expressed his pleasure by a smile. This practice of reading and talking was steadily persevered in for a number of weeks; during which time, I was enabled to gain his confidence, little by little; and during the four years which followed, he more than answered my highest expectations, becoming a marvel to his friends and those who had previously known him. At the end of that time, he could read intelligently and walk about like other children. (Richards, 1976 [original 1853])

Unfortunately, this spirit of enthusiasm was short-lived.

Controlling the menace: the guardians

By the 1880s the bloom was off the rose. The original students, now adults were judged to be still too impaired to return to their communities. The

original school program had expanded to institutional proportions. Staff were less enthusiastic about treating the large numbers of referrals arriving not only from Pennsylvania but from several surrounding states as well. Large buildings were being erected to be known as the "Asylum Village" to house those persons judged to require custodial care and to lack potential for substantial improvement beyond basic demands for cleanliness and self-control. The new science of genetics was widely accepted as providing the mechanism for the propagation of mental deficiency. It brought with it an aura of irreversibility. The concept of the "moral imbecile," offered by Fernald (1893) was endorsed by both Kerlin (1889) and Barr (1909) at Elwyn.³ Martin Barr, publishing the first American textbook in the field, was moved to write:

In endeavoring to emphasize the utter hopelessness of cure, and also the needless waste of energy in attempting to teach an idiot, I have sought to make clear the possibilities that may be attained in the training of the imbecile, the urgent need for preventing the backward child from degenerating into imbecility, and of safeguarding the absolutely irresponsible amoral imbecile from crime and its penalty. . . . [There is] a dangerous element in our midst, an element unprotected and unprovided for, this is our heritage from the last century. The safety of society, therefore, demands its speedy recognition and separation in order to arrest a rapid and appalling increase and furthermore, its permanent detention lest it permeate the whole body socialistic. (Barr, 1904)

The first sterilization of the "unfit" was performed at Elwyn by Kerlin to control behavioural problems and "improve the stock." This practice was followed by both of his successors, Barr (1893-1930) and Whitney (1930-1959) with the endorsement of the board of directors.

In general we feel that we can select two distinct groups for sterilization and for two distinct reasons. The first, and by far the most important group, is that of the high-grade to borderline case in which there is unquestionably hereditary mental deficiency. This group needs selective sterilization to prevent further propagation of their kind. More of this type of individual are outside than within the institution. However, if those who are institutionalized could be rendered sterile, release or parole would be safer for the individual and for the community.

The second group, which is entirely an institutional type is the low-grade imbecile of obscene habits. We have found that sterilization has a definite value with these. We do not advocate it to prevent their propagating their kind because they are permanently segregated and in nearly every case are physically incapable of reproduction. . . (after sterilization) most of them brighten up and

the majority seem more easily managed and less temperamental. (Whitney & Shick, 1976 [original 1913]).

The post-war years of Elwyn, under the leadership of E. Arthur Whitney, were repressive. A picture of the institution and its underlying philosophy is provided by the annual reports of the institution from 1947 to 1958.

Residents were still referred to as "children." There was little regard for human rights, and institutionalization was generally considered "for life." Such placements were judged by professionals as the treatment of choice for the "mentally deficient." Only persons testing intellectually between the IQs of 50 and 75 were accepted. Since placement implied adjustment to life as an institutional resident, families were discouraged from visiting. Nor were home visits allowed.

A number of institutional trades were available and many residents became skilled at shoe repair, laundry work, farming, and other plant maintenance activities. Indeed, the daily operation of the institution depended largely on the labour of residents. Once trained, there was little opportunity for workers to leave their institutional job for one in the community. While vocational skills were valued, it was assumed that social deficiencies precluded community living.

Staff and residents formed a more or less cohesive community. Staff held life-long positions in many instances. Many who died were buried on institutional grounds. Staff, and particularly the superintendents, maintained a paternalistic attitude towards the residents. Institutional events, holiday celebrations, and recreational activities were enjoyed by staff as well as residents. Residential supervisors, always female, were called "matrons." Residents addressed them as "Mom." Authority within the institution was clearly medical, with the superintendent serving as highest authority and his assistant, the chief physician, next in command.

There was a sense of importance and dignity attached to the work and a grave concern about the "menace" of mental retardation as a destructive social factor. Research into etiology and prevention and dissemination of scientific information were viewed as high priorities.

Appropriate behaviour, etiquette, and social graces were strictly enforced. Paddling and head shaving were practiced as punishment by the superintendent. Staff behaviour was as rigidly controlled as that of residents. Visitors to the institution were extended every courtesy. There was an implicit faith in the work ethic and a basic distrust in the growing attitude of "entitlement" being promulgated by labour unions.

Cost effectiveness of programs was a necessity. Staff salaries were low and parsimony in operations was practiced. Financial self-sufficiency of the institution was a valued goal. The productivity of farm lands received considerable attention in annual reports. Maintenance of older buildings was a constant problem. Fund raising was a critical activity and was conducted primarily through individual contributions.

Habilitation: the providers and fixers

Gerald R. Clark, a psychiatrist with a public health background, was appointed superintendent in 1960 and was responsible for radical changes in the institution. He appointed Marvin S. Kivitz, a psychologist as Director of Rehabilitation. In 1979, Kivitz succeeded Clark as president, continuing Clark's programs and expansion into many community sites. During the years of Clark and Kivitz, Elwyn made rapid strides away from the closed custodial model and became a more open school and habilitation centre for multihandicapped children and adults. The emphasis shifted from segregation and shelter toward community-oriented training, with the goal of helping mentally handicapped individuals find a useful role in society.

