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Providing Services for
Persons with Mental Retardation:
Looking to the 21st Century

Guest Editors: Jacob A. Burack
Jeffrey L. Derevensky

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Editorial

Points of View in the Education of Persons with Mental Retardation

In this special issue, Jake Burack and Jeff Derevensky have brought together an impressive collection of papers dealing with some of the most controversial, and sometimes contentious, issues in the area of education of persons with mental retardation. (The term "persons with mental retardation" is used because it seems to be the most widely used one among those scholars who are writing about the special population discussed here.) These papers come from respected and well-known professionals in the field, and while there may be some overlap with regard to the citation of sources, the content of each paper reflects a unique and informative point of view. The authors of these papers come from a variety of institutions throughout North America, thus they reflect concerns that are linked to various regions and institutions.

This issue begins with an introduction by Burack, Kurtz, and Derevensky regarding the controversies surrounding the delivery of services to persons with mental retardation. They examine the educational, political, and social debates that have developed in relation to the various types of services that have been offered in the past and those that are projected for the future.

Professors Hodapp and Zigler examine the integration issue in contrast to the idea of normalization, which in their view seems to be a fundamental debate of science and values. They analyze both positions, giving equal representation to both sides of the debate. The authors look at parallel issues in education of the deaf and how educators of persons with handicaps other than mental retardation have facilitated the integration of these people into society.

Lusthaus, Gazith, and Lusthaus examine the controversies surrounding the placement of children with mental disabilities within the regular classroom. They present a rationale for full integration of these children, examining not only the benefits derived by the child with a mental disability but those derived by their nondisabled peers as well.

The controversy surrounding deinstitutionalization of persons with mental retardation has become a policy issue more than a research issue, according to Professor Rammler, who discusses the benefits of deinstitutionalization for persons with mental retardation. She points out that empirical research may not throw as much light on the issue as would approaching it from a philosophical view that considers the quality of life to which human beings are entitled.

Dr. Walsh, in contrast, looks at the opposite side of the issue to a certain extent, and reviews the benefits that people with mental retardation can receive from institutions, especially if they are envisioned as resource networks or regional resource centres. He alerts us to the fact that community settings *per se* may not always be able to offer the full range of necessary services, but that "institutions" could be used to strengthen and support community-based services.

Caro and Derevensky give an overview of a family systems model for developing intervention strategies for families who have young children with developmental delays. The family systems model involves the entire family in learning techniques for implementing, among many things, more effective coping strategies and more positive parent-child interactions. In addition, siblings may learn more effective behaviours in interacting with the brother or sister who has developmental problems.

Professor Moss and her colleagues, Gosselin and Parent, probe the issues surrounding the social integration of children with intellectual deficiencies and how integration, in the past, may have been affected negatively by a preoccupation with cognitive functioning. Studies are cited to support the idea that social integration does not appear to be difficult, especially in the preschool setting, for the low-IQ child.

Finally, Wizner and Lucht discuss, from a legal view, the cases of two institutionalized individuals with mental retardation. They describe the process whereby their advocates bring a lawsuit for the purpose of securing the [United States] constitutional rights of these two persons. The outcome, results, and implications of their case, as well as some other court cases, are illuminating and encouraging.

This issue of the Journal should certainly prove to be a useful resource for persons in the field of educating persons with mental retardation, and for persons who are studying in a program of special education.

W.M.T.

Services for Persons with Mental Retardation: A debate for all seasons

The intensity of emotion regarding the issues of services for persons with mental retardation is not surprising, but the scorn and animosity directed by each side at the other is particularly enigmatic. In contemporary western society, social policy debates often evoke passion, especially when persons perceived as underdogs or typically downtrodden are involved. When such populations are identified, concerned individuals, with differing backgrounds and ideologies band together, to champion the cause and attempt change through a variety of activities. These activities are often varied and might include fund raising, political protests, raising public awareness, increasing research activities, working with (or against) government and related public agencies, and planning appropriate programs. The conflict in such situations is often between the advocates of social change and government or other public agencies who are viewed as the agents of the unacceptable *status quo*. Although this scenario of advocates *versus* establishment represents a standard struggle for those involved in providing services for persons with mental retardation, the dispute between the proponents of integration and those who favour services in a segregated setting remains a particularly bitter one.

This debate is fueled by several sources. The two sides emanate from different histories, traditions, ideologies, and philosophical premises that lead to very different visions. The integrationists view themselves as offsprings of the civil and human rights activists of the latter half of the twentieth century. Armed with President Kennedy's *PL94-142* and the examples of countries with strong social programs, such as Sweden, they argue for the rights of each person with mental retardation to be placed in the least restrictive environment throughout one's life-span. It is argued that the denial of this right is the denial of the inherent right of each individual. Since the 1970s, the integrationists have successfully raised public awareness and effected social policy through social protests, litigations, and governmental lobbying.

Conversely, those in favour of special service agencies are the heirs of those who have provided residential, educational, recreational, and employment services to persons with mental retardation during the past two centuries. The special program tradition has fostered the scientific study of the biology, behaviour, development, and adaptation of persons with mental retardation. Its adherents have criticized "upstart" movements and methods that do not have strong empirical support. For example, adherents of this tradition have referred to the mainstreaming movement as a "masthead without a ship." This tradition has given rise to much progress and advancement in the understanding of persons with mental retardation and the services they receive. Paradoxically, it is now typically viewed by the integrationists as part of the establishment and representative of outdated ideologies and practices.

Although certainly a major source, the passion in this debate is not fueled simply by current philosophies and orientations. Rather, it seems to be driven by histories in which each tradition arose. In both cases, concerned individuals reacted to dire circumstances and times in which services and social policies for persons with mental retardation were either nonexistent or had gone awry. In particular, the special service tradition emerged centuries ago as persons with handicaps were ignored, received no intervention, and wandered aimlessly, often dying needlessly, in the streets of their communities. This phenomenon is not uncommon even in this current era of deinstitutionalization. Conversely, integrationists recall the institutional atrocities of the great institutional warehouses and inadequate special education programs. This points to the labelling and segregation of persons with mental retardation during eras in which special-service institutions reigned. Thus, it is the history of failures and tragedies that fans the flames of passion in this debate.

The social experiences of persons with mental retardation within communities are replete with apparent contradictions, anomalies, progress, and disappointment as they are interwoven with the histories, morals, economics, philosophies, and values of communities at a specific time. Accordingly, quality of care and services across communities and over history cannot be compared and certainly cannot be judged by contemporary standards. For example, historians of mental retardation cite archaeological evidence to indicate that a person with a handicap functioned adaptively in a Neanderthal community (Scheerenberger, 1983), but that persons with a handicap were excluded from Plato's plans for a "Republic," and were slain in Rome (Rosen, Clark, & Kivitiz, 1976). This apparent paradox in which a person with a handicap is integrated into a community of a most primitive form of man, but excluded from a more "civilized" society of antiquity, highlights the complex and fluid nature of the topic. In this comparison, it is probable that a person with a mental handicap was probably better able to function within the relatively basic societal demands and lifestyle of the Neanderthal community, as compared to the more sophisticated and achievement-oriented societies of Greece and Rome.

Many years later, as we enter the 21st century, it is even more apparent that the criteria for evaluating and establishing services for persons with mental retardation must be wide-based and considered within a societal context. For example, political, economical, philosophical, and ethical mores will continue to be major factors, although it must be realized that they will differ across communities and will continue to change and evolve (or regress) over time even within communities. Scientific work regarding the efficacy of various programs should play an ever increasing role as the relevant data-bases continue to grow. However, rather than being used as weapons in wars of ideology, empirical evidence should be consolidated to better our understanding and implementation of programs. The resources of the community need to be considered, as ideal programs often require significant amounts of resources, that may not always be available to communities. And, clearly, the voice of the individuals receiving the services, as well as that of their families, need to be increasingly considered. As is with any group, these people are not uniform in their views and wishes and, therefore, cannot be represented by advocates of any single position.

These factors are not independent or mutually exclusive, and must be seen as interactive. For example, societal attitudes will influence the types of research undertaken, the manner in which empirical findings are interpreted and disseminated, and the extent to which scientific data will influence social policy. The conflicting reports of the implications of empirical data regarding mainstreaming exemplifies the ways in which data can be manipulated to support a cause. Findings are reported judiciously in favour of one view or another, and support for another position is readily dismissed. In another example of the interconnectedness of factors, community resources constrain the accessibility and appropriateness of certain programs. Many well-designed and good-intentioned programs have run amuck, often with tragic results, due to the lack of funding and /or other resources. This resource programming relationship is further complicated by the prevailing societal attitudes and the interests of the persons with mental retardation and their families. How do we make sense of this picture in order to provide the best services?

It is our contention that researchers, advocates, educators, policy makers, and mental health professionals must acknowledge differences among communities and the constantly evolving societal issues in advocating for programs for persons with mental retardation. They cannot present simple ideologue positions, but rather must clarify the relevant factors so that communities can make appropriate decisions. Thus, all relevant empirical data need to be presented in as objective a manner as possible. These data would include current assessments of programs as well as historic precedents of successes and failures of similar programs. Although the presentation of data needs to be differentiated from the societal agenda, the priorities of the society, community, and family need to be explicitly stated within the context of the available resources. Given this type of information, each community will be able to make

appropriate choices, and these decisions might well differ markedly across communities, societies, and over time. Some communities may choose to follow the paths of the empirical evidence, whereas others may feel that ethical or ideological issues should take precedence even when in conflict with the empirical evidence. The possible options available to communities will vary as a function of available resources, the priorities given to services for persons with mental retardation, and general community attitudes. Without taking differences among communities into account, proponents of the various programs are neglecting crucial ingredients for success and may be prescribing recipes for tragedy.

The contributors to this special issue provide us with much insight into the types of programs and services that need to be considered as we approach the 21st century. We hope that the positions presented here will fuel productive debate that will lead to the improved lives of many of our citizens.

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Integration and Development: Reconciling two conflicting perspectives

Abstract

Integration and development can be seen as two distinct "world views," each with its own history, values, and assumptions. This article examines the history and underlying assumptions of each perspective and notes how analogous issues have pervaded the field of deaf education for over 100 years. Although a rapprochement of integration and developmental perspectives will be difficult, better educational and residential services for persons with retardation are likely to occur if each side attempts to understand the perspective of the other.

Résumé

L'intégration et le développement peuvent être perçus comme deux "vues du monde" distinctes, chacune ayant sa propre histoire, ses valeurs, ses suppositions. Cet article examine l'histoire et les suppositions rattachées à chacune de ces perspectives, et note à quel point des questions analogues ont envahi le secteur de l'éducation pour mal-entendants depuis au-delà d'un siècle. Bien qu'un rapprochement entre les perspectives d'intégration et de développement sera difficile, une amélioration des services pédagogiques et résidentiels pour les arriérés pourra être réalisée si les deux parties essaient de comprendre la perspective l'un de l'autre.

At least since Galileo, there has been a clash between science and society. Specifically, those interested in scientific explanations have fought with those who explain the world in accordance with religious, political, or social values. This conflict has usually been portrayed starkly, with "objective" science the victor over "irrational" values in most historical accounts. We therefore hail Galileo for his view that the earth revolves around the sun, or

Darwin for his theory of evolution, while we simultaneously denigrate those who opposed them on religious or political grounds. Our sense is generally that the more rational, progressive view is held by the scientists, the more irrational and reactionary view by their value-oriented opponents.

The integration issue in the field of mental retardation presents a curious twist to the science-values debate. Here too science and values clash, but in this instance many would claim that the positions are reversed. The adherents of normalization—usually considered to be the values side of the debate—appear more progressive, more interested in social change. To integrationists, the value of integration demands that major changes be made in a wide variety of social systems. Normalization proponents thus advocate the mainstreaming of all children with retardation and the community living of all adults. On the surface at least, advocates of integration occupy the more progressive pole of the normalization debate.

In contrast, those interested in promoting individual development—usually thought of as the science side of the issue—generally favor the maintenance of many aspects of the existing service-delivery system. While noting that improvements in many services are needed (Zigler & Hodapp, 1986), developmental workers advocate the traditional continuum of services from normalized to specialized. As long as the service-delivery system renders services tailored to the individual's developmental needs, developmentalists argue, the system may need improvement but not radical alteration. Developmentalists assume that good services can be delivered in any setting, be it normalized or specialized.

The above recap sketches the two positions, but it also makes clear that the essential problem in the normalization debate is that each side overlooks the concerns of the other. On their side, adherents of integration fail to consider the role of individual development when they discount the need for special services. Conversely, developmental workers insufficiently emphasize the societal value of full participation of persons with mental retardation into society.

To most integrationists, then, there is a single, overriding good arising from integrating into the society all persons with mental retardation. As Burton Blatt (1987) notes, "The 'freedom' [i.e., integrationist] argument does not address whether segregation or integration is 'clinically better' for mentally retarded people. Rather, this argument is based on the conviction that people are entitled to live free in a natural setting, irrespective of what particular environment most enhances their reading capability or vocational aptitude" (p. 161). Greenspan and Cerreto (1989) further suggest that "value systems cannot, and should not, be subjected to empirical testing" (p. 448).

Conversely, developmental workers call for research examining interactional processes and developmental effects of various educational or living settings, but only secondarily consider the importance of integration as one of those processes or effects. Zigler and Muenchow (1979) note that, for mainstreaming, "the proof is in the implementation," with implementation here focused primarily on aspects of the child's development. In the same way, Zigler, Hodapp, and Edison (1990) call for a field that goes beyond the "social address" model in service delivery to examine the actual interactions taking place within various settings. In all cases, adherents of the developmental view emphasize what is best for the individual with mental retardation; they pay much less attention to the social or societal values inherent in the integration movement.

In this paper we will argue that both sides are incorrect, that each advocates only one of several nonexclusive values. Neither individual development nor societal integration is an all-encompassing value that should be followed in every instance. At various times in recent history, society (or large segments of society) has sacrificed integration and individual development for a greater social good. In describing and critiquing these two views and in reviewing the parallel history of this issue in deaf education, our goal will be to reach some balance between these two conflicting perspectives.

Conflicting World Views

Normalization has been characterized as "a banner in search of some data" (Zigler, 1976) and as a debate generating more heat than light (Zigler *et al.*, 1990). Conversely, the view espousing the need for some specialized services has been called "archaic" (Menolascino & McGee, 1981) and "inconsistent with history, contemporary practice, and public policies" (Krauss, 1990). Adherents on both sides are generally amazed at how little each understands the other. Unbiased observers (if any exist) note that the two sides are talking past each other, unable or unwilling to understand the other's perspective.

Such misunderstandings have been described in the history of science as the problem of "differing world views." First extensively discussed by Pepper (1942), differing world views occur when two persons disagree on deeply held, widely applicable, meta-theoretical perspectives. For example, children can be conceptualized as either machines (the mechanistic view) or as living systems (the organismic view), and the metaphor one chooses will greatly affect subsequent ideas about the nature of children's development. Divergent histories, philosophies, and rules for what constitutes evidence also accompany differing world views, and it is debatable whether two world views can ever be successfully reconciled (Pepper, 1942; Reese & Overton, 1970; Zigler, 1963).

Similarly in the normalization controversy, the possibility of reconciliation remains unknown. As adherents of two opposing world views, integrationists and developmentalists rely on differing histories and assumptions in advocating their respective positions. Although some rapprochement might be possible, we first need to explore these histories and assumptions before offering at least a preliminary reconciliation.

The Integration Movement

The integration movement in North America has several sources, from both the United States and Europe. In the United States, the 1950s and 1960s featured the movement toward civil rights for blacks and other minority groups. This movement was highlighted by the Supreme Court's *Brown v. Board of Education* decision on separate school systems in 1954 and culminated in the adoption of the many civil rights laws in the 1960s.

During roughly the same period, professional and media attention exposed horrible living conditions in several large institutions. Blatt and Kaplan's (1966) *Christmas in Purgatory*, Geraldo Rivera's television exposé, and Robert Kennedy's trip to Willowbrook all documented large, impersonal institutions in which residents were isolated even though in large groups, privacy was minimal, and abuse and neglect were rampant. The physical environment was also bleak, featuring large, dimly lit rooms, blank or dirty walls, and little furniture or decorations of any kind. These conditions at Willowbrook, Pennhurst, and other large institutions led to a public outcry and, later, to court cases and decisions that changed institutional practices and settings (Vitello & Soskin, 1985).

In education as well, there was a movement to integrate children with handicaps into classes with nonhandicapped children. Although not as shocking as the institutional history, in the educational system, too, individuals with mental retardation were being neglected in that parents and professionals struggled to force school systems to educate children with retardation (Lazerson, 1975). This struggle, along with the feeling that the application of new educational advances could accommodate children with mild handicaps into regular classes (Dunn, 1968), led to the passage in the United States of PL 94-142, the *Education for All Handicapped Children Act of 1975*. For the first time, "a free, appropriate" public education was deemed a right (not a privilege) for all children with handicaps. Further, this education was to take place in "the least restrictive educational environment," which has generally been translated into an education within mainstream classes alongside nonhandicapped children (for a review, see Scheerenberger, 1987).

In addition to these more publicized events, Scandinavian workers developed the philosophical position that served as the underpinning to the

integration movement. In 1968, the Swedish worker, Bengt Nirje, described his concept of "normalization," the idea that persons with mental retardation should enjoy as close to a "normal" lifestyle as possible. Nirje defined a normal lifestyle as those practices common for individuals in the culture; in Western societies, a normal lifestyle features a daytime routine that includes work or school, a week that includes work-days and week-ends, and a year that includes vacations as well as work.

Although Nirje's original focus was on the normalization of one's style of life, the focus shifted in 1972 with Wolfensberger's book *Normalization* (Mesibov, 1976). According to Wolfensberger, a normal lifestyle could only occur through a normalization of services. Wolfensberger, Blatt, and others maintained that only in mainstreamed classes or in community living settings could persons with retardation ever hope to achieve a more normal style of life. To many, normalized placements came to appear the only logical and humane treatment for persons with mental retardation.