The use of the term "children" for older students was abandoned. Physical punishment was discontinued. Instead, students were provided with increasing responsibilities and privileges for appropriate behaviour. The staff titles of "matron" and "attendant" were replaced by "house parent" and "counselor." Males as well as females served in these positions. Closer relations with family were encouraged by increasing the frequency of visiting and by family counselling procedures. Vacation periods were introduced at Christmas, Easter, and Thanksgiving. The practice of censoring incoming and outgoing mail was discontinued. All locks were permanently removed from doors of dormitories and dayrooms and panic-bars were installed on all exit doors. For the first time, residents were permitted to chew gum, and smoking on the grounds was allowed. Greater provision was made for recreation and entertainment of residents. Increased opportunity was provided for participation in religious services and instruction.

Educational programs were expanded with the opening of a new education centre. All levels of mentally retarded children were enrolled in full-day educational programs. The old classifications of "moron," "imbecile," and "idiot" were replaced by classifications of mild, moderate, and severe mental retardation.

Kivitz was given the mandate to develop a vocational training and community preparation program for adults with mild retardation, who constituted the major proportion of residents. Most of these persons had been living in the institution since childhood and were performing useful work in service

and maintenance positions. Vocational training courses for this population were developed. The Pennsylvania Bureau of Vocational Rehabilitation provided training funds to support these programs. A sheltered workshop was established on the grounds for lower functioning students. Day students were accepted for the first time and integrated into programs with institutional residents. An active community preparation program was introduced. By the early 1970s, these changes had been consolidated and greater effort was expended in developing community workshop and habilitation centres, a half-way house in Philadelphia, and group homes.

The primary concept was a hierarchy of social and work experiences, progressing from lesser to greater complexity, and remediation of educational and social deficits resulting from mental retardation and sheltered institutional experience. Components of the program included psychological and vocational evaluations; an activities program; preindustrial experience; exploratory work; vocational training using existing service and maintenance departments; adult education; personal adjustment counselling; community work; community half-way house experience; discharge; and follow-up services (Rosen, Clark, & Kivitz, 1977).

By the late 1980s, rehabilitation had been generally accepted in the field and new changes ensued. Normalization and deinstitutionalization were federally mandated and institutions were under attack (Wolfensberger, 1971a; 1971b). Despite its community programs, Elwyn found itself a target of criticism because of its size and institutional campus. Elwyn defended its programs (Crissey & Rosen, 1986) but more militant voices in the field predominated. Furthermore, the residential population had drastically shifted from mild to severe and profound retardation, multihandicap, geriatrics, and to the medically fragile and behaviourally disturbed individual. The original training model introduced by Kivitz could not be applied easily to persons with more severe deficits. Elwyn accepted an ICF/MR⁴ model for a large portion of its residential campus. ICF/MR implied an active treatment component administered within residents' buildings rather than through generic services, as had been Elwyn's style since the early 60s. Dissatisfaction with institutional programs in general at the state level continuously jeopardized funding streams. Increasingly, Elwyn was forced to alter its programs to comply with externally imposed regulations.

Empowerment: the advocates

On July 1, 1991, Sandra Cornelius, a social worker, assumed leadership of the historic facility. With a background in human resources, Cornelius initiated a process of change unencumbered by Elwyn's traditional institutional history.

New Directions And Trends

While it is far too early to characterize the new directions of Elwyn, several trends under the leadership of Cornelius already appear:

- * A new focus on personal choice of clients and movement toward a supported living model. Larger institutional programs and buildings erected in the 1970s are gradually being phased out in favor of small group homes, either on the institutional campus or in the community.

- * An outreach to community schools and attempts to provide special educational programming to communities at a local level.

- * Exploration of new funding streams, such as child welfare, unrestricted by present state and federal regulations for mental retardation services.

- * A greater inclination to expand programs beyond mental retardation. Declining census on the institutional campus makes it expedient to look toward other special need and even high-risk populations and to develop socialized programs.

- * Quality of life within residences is accepted as a priority, going beyond minimal requirements for training adaptation and independence.

- * Interest in instituting "treatment" rather than merely program, implying more emphasis in diagnosis, therapy, counselling, and family and genetic approaches.

- * Research in both medical and programmatic areas. Program evaluation particularly for persons being selected for community placement.

- * A growing recognition that genetically determined and biologically driven behaviour may be more prevalent than originally believed.

- * An effort to decentralize administrative authority and to provide staff more freedom to develop their own programs.

- * Greater recognition of the need to provide specialized training and career development to staff.

- * Attempts to chart new directions apart from regulatory mandates of outside agencies so that Elwyn may once again determine its destiny.

The rapid changes and present uncertainties in our field make prediction difficult, indeed. If Elwyn is truly representative of other large provider

agencies, the directions outlined above may increasingly take hold nationally. In every era Elwyn has shown leadership and may once again emerge as a barometer of change.

NOTES

¹ He served only a few months.

² An historical archives and museum is maintained at Elwyn, preserving many of its early records, photographs, and artifacts.

³ The school assumed the name Elwyn in 1927.

⁴ Intermediate Care Facility for the Mentally Retarded, a federally-funded program falling under the Social Security Administration.

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