Before examining the developmental argument, it is necessary to highlight some assumptions held by many integrationists. These assumptions involve ideas about human development, segregated settings of any type, and a sense of history.

The first assumption is about those factors that promote human development and the self-evident nature of these factors. Essentially, this argument states that integration is good and segregation bad for human development. This assumption is probably best exemplified in what has been called the "contact hypothesis" in the mainstreaming literature (Christopoulos & Renz, 1969), the idea that placing children with retardation within the regular classroom will result in more contact with nonimpaired children (and vice-versa). The evidence for this assumption is tenuous: without special efforts, children in mainstream classrooms do not interact much with nonretarded peers (Gottlieb, 1981, 1990), nor do group homes placed in community settings necessarily promote more interaction with surrounding neighbors (Landesman, 1988). More normalized settings can promote more integration, but whether they always or even usually do is another matter.

The second assumption involves segregated settings. To most integrationists, segregation *per se* is bad, for any reason. Even the idea of segregation for special services is denigrated. Yet each of us every day takes part in segregated services: we go to hospitals when sick and age-graded schools throughout childhood. Granted, these services differ from segregated services for persons with mental retardation, as such "normally segregated" facilities serve individuals either for shorter intervals (e.g., hospital) or for specific and societally important functions (schools for learning). But the need for special services—and the possibility that special services sometimes work

better in segregated settings—seems at least arguable in cases such as specialized group homes for persons with Prader-Willi Syndrome (Walsh & McCallion, 1987) or small institutional settings for those with severe emotional, behavioural, or medical needs (Craig & McCarver, 1984).

The third assumption involves history or, more precisely, the lessons of history. The adherents of normalization draw on history to make their point about the need for integrated services. In particular, the history upon which they draw involves experiences of abuse, neglect and human intolerance, both from the 1960s (e.g., Willowbrook, Pennhurst) and before (American slavery, the Holocaust) (Blatt, 1987). These experiences, they feel, serve as object lessons in what can happen when any group becomes marginalized, labeled, or segregated.

The Developmental Perspective

Although not as clearly a “movement” as normalization, the developmental or clinical perspective also has a history and underlying philosophy. Its history involves the debate about best practices that have occurred over the past century and its philosophy is one that emphasizes research over values. Both the history and philosophy of the developmental view center around the goal of providing services that will lead to better functioning and development for persons with mental retardation.

In residential services, this history is exemplified by Walter Fernald, the main leader in the mental retardation field in the early 20th century. Over a long and distinguished career, Fernald initiated multidisciplinary assessments (Fernald, 1922), was twice president of what later became the American Association on Mental Retardation, produced numerous studies, and served as the director of the Waverly Facility in Boston (later the Fernald State School in Waltham) (Wallace, 1925). To some, he is best known for his often-quoted “legend of the feeble-minded,” his statement in 1912 that “the feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs.” According to this view, all persons with retardation require life-long institutionalization. But later, Fernald changed his views. Swayed by his own study showing good outcomes for half of the 646 residents “paroled” from the Waverly facility, Fernald (1919) noted that “the survey shows that there are bad defectives and good defectives. . . . And it shows much justice in the plea of the well-behaved adult defective to be given a trial outside, for apparently a few defectives do not need or deserve life-long segregation” (from Davies, 1930, pp. 200-201). Although such sentiments today seem unenlightened, Fernald’s view of research and of the importance of promoting individual development are hallmarks of the developmental perspective.

In schooling as well, the emphasis among developmentalists has been on examining which practices will best promote the child’s development. As Lazerson (1975) notes, special classes arose from the universal schooling

movement and the public schools' practice of "tracking" children by age and level of ability that began in the early 1900s. Indeed, the very idea of special classrooms arose out of the feeling that regular classes and classroom teachers could not accommodate children with special needs. Even relatively recently, Robinson and Robinson (1965) noted that "the consensus of special educators today definitely favors special class placement for the mildly retarded" (p. 436).

However, the findings for what are the best educational practices for children with mental retardation are mixed, providing little support for developmentalists or integrationists. As summarized in several reviews, children with retardation perform about equally well academically in special versus integrated classes. The children in mainstreamed classes show higher social skills, but are stigmatized by nonhandicapped peers. Levels of racial segregation are about equal in the two settings. Costs are less in mainstreamed than in segregated classes, but the instruction may not be as individualized to the needs of the child with retardation. In addition, regular class teachers often feel unprepared to instruct children with handicaps, with this discomfort increasing in the higher grades (cf. Zigler & Hodapp, 1986, Ch. 11). There is, in short, no easy answer to whether mainstreamed placements better promote development for children with retardation.

Before commenting more fully on both perspectives, it is important to examine some underlying assumptions of the developmental view. The first is its research base and its emphasis on findings over argument. With the exception of obviously poor practices, developmentalists believe that research is necessary to tell us which educational or residential settings are most effective, for which particular individuals. A corollary to this view is that the processes and outcomes of particular settings are not always obvious. Thus, studies show that some large institutions are home-like and not "institutional" (Butterfield & Zigler, 1965), and some group home settings do not, in fact, promote the community living for which they were designed (Landesman & Butterfield, 1987). Concerning both processes and outcomes, then, developmentalists believe that research is needed to determine which practices are best for the individual's development.

A second assumption involves history or, again, the lessons of history. As opposed to the history of alienation, abuse, and neglect emphasized by integrationists, developmentalists focus more on historical trends in mental retardation over the past 130 years. They note that the field is beset by over-optimism followed by over-pessimism (Zigler & Harter, 1969) and caution that what is considered the "best practice" in service delivery changes over time. Developmentalists further argue that only by closely monitoring both the provision and effects of various service options can we best serve persons with mental retardation.

This historically-based caution leads developmentalists to be skeptical of several of the changes brought about by normalization. For example, the integrationist, Burton Blatt (1987), notes that mainstreaming "... does not suggest dumping the child in an untenable regular classroom, ignoring special needs, or discounting specialized teaching, equipment, or curricula" (p. 167). Similarly, regular-class teachers and students should be well-prepared and supported when children with handicaps enter the regular classroom. But, developmentalists argue, just how often does such "perfect" mainstreaming occur? Or, is it instead the more common experience that "general educators in urban school systems seldom see the child's Individualized Education Plan (IEP), and many believe that if a child is mainstreamed that child should be able to succeed without any modifications to the regular class program" (Gottlieb, 1990, p. 17)? Furthermore, when high-quality mainstreaming does not occur, are children with retardation better off in segregated or mainstreamed settings?

Developmentalists also note the historical ambivalence between regular school and special education personnel (Lazerson, 1975) and how such tensions have been exacerbated by recent cost-cutting and taxpayer revolts common in many cities and towns. In effect, they wonder whether mainstreaming is often simply a convenient, "politically correct" device for hard-pressed school administrators to cut costs. Similarly, developmentalists worry about the community residence movement as it actually operates, pointing to the recent evidence of abuses within certain community-based settings (Hurst, 1989 a, b, c). Like the integrationists, then, developmentalists too have their own philosophy, history, fears, and goals, all of which lead to their sense that at least certain specialized services might be needed in educational and residential services for persons with mental retardation.

Parallel Issues in Deaf Education

Although many issues with *PL 94-142* have arisen around children with mental retardation, these have not been the only children affected by this law. Children with motor impairments, blindness, deafness, emotional problems, learning disabilities, and other handicaps are included within the law's provisions.

For most of these groups, integration into society has generally been considered a good idea—Landesman and Butterfield (1987) note the consensus over the goals (but not the practices) of normalization. For children with deafness, however, even the goal of normalization is debated, with most in the deaf community against—or at least skeptical of—the entire mainstreaming movement.

To understand this skepticism, some historical background is necessary. For nearly 100 years, leaders in the deaf community have argued passionately

about whether to teach deaf children through the oral method (i.e., teaching children to produce and understand spoken language) versus the "combined" or "total communication" method (teaching children to sign and, if possible, to speak as well). Although the debate dates to the late 1700s, it is most clearly seen in the decades-long controversy between the oralist Alexander Graham Bell (the inventor of the telephone) and combinist Edward Miner Gallaudet (president of what became Gallaudet University and son of Thomas Hopkins Gallaudet, the first teacher of the deaf in the United States).

In many ways, Bell and Gallaudet's struggles mirror today's controversy between integration versus developmental perspectives. As Winefield (1987) summarizes the positions in the late 19th and early 20th centuries:

A key difference in the nineteenth century oral and combined philosophies was the expected outcome of each approach. The oralists advocated integration as the primary desired outcome. While not eschewing language skills and other academic attainments, they saw these more as means to an end, that end being assimilation. The combinists, in turn, did not reject integration as a desired outcome. To them, however, it was not crucial; their emphasis was on the intellectual and social development of the individual. (p. 80)

This argument about how best to educate deaf children—and about which value is most important—continues to this day. At present, approximately 65% of classes for the deaf in the United States practice combined or total communication methods, while 35% are oralist (Winefield, 1987, p. 96). To most leaders in the deaf community, the value of development has been chosen over integration.

The practice of mainstreaming, too, is problematic. For children with profound levels of hearing loss, most deaf leaders favor special class or even special school placements at which combined methods are used and children can interact in sign with other deaf children. These leaders fear that the "specialized services" supposedly present in mainstream classes simply will not be provided, as most school districts have only one or a handful of deaf children (Neisser, 1989; Schein, 1989). The end result, these leaders believe, is a child who is "not fully accepted by either the deaf or the hearing community" (Garretson, 1983, quoted in Schein, 1989, p. 143).

This review of mainstreaming for deaf children is provided not to criticize the idea of integration, but rather to show that neither integration nor development are all-important or all-pervasive. Indeed, in the preface of his book reviewing the 100 year history of the oralist-total communications issue, Winefield (1987) provides examples of two children harmed by the stridency

of this debate. One child, who was only slightly hard of hearing, could have benefitted from placement in a mainstreamed class, but was never allowed such a placement. The child spent many years learning sign language with other deaf children in a residential school, never interacting with hearing children. Another child, with a more severe hearing impairment, spent many years unsuccessfully learning spoken language in a mainstreamed setting. This child eventually was taught sign in a special school for the deaf, and blossomed as a result. In both cases, total communication and oralist proponents acted in ways that did not benefit either child. In short, both integration and development are single values among many, and neither is all-pervasive.

Toward Reconciliation

In a debate that seems irreconcilable, the integration versus development issue in mental retardation does indeed seem a contrast of two conflicting world views. Yet as we have tried to demonstrate, neither societal integration nor individual development are overriding values that apply in every instance.

More importantly, both integration and development embody philosophies and histories that instruct the other. On the integrationist side, we must continue to acknowledge that institutional abuses have occurred, more often and to a greater degree than has yet been documented in group homes. Therefore, when specialized settings are required—for the most profoundly impaired individuals or for those with particular, specialized needs—these settings must work hard to promote as much integration into the society as possible. In short, a lifestyle with the goal of maximum participation into the wider society needs to be considered an important aspect of individual development.

In the same way, developmental values need to be emphasized within integrated settings. Mainstreaming cannot be allowed to feature placements without necessary adaptations to the specialized needs of the child with handicaps. Indeed, such practices are antithetical to the school's primary purpose of promoting individual development. Developmentalists' skepticism about the use of mainstreaming to cut costs is also partially justified.

This suggested reconciliation between integrationists and developmentalists may already be beginning. In his 1990 presidential address to the American Association on Mental Retardation, James Ellis first advocates taking account of the potentials and limitations of persons with retardation. He acknowledges that "there are things that others know, and can do, and can learn that people with mental retardation do not know, cannot do or learn, or, as is often the case, can do or learn only with special assistance and under favorable circumstances" (p. 265). At the same time, however, Ellis notes that "we must continue to insist on public policies that will enhance the integration and

competencies of people who have mental retardation" (p. 266). This "newly realistic approach" to mental retardation thus combines acknowledgement of disabilities with the twin goals of integration and development for persons with retardation.

In this reconciliation among integrationists and developmentalists, science too plays an important role. The old dichotomy should be discarded and neither the developmental nor integrationist perspectives should be equated with research or science. Research can determine the effectiveness of practices promoting either development or integration. The extent to which particular practices promote individual development can be measured in any number of ways, as can the degree to which settings promote the integration of individuals with mental retardation into the larger society. Ultimately, as Bronowski (1965) notes, science and human values do not conflict with, but reinforce, one other. Let us therefore allow our scientific talents to be used in multiple ways, as we promote the two human values of societal integration and individual development.

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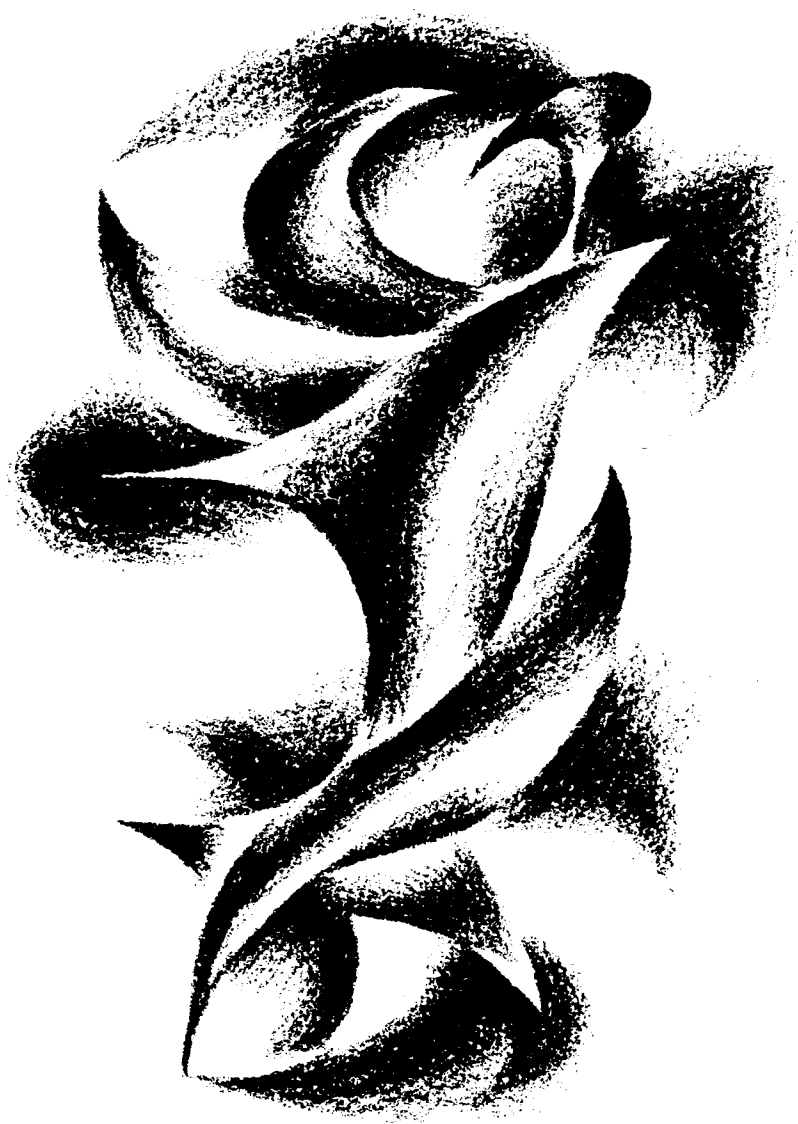
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Each Belongs:

A rationale for full inclusion

Abstract

The issue of special vs. regular education, which has dominated the field of mental retardation for more than thirty years, is no longer an issue. Children with mental disabilities can and should be fully included in regular classrooms and schools. Educators are now focusing their attention on implementation: developing, testing, and refining their knowledge about how to facilitate the full integration of students with disabilities in the most effective and responsible manner. This paper presents a rationale for full integration, exploring a range of perspectives—historical, human, ethical, legal, developmental, social, and educational. The benefits to children with disabilities, to their nondisabled peers, and to society are discussed.

Résumé

La question de l'éducation de l'enfance en difficulté par rapport à l'enseignement normal qui domine le secteur de l'arriération mentale depuis plus de trente ans, ne constitue plus un problème. Les enfants atteints de difficulté mentale peuvent et doivent être entièrement intégrés dans les classes et les écoles du courant dominant. Les éducateurs se penchent aujourd'hui sur la façon d'étoffer, de mettre à l'essai et de peaufiner leurs connaissances sur la façon de faciliter l'intégration des élèves en difficulté de la manière la plus efficace et la plus responsable possible. Les auteurs de cet article établissent le bien-fondé de l'intégration complète, en analysant tout un éventail de perspectives—historiques, humaines, éthiques, juridiques, développementales, sociales et éducatives. Ils analysent les avantages qui en découlent pour les enfants en difficulté, pour leurs camarades sans handicap et pour la société en général.

The issue of "special vs. regular" education, which has dominated the field of mental retardation for more than thirty years, is yesterday's issue. Whether individuals with the label "mental disability" can and should be fully included in family, school, and community life is no longer the question. As we move into the twenty-first century, educators are now attending to questions of implementation: developing, testing, and refining our knowledge about how to facilitate the full integration of students with disabilities in ways that are responsible and effective for all involved.

Why have so many educators agreed that integration is a valued and desired goal? The purpose of this paper is to present a rationale for integration, drawn from a rich array of perspectives – historical, human, ethical, legal, developmental, social, and educational.

To begin, it is important to clarify terminology. The terms "educational integration," "mainstreaming", and "full inclusion" are used interchangeably in this paper. By definition, these terms mean that: (a) children with the disability are educated for all or most of the day in an ordinary classroom with their age peers, (b) the educational program is adapted to meet their social and academic needs, and (c) the child and teacher receive the support and assistance they need to succeed. These terms **never** mean simply placing a child with challenging needs in an ordinary classroom without adaptations or supports.

The model of full inclusion differs from the cascade model, prevalent during the past two decades. Using a cascade model, students with challenging needs are assessed, categorized, and (depending upon level of disability) placed into service options that vary in the degree of integration with others—from regular class, to special class, to special school, to institution. A child may be bussed far from his or her home in order to "fit" into a class for "mildly", "moderately", or "severely" mentally disabled children. In our opinion, this is an outdated model that is based on values, such as, only some children belong, homogeneity in classrooms is desirable and achievable, and segregated education is acceptable for students who are "different".

In contrast, in a model stressing full inclusion, students with challenging needs attend ordinary school with their brothers and sisters, neighbours, and friends. They are assessed to determine strengths and needs; this assessment is done for planning and programming purposes, rather than for placement purposes. A team of regular and special educators plan curriculum to ensure social and academic needs are being met; the child, parents, and other students may be significantly involved in the planning and implementation process. This model is based on values, such as, it is important to make schools into communities in which all children are welcome, diversity in the classroom is desirable as well as realistic, and segregation is unacceptable.

Thus, the underlying philosophy of educational integration is that "each belongs" and that schools can make accommodations to ensure that a child with special needs belongs.

Regular education for all students means creating a community in which each person belongs. It is first and foremost a social ethic of acceptance of diversity, followed by common sense curriculum planning. (Forest & Lusthaus, 1989, p.44)

Historical Context

Noted historian, advocate, and Professor Emeritus Gunnar Dybwad has characterized this century as a struggle toward progressive inclusion for people who have been labelled as mentally disabled. Inclusive education is one part of an overall movement to bring people who have been left out back into our communities and into our lives.

Early years

The turn of the century was perhaps the blackest of times in the history of how society has treated people with disabilities. During the early 1900s, scientists viewed people with a mental disability as subhuman organisms, referring to them as animals and vegetables, or even worse, as garbage or refuse. In 1916 thousands of Canadian citizens signed a petition to the Prime Minister and the legislatures of each province that called for a study on how to control the great menace that the "feeble-minded" presented to the community (National Institute on Mental Retardation, [NIMR], 1981).

This was the era of the eugenics movement, a movement conceived on the faulty notion that society's problems could be reduced by improving the racial strain of the human species. Eugenicists promoted the myth that mental retardation was the cause of poverty, crime, and all social evils. Early in the century, leaders decided upon two possible means of eliminating the problem: sterilization and lifelong segregation.

Within a few short years, some legislatures in Canada and the United States had passed compulsory sterilization laws and many people with mental disabilities were sterilized and warehoused in large, isolated, barren institutions where they were abandoned, mistreated, and left to die. As Cranefield (1966) said of the eugenics movement:

Seldom in the history of medicine have so many intelligent and well-meaning men embarked on so vicious and brutal a program with so little scientific foundation for their actions. (p.13)

Laws were passed that mandated permanent commitment; residents could only be released by court order. In the institutions, people were stripped of their most fundamental rights. There was no right to privacy, no right to property; there was censorship of mail and restricted visiting. Sexes were segregated; and institutions were surrounded by high fences. There were no programs or activities.

We will probably never know the full extent of the crimes perpetrated against mentally handicapped people and humanity itself within the walls of residential institutions around the world. (NIMR, 1981, p.16)

The beginning of change

The 1960s and 1970s saw the beginning of change and "the end of a long tragic era when disabled children were to be hidden away in shame and fear" (NIMR, 1981, p.18). Many factors at work during these decades resulted in a movement to bring people out of institutions and into the community. A number of authors had documented the horrible, abusive treatment in many institutions (Blatt & Kaplan, 1966; Braginsky & Braginsky, 1971; Wolfensberger, 1975). This led policy makers in both the United States and Canada to make improvements of life for people with mental disabilities a national concern. Parents of children with special needs began to organize and lobby for their children's right to live in the community and be educated in noninstitutional settings. Leaders in the field of mental retardation began to define a philosophy of "normalization" and integration, which called for people with mental retardation to have the opportunity to lead culturally valued lives (Nirje, 1969; Wolfensberger, 1972). Finally, courts around the world began to articulate the rights of people with disabilities and their societies' responsibilities to them.

By the middle of the century, the movement had begun to bring people with mental disabilities out of the institutions, but their entrance into the community was usually an entrance into special settings, such as, group homes, sheltered workshops, and special schools or special classes. Community "integration" was still very segregated.

Although segregation within the community was not as blatant as segregation behind institutional walls, it still had a negative effect. It continued to keep people away from each other. Furthermore, researchers later found that specialized, segregated settings within the community did not succeed in preparing people with disabilities to live in the real world. Large group homes continued to have institutional cultures; sheltered workshops did not provide people with the skills they needed for real work and real jobs; special schools did not provide children with the skills they needed to integrate with others (Bruininks & Lakin, 1985; Certo, Haring, & York, 1984; Novak & Heal, 1980).

In all, progress toward integration was made during these decades, but opportunities for mentally disabled individuals to play valued social roles and to participate fully as community members were very limited.

The current era

Since the 1980s, there has been a vast effort across North America to overcome the continued segregation of people with disabilities and to facilitate their full inclusion into the fabric of the community. People who are labelled "mentally disabled" can now live in homes that are truly integrated into the community, work in jobs that are part of the actual work force, and go to school in classrooms with nondisabled children (Taylor, Bogdan, & Racino, 1991; Villa, Thousand, Stainback, & Stainback, 1992; Wehman & Moon, 1988).

In each of these integration efforts, the underlying approach is to provide individuals with the support they need to fully participate in "normal life," in valued roles, in relationship with others. This is an ideal towards which people in the field of mental retardation continue to strive. Integration in school is one part of this overall movement, the next logical step in the progression to full inclusion.

Human Perspectives: The Voice of *People First*

Members of *People First*, a self-advocacy organization of individuals who have mental disabilities, many of whom have lived in institutions, have explained clearly that full inclusion means being recognized as a person and being accepted as having an ordinary life like everyone else. Specifically, it means enjoying the same rights as others; being able to go to school, work, and the movies; having a real job with real pay; making choices about where to live; having a say over one's body; being called by one's name rather than "retarded"; and being given the opportunity to make a contribution to others (French, 1991).

People First, now ten years old, is a strong and powerful force in defining what is "right" for people with a mental disability. Says Barb Goode, founding member of *People First*:

People feel alright as long as they are loved, needed and included by their family, friends, and society. . . . Most people with a mental handicap don't have a chance to be alright. (G. Allan Roeher Institute, 1991, p.1)

Members of *People First* have clear goals about how they want to be treated and are advocating successfully to have those goals met. They lobbied

successfully to have the name of the Canadian Association for the Mentally Retarded changed to the Canadian Association for Community Living, a change that reflects both their negative feelings about being called "retarded" and their passionate desire to be fully included in community life. In 1986, they testified before the Supreme Court of Canada on behalf of Eve, a woman with a mental disability who was fighting for her right not to be sterilized without her consent. The Supreme Court upheld her plea.

Members of *People First* are speaking in public about their experiences, and to educate the community at large about the devastating effects of being called "retarded", and the demeaning results of being segregated. They report that separation from their siblings and neighbours into special schools and special classes has been very harmful to them. They speak very clearly about the need for full inclusion into ordinary schools and classrooms.

Although researchers and professionals have long concerned themselves with serving people labelled "mentally retarded", the people with the label have rarely been consulted about what they want; on the contrary, their choices have been restricted and their voices repressed. Now, their voices can add new meaning to our concepts of research and service (Jackson, 1991; Lord, 1990). It is important that as researchers, educators, and policy makers, we listen carefully to what people with disabilities are telling us about the need to be included.

Ethical Perspectives: A Question of What's Right

When a single person, who has not broken any law, is excluded from the mainstream of school and community life, all of society becomes vulnerable. (Stainback & Stainback, 1990, p.7)

Whether a child with a mental disability or any other challenging need should be able to go to school with others is an important ethical and moral question. Biklen stated in 1985 that the issue of integration for students with disabilities is a question of morality, not science:

Science cannot offer a yes or no decision on integration. . . . At the time of the American Civil War, should Abraham Lincoln have asked to see the scientific evidence on the benefits of ending slavery? Should he have consulted with "the experts," perhaps a sociologist, an economist, a political scientist? Of course not. Slavery is not now and was not then an issue for science. It is a moral issue. (p.16)

Research on the effects of integrated education is essential, but should not be the only basis of judgment in this issue.

Research cannot be expected to solve problems that are substantially moral in character. The fundamental choices we face, as a society, in our efforts to come to terms with extremes in individual differences, are not going to be resolved by research. Having decided what it is we must do, then research is one means available that may tell us how to do it; that is all we can promise, nothing more. That is why research needs public policy. (Baumeister, 1981, p. 456)

Many authors have likened the struggle for school integration for children with disabilities to the civil rights struggle for racial integration in the United States. In the case of *Brown vs. the Board of Education* (1954), Chief Justice Earl Warren stated that separateness in education is inherently unequal, and can cause irreparable damage. John W. Davis, the chief advocate for the defense, argued that if segregation for black children was unconstitutional, surely it would be found that segregation of children defined as disabled is also unacceptable (Gilhool, 1976).

Parents, professionals, politicians, and community members who are working for the full inclusion of students with disabilities into regular education believe that it is simply unfair and morally wrong to segregate any students, including those defined as disabled, from the mainstream of regular education. The goal of fully including students with disabilities reflects an important societal value, a value that includes maximizing student development, but goes beyond it to creating a just society.

The inclusion and participation of all people in the social and political life of the community is at once a fundamental value of democratic societies, and the principle means by which such societies are sustained. (Peck, 1991, p.5)

Legal Perspectives: Justice and Equality

The legal concepts of justice and equality provide a further rationale for full educational integration. The idea that persons with intellectual disabilities are people with human and legal rights is a fairly new concept. Until recently, they were not considered to have rights, and "most courts simply would not look into the area of mental health care or the treatment of the developmentally disabled" (Martin, 1978, p.5). Recently, Stephen Lewis, noted Canadian human rights advocate, commented on the fight that persons with a mental disability have pursued to gain their full citizenship rights: "It is a struggle that will never end. . . . But rights are not just the privilege of a few," he wrote. "They belong equally to all of us" (Lewis, 1991, p.iii).

In the 1960s, growing interest in human rights increased consciousness about the rights of people with disabilities. By 1975, the United Nations had proclaimed the *Declaration on the Rights of Mentally Retarded Persons*, and

the *Declaration on the Rights of Disabled Persons*, which included the rights to life, to community living, to education, to work, to vote, to marry, to become a parent, to enter into contracts, and to have representation in court.

By the 1970s and 1980s, advocates were working to entrench these human rights into legal rights. In 1977, the *Canadian Human Rights Act* stated that no one should be discriminated against for reasons of physical or mental disability; this Act only applies to matters under federal jurisdiction. The provisions of provincial human rights codes provide analogous protection for matters which fall under provincial jurisdiction. On April 17, 1985, Section 15 of the *Canadian Charter of Rights and Freedoms* came into effect, prohibiting discrimination based on physical and mental disabilities for every level of government in Canada. Canada is the only country in the world that constitutionally guarantees the rights of persons with a mental disability to legal equality (Endicott, 1990).

The Canadian Charter is having a dramatic effect on issues of full inclusion all across Canada (MacKay, 1987; Poirier & Goguen, 1986). Now the question of whether children with disabilities can go to school with others is not only a moral, pedagogical, or research question, but it is also a legal one. Do students with disabilities have the right to go to the same school as others and receive an appropriate education in that setting? Is it discriminatory to deny them access to education with others? What is considered fair treatment?

Since the Canadian Charter was passed, many important cases involving children with mental disabilities who have been denied access to integrated school situations have been prepared for court (Porter & Richler, 1991). These cases were settled before they got to court; the children were accepted into integrated schools with support for the children and the teachers. In 1991, in Quebec, in the first case brought before the newly created Québec Human Rights Tribunal (Re: *David M. and Commission scolaire Saint-Jean-sur-Richelieu*), the tribunal ruled that David M., aged 9, was the victim of direct and indirect discrimination under the Québec Charter and ordered the school board to integrate him into a regular classroom, with necessary adaptation and support (Smith, 1991).

The question of whether a student with a mental disability, including a moderate or severe disability, has the right to go to school with everyone else is new. Until now, officials at each school board have placed students in the setting provided for the child's "category" of disability, usually one that was available in the existing system of services. The 1991 ruling in Quebec, which is being appealed, may change this practice significantly, requiring school boards to respect the rights of the individual child to have access to regular school programs, with modifications to meet their needs.

Developmental Perspectives: Benefits to Integrated Students

Do students with special needs benefit more from regular class or special class placements? Although there has been a variety of conflicting data that covers more than a thirty-year period, there is now consensus that students with a mental disability can develop maximally socially and academically when they are integrated in regular classes in which accommodations are made to meet their individual needs (Gottlieb, Alter, & Gottlieb, 1991; Halvorsen & Guess, 1991; Madden & Slavin, 1983).

Students with mild disabilities

During the 1960s and 1970s a series of "efficacy studies" was conducted to determine whether it was better for students defined as mildly mentally retarded to learn in regular or in special classes. The efficacy studies were a response to the proliferation of special classes for mildly disabled students, and to the disproportionately high percentage of minority students placed in special classes. Educators began to question whether these classes were doing more harm than good to the students in them (Dunn, 1968; Johnson, 1962).

Dozens of studies were published and their findings were mixed (Carlberg & Kavale, 1980; Corman & Gottlieb, 1978; Semmel, Gottlieb, & Robinson, 1979). Most researchers found that students in special classes did not have better outcomes than comparable students in regular classes. These findings shook the special education establishment and raised questions about the assumptions underlying special education. Why wouldn't these students do better in small, homogeneous classes, with specially trained teachers and special education methods and materials, than in regular classes? Researchers hypothesized that perhaps students did not learn more because there may have been lowered expectations, watered-down curriculum, and a lack of peer models in the special classes.

Other studies found that students in special classes had better academic outcomes and better self-concepts than those in regular classes; these authors suggested that students mainstreamed into regular classes were being deprived of the attention they could receive in special classes. Many authors noted that the differences in the findings from the efficacy studies may be due to a number of conceptual and methodological problems in the studies themselves.

In 1983, Madden and Slavin published a comprehensive review of the efficacy studies in the *Review of Educational Research*. Selecting only studies that had adequate methodological controls, they found that children with a mild mental disability performed better academically and socially when they were in regular classrooms with modified curriculum than when they were in special

classrooms. They found that several instructional and organizational processes enhanced social and academic outcomes for integrated students: individualizing curriculum, using cooperative learning methods, teaching social skills, and facilitating interaction among the children.

In 1987, Gartner and Lipsky outlined the negative effects of segregated schools and classes. They called for the creation of one unified system of education, with improved instructional practices, to replace the dual system of regular and special education. They stressed the need for appropriate support to regular educators and special-needs students to allow for adequate modification of the curriculum.

Gottlieb, Alter, and Gottlieb (1991) reiterated the extreme importance of considering instructional processes when assessing the outcomes of special vs. mainstreamed education. "The literature has shifted from research on mainstreaming as placement . . . to research on mainstreaming as an instructional program" (p.104). After reviewing research using this paradigm, they concluded that the data on mainstreaming are quite clear. When effective programming is in place, and when a variety of steps are taken by the school district to increase the chances for success, mainstreamed students have beneficial results. Placement in regular classes, in the absence of these processes, does not result in improved social or academic outcomes.

Skrtric (1991), in the *Harvard Educational Review*, added to the concept that special class placement had little to add to the improvement of education for students with special needs. He called for a rethinking of the process of education, recommending that educators move from a rigid, bureaucratic system to a more flexible, collaborative system of decision-making, in order to meet all students' educational needs in one unified system.

Students with severe disabilities

In the early part of this debate over special vs. regular class placement, no one seriously considered the integration of students who were labelled severely disabled. However, students with severe disabilities, including severe intellectual problems, have been integrated more and more frequently into ordinary schools and, often, into ordinary classrooms (Ford & Davern, 1989; Forest, 1984, 1987; Giangreco & Putnam, 1991; Sailor, 1989).

In 1991, Halvorsen and Sailor published a thorough review of studies concerned with school integration for students with severe disabilities and concluded: "Virtually all available research reviews indicate better educational outcomes associated with integrated placements as compared to their segregated counterparts" (1991, p.143). They cited the following summary of benefits of integrated education: improved social and affective development, improved interactive development, increased skill generalization, improved parental expectations for their child's future, increases in the proportion of

objectives obtained, improved attitudes of nondisabled students to peers with disabilities, improved future work earnings, improved proportion of normalized living arrangements.

In sum, researchers have found that students with a mental disability benefit socially and academically when integrated into regular classes in regular schools, keeping in mind that integration by definition includes adaptation of the curriculum and adequate support for students and teachers, not just physical placement.

Social Perspectives: Benefits to Nondisabled Students

May and Richard, who had been in a special class for students with moderate mental disabilities, are now part of a class at St. Francis School in Kitchener, Ontario. Their peers report:

Ever since I became friends with Richard, we're always talking and fooling around. So like they're no different than. . . the rest of us; just maybe on the outside. May has feelings. . . . She's a lot smarter than I thought she was. . . . She's a person. . . . She can cope with her problems. . . . If she gets hurt, she'll tell people. She won't just keep it bottled up inside. . . . And she's a person, not just a thing that you're supposed to be nice to, but an actual person like everyone else! (Meyer, Peck, & Brown, 1991, p.xvii)

Snow (1989) reminds us that all children are gifted, and when given the opportunity, they can bring their gifts to the community. When they are excluded, the community suffers the loss of their unique gifts.

Individuals with special needs, when given the opportunity, can play the valued social role of contributor (Lusthaus, 1986; Perske, 1988). A number of researchers have studied the positive contributions that people with disabilities make to their families and communities. Turnbull (1985) and Cunningham (1982) found that within the family system, children with disabilities often provide a source of joy, pride, and family strengthening. Perske (1980) discovered that adults with developmental disabilities who moved into well-run group homes enhanced their neighbourhoods by drawing neighbours closer together; and Vanier (1971) reported that communities with disabled people were enriched by their gifts of openness, love, and trust.

These same themes have emerged in many schools that have integrated students with challenging needs. Educators have stressed how the students' presence and participation have enriched the entire school (Brown, Ford, Nisbet, Sweet, Donnelan, & Gruenewald, 1983).

Researchers have identified a number of important social benefits for students attending ordinary schools where children are integrated (Bogden &

Taylor, 1989; Murray-Seegart, 1989; Snell, 1991; Voeltz, 1982). Benefits to nondisabled students include: improved self-concept; increased understanding, acceptance, and tolerance of differences; increased empathy toward others; and development of personal principles. Nondisabled students express feelings of reduced anxiety and fear towards others; they develop confidence in their own ability to act appropriately in interpersonal relationships; and they learn to understand and develop friendships with their disabled peers. For example, Peck, Donaldson, and Pezzoli (1988) found that high school students said that their experiences with severely disabled students played an important part in how they developed their personal values and principles of moral action.

Snell (1991) summarized literature regarding the benefits to nondisabled students integrated with severely disabled students and indicated that the nondisabled had: (a) improved expectation for, and attitudes toward, students with disabilities; (b) enhanced capabilities at facing parenting due to being better informed and from having a positive base of experience; and (c) greater appreciation of human diversity and individual differences in achievement that are a part of life.

Furthermore, several studies have indicated that the academic outcomes of nondisabled children are not compromised by well-planned integration; in fact, in situations where teachers have applied the concept of individualization of instruction, nondisabled students have improved their academic outcomes (Madden & Slavin, 1983; Putnam, Rynders, Johnson, & Johnson, 1989).

In all, educating students with the label "disability" in ordinary classrooms may be providing all students with opportunities to grow in tolerance and acceptance of differences. Students may be learning a lesson in humanity that is difficult to teach. Almost all studies find that nondisabled students discover, to their surprise, that their classmates with disabilities are "just like us". The students' ability to grasp the profound essence of their sameness, with those they view as different, may be a crucial lesson for everyone's future.

Educational Perspectives: Is Full Inclusion Possible?

It is clear from the wealth of documentation that it is possible to achieve integrated education, at least in systems that plan and implement systemic change efforts to reach this goal. School boards throughout Canada, the United States, Europe, Australia, and New Zealand are implementing various models of inclusive education. They are not just attempting to include students with disabilities into regular schools, but are working on restructuring their educational systems to make them more responsive to a diverse student population in a multicultural society. As George Flynn, leading Canadian educator, states:

In my view integration is probably the most important issue in education today because it provides for a focus for restructuring our schools. . . . It develops attitudes about how people work with

other people. . . how people live in our society together, support one another, and develop community. (Flynn & Forest, 1987)

Educators and researchers have stressed that there is no single recipe for integration, no one way that is right. In schools that have restructured to implement an integrated system, many practices have been found effective. These include organizational processes, such as, unifying special and regular education, redefining professional roles and responsibilities, developing collaborative team structures, developing in-service models and coaching processes, and creating support networks for students and teachers. Effective instructional processes include: individualized and adapted instruction, cooperative learning, peer tutoring, friendship circles, transitional planning, and integrated support services (Giangreco & Putnam, 1991; Lipsky & Gartner, 1989; Porter & Richler, 1991; Stainback, Stainback, & Forest, 1989; Villa, Thousand, Stainback, & Stainback, 1992).

Some question the wisdom of pursuing this educational change without a great deal more research and analysis about its effectiveness and practicality (Fuchs & Fuchs, 1991; Kauffman, 1991). A number of concerned educators have indicated that full inclusion is too lofty an ideal, not sensible to work toward because it is unrealistic and unlikely to be achieved (Lieberman, 1985; Messinger, 1985).

In our opinion, given the moral, legal, and developmental evidence, the pursuit of educational integration, even with its attendant problems, is essential. "Does mainstreaming work?" is a silly question. . . . Where it is not working, we should be asking what is preventing it from working and what can be done about it" (Bogden, 1983, p.427).

Conclusion

Although the actual practice of integrated education is still in its infancy, educators and researchers have shown it to be possible and beneficial, and there is a growing body of knowledge about how to implement this educational reform effectively.

To continue to ask whether integration is a good idea is to ask the wrong question; rather, the question to be asked when examining integrated environments is: How do we make integration work for all children?

In considering these questions, we as educators must think with our hearts as well as with our minds. Relegating students with special needs to a separate system of education is unfair and unnecessary. They can grow and develop optimally in ordinary classrooms when accommodations are made to meet their needs.

Furthermore, nondisabled students can benefit from the opportunity to grow and learn with a diversity of children. They need to learn that their differences are ordinary, not threatening; that within their differentness, they share a fundamental human sameness; and that they all have gifts, in their own unique ways. Children with disabilities must be allowed to bring their gifts and special needs to the ordinary classroom, enter into relationships with their classmates, and add to the quality of education for everybody.

Educating all students in the mainstream of regular education raises deeply provocative educational and social issues. What do we want our society and communities to look like? What life do we want for ourselves and our children? Welcoming children who have been left out may provide all students with the opportunity to build a bridge to a more humane future.

It is time to turn our energies to developing school communities in which all children can belong and share their gifts, and to make integrated education a way of life.

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About the Lives of Other Human Beings:

The benefits of deinstitutionalization for people with mental retardation

Abstract

Deinstitutionalization is more than a policy issue and a matter for empirical research. It is an issue that, at its most fundamental level, has to do with human beings and the quality of life to which human beings should be entitled. This paper explores the benefits of deinstitutionalization in human terms and discusses the impact of implementing deinstitutionalization as a public policy for people who have mental retardation. Empirical support, both for deinstitutionalization and for ameliorating problems that have occurred in the movement toward community-based models of service delivery, is presented.

Résumé

La réinsertion sociale est davantage qu'une question politique ou de recherche empirique. À son niveau le plus fondamental, cette question concerne les êtres humains et la qualité de vie à laquelle ils ont droit. Le présent document traite des avantages de la réinsertion en termes humains et examine l'impact de la mise en application d'une politique publique de réinsertion sociale des personnes atteintes d'arriération mentale. Nous présentons un appui empirique aussi bien à cette réinsertion qu'à la solution des problèmes associés au mouvement d'adoption de modèles de prestation de services axés sur la collectivité.

Recently, while doing my banking, I overheard a woman ask her teller if she could cash the paper she had in her hand. It turned out to be a notice that she had a federal income tax refund due but would need to file a return in order to collect it. Two other bank employees who knew this woman by name offered to help; one of them explained in detail what the notice said and what the woman should do next. During this transaction, I recognized this woman but the last time I saw her she was in a large ward at a state institution where she was in restraints.

In the grocery store the other day, I overheard one clerk telling another about a ball game at Boston's Fenway Park that he had attended. His description of the game was animated and his co-worker hung on every word with equal excitement, sharing the joy of the game. The clerk who had not gone to the game is a student at a local community college. The clerk who had gone is a former resident of a state institution.

Several months ago, I ran into an older woman whom I had known very well. She told me she was shopping with friends. Afterwards, she was going out to a bar with her boyfriend because they liked to go dancing. She also invited me and my family to come visit her apartment that she had furnished by herself and that she described with great pride as being "absolutely beautiful." I knew this woman because I used to be the recreation aide at the "training school" where she lived. I had previously taken her on group field trips to the zoo, the park, and the playground. I also brought her to my family's home one year for Christmas and once just she and I went out to dinner and to a musical. She reminded me of this when we met.

The story of deinstitutionalization indeed reflects one of the more pressing public policy issues of our time and certainly has been the subject of considerable research. More importantly, the story of deinstitutionalization is the story of people . . . people like the three just described whom I happen to know personally and who are some of the 100,000 or so individuals who, in the past 20 years, have benefited from moving out of large facilities and into home-like settings in typical communities (Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991; Scheerenberger, 1982). The story of deinstitutionalization is about people taking care of themselves, being empowered to make their own decisions, handling their own finances, having the freedom to do the things they like, having friends and lovers, living in a "real" home, and having a meaningful job.

The History of Deinstitutionalization

The popularity of institutions for people with mental retardation and other disabilities has waxed and waned during different periods of history (Zigler & Hodapp, 1986). The wave of unpopularity behind the present

deinstitutionalization movement can be traced to several factors present in the 1960s and 1970s that in combination focused the attention of policy-makers on the atrocious conditions present in large institutions for people with mental retardation and other disabilities (Nisbet, Clark, & Covert, 1991).

One factor was the public's shock at such exposés as *Christmas in Purgatory* (Blatt & Kaplan, 1966) and Geraldo Rivera's national broadcast in 1972 about New York's Willowbrook State School (cited in Rothman & Rothman, 1984). These accurately depicted human warehouses in which inhabitants were unclothed, barely fed, constantly in restraint, and left to languish in filthy environments. Other factors included the increasing political activity of many advocacy groups representing and including people with disabilities and their families (Knight, 1980); increased federal awareness of, and initiatives to address, the service needs of people with disabilities beginning with the establishment of John F. Kennedy's President's Panel on Mental Retardation in 1961 (Braddock, 1986a; Braddock, 1986b); and litigation in many states including such landmark cases as *Wyatt v. Stickney* (1972) in Alabama and *Haldermann v. Pennhurst State School and Hospital* (1977) in Pennsylvania. Fueling the deinstitutionalization movement internally was a growing tension between the behavioural orientation of most mental retardation professionals (Baldwin, 1985) and the views of humanistic psychologists (McGee, Menousek, & Hobbs, 1987) and social role theorists (Wolfensberger, 1991) who challenged service delivery models that stripped the people they claimed to help of respect and dignity.

Settlements of lawsuits, in particular, led to a fundamental change in the quality of life for individuals with disabilities in establishing rights that previously were unrecognized for people "incarcerated" on an involuntary basis in large institutions solely for reasons of disability. These legal rights include adequate food, shelter, clothing, medical care, safety, freedom from unnecessarily restrictive confinement, such as "non-therapeutic" use of restraint, and minimal habilitative programming (*Youngberg v. Romeo*, 1982). In practice, however, involvement of the judicial system has resulted in more substantial changes in the way services were to be delivered, and policy makers inside and out of the disability field sought alternatives in the form of community services (Scheerenberger, 1980).

Current Status and Trends

As a result, institutional populations in the United States for people with mental retardation declined from approximately 190,000 nationwide in 1970 (Scheerenberger, 1982) to 90,000 in 1988 (Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991). During the same two decades, there was a decline in the rate of placement into such settings corresponding to growth in the number of community residential facilities (Lakin, White, Hill, Bruininks, & Wright,

1990). In 1988, for example, there were almost 180,000 community residences compared to less than 25,000 in the late 1960s. Additionally, at least 18 large institutions have closed since 1980 compared to only six shut down between 1970 and 1980 (Braddock & Heller, 1985a). Trends similar to those in the United States are found in other nations such as Sweden (Pedlar, 1990) and Canada (Flynn & Nitsch, 1980; Roeher, 1980).

Originally, the concept of deinstitutionalization focused on three issues: 1) making institutions more humane and homelike, 2) decreasing institutional populations through placement of residents into community facilities, and 3) prevention of institutionalization (Turnbull, 1988). Today, the focus has shifted away from making institutions more homelike due to the high costs of institutional care and the dual expense of maintaining both institutional and community-based services simultaneously (Braddock & Fujiura, 1991; Castellani, 1987). Given that 85% of people with mental retardation have always lived in their communities (Bruininks, 1991) and given models of successful delivery of community-based services to individuals with severe medical and behavioural challenges (cf. Smith, 1990), the philosophical and programmatic justification for this trend is a growing recognition that little can be accomplished in segregated settings that cannot be done as well or better in more typical environments.

Another trend has roots in the lack of operational definitions of community residences at the beginning of the deinstitutionalization movement (Hill & Bruininks, 1986). Motivated by the availability in the United States of Medicaid reimbursement, a number of states initially "deinstitutionalized" residents of large public institutions to smaller private facilities such as regional centres, nursing homes, and group residences of 16 or more beds (Lakin, Hill, White, Wright, & Bruininks, 1989; Mitchell & Braddock, 1990; Neufeld, 1977; State of Connecticut Department of Mental Retardation, 1979). Although labeled community-based programs, these smaller facilities were nonetheless institutions offering little relief from the problems associated with large public settings. Thus, the current trend is toward small community residences such as family living arrangements or group residences of six or fewer beds (Nisbet, Clark, & Covert, 1991).

Empirical Evidence of Benefits

Individuals who remain in institutions typically display increases in maladaptive behaviour (Conroy, Efthimou, & Lemanowicz, 1982) and decreases in cognitive functioning (Eyman & Widaman, 1987). In comparison, people who have been deinstitutionalized to smaller community settings show increases in overall adaptive behaviour (Conroy, Efthimiou, & Lemanowicz, 1982; Fine, Tangeman, & Woodard, 1990); hopefulness, self-confidence, and independence (Edgerton, Bollinger, & Herr, 1984); academic skills, social

interactions, community orientation, use of free time, and vocational pursuits (Eastwood & Fisher, 1988); involvement in activities (Braddock & Heller, 1985b); and responsibility and language development (Kleinberg & Galligan, 1988).

Improvements in adaptive behaviour are greatest immediately following community placement and continue at a slower rate thereafter (Conroy & Bradley, 1985; Hemming, 1986). Greatest gains are exhibited by people who originally have lower adaptive behaviour scores (Conroy & Bradley, 1985) and are dramatic even for short-term visits to typical environments (Baker & Salon, 1986). Indeed, in their review of the literature, Larson and Lakin (1989) concluded that the available research denies support for the assertion that people obtain greater or even equal benefits in increased adaptive behaviour from living in large public institutions. In fact, this research suggests that those benefits very consistently accrue more to people who leave public institutions to live in small community residences (p. 330).

In a series of studies in several states, Conroy and Feinstein Associates and the Temple University Developmental Disabilities Center/University Affiliated Facility showed that these benefits accrue in two ways to people with mental retardation who have been placed in community residences (Conroy & Feinstein, 1986). The first is by enabling individuals to use skills they apparently had prior to institutionalization but were restricted from applying in the institutional environment. The second is in acquisition of new skills, including skills that had been targeted for instruction in institutional programs but were never mastered by the program participant. This is consistent with the literature documenting the greater success of teaching skills to people with mental retardation in natural, as compared to contrived, contexts (Dunn, 1991; Freagon & Rotatori, 1982).

In addition to improvements in personal competence, consideration of the benefits of deinstitutionalization must take into account indicators of quality of life and consumer satisfaction (Landesman, 1986). The quality of life of people with mental retardation has been found to improve following deinstitutionalization as individuals have greater control over the environment, more opportunities for social interaction, and increased use of community resources (Schalock & Lilley, 1984); live in more home-like living environments (Thompson, Robinson, Graff, & Ingenmey, 1990); and are in proximity to population clusters and neighborhood resources (Janicki & Zigman, 1984). Compared to large institutions, smaller community-based facilities offer more encouragement for individual autonomy, more things to do, greater use of community facilities, and more satisfied direct-care staff (Rotegard, Hill, & Bruininks, 1983). People living in them benefit from higher rates and longer duration of staff interactions and more engagement in purposeful activity (Felce, deKock, & Repp, 1986).

With respect to consumer satisfaction, individuals who live in institutional settings express greater dissatisfaction with their living arrangements than do individuals living in smaller community-based residences (Conroy & Bradley, 1985; Eisenberg & Rammler, 1989). Studies have documented both the negative opinions about community living of family members when their relatives still are in institutions (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987) and the significant change in positive attitudes toward deinstitutionalization that occurs among family members following their relatives' community placement (Braddock & Heller, 1985b; Conroy & Bradley, 1985. See Larson & Lakin, 1991, for a review). Families also have been shown to have higher expectations for their relatives following deinstitutionalization (Grimes & Vitello, 1990) and perceive their relatives as being significantly happier in community settings than they were in the institution (Conroy & Feinstein, 1985).

Deinstitutionalization has benefited people with mental retardation by markedly increasing the numbers who are contributing to society through competitive or supported employment (Rusch, Chadsey-Rusch, & Johnson, 1991). Individuals with disabilities, including mental retardation, themselves now participate in public policy-making as program evaluators (Allen & Gardner, 1985; Rammler, 1986), as members of agency executive boards (Gibbon & Osborne, 1981), and as expert witnesses before congressional committees and other policy-making bodies (Kennedy, 1991).

Problems and Solutions

Clearly, small community facilities have many benefits over large institutions for people with mental retardation yet they have not been exempt from problems. For example, not all community placements have been successful. Recidivism is highest among individuals who have more problem behaviours and decreased behavioural control (Intagliata & Willer, 1982); who are older, have poorer sensori-motor functioning, have lower IQs, or have less family involvement (Schalock & Lilley, 1986); and have unmet needs for dental, medical, and therapy services (Jacobson & Schwartz, 1983). The likelihood that individuals who never have been institutionalized will be admitted for the first time is less than the likelihood that individuals with a prior history of institutionalization will be re-admitted (Black, Cohn, Smull, & Crites, 1985).

Despite quantitative indicators of success in community placements (e.g., decreased use of medication and greater participation in home life), individuals who have moved to community settings have reported having little in common with their housemates, being disconnected from real participation in their communities, having to depend entirely on staff for social and

emotional support, having little power to make decisions, and not being able to relocate to another residence if they wish (Lord & Pedlar, 1991). Compared to typical adults, group home residents have fewer choices on such basic matters as when to do certain things like go to bed, what to eat for meals and snacks, and how to spend their money and leisure time (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988).

Quality of life outcomes are experienced differentially. Not as well off are individuals with fewer skills (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988), residents of larger community residences, and individuals in sheltered as compared to supported employment settings (Schalock, Keith, Hoffman, & Karan, 1989). More stringent standards for care and treatment in group homes with federal intermediate care facility for the mentally retarded (ICF/MR) certification makes such residences more like institutions than homes (Fernald, 1986).

The research comparing individuals in institutional settings to those living in community residences strongly suggests that a "right" to community living has been recognized only for certain groups of individuals. These groups include people with higher overall levels of adaptive behaviour (Vitello, Atthowe, & Cadwell, 1983); fewer problems in the areas of ambulation, self-care, and communication (Hauber *et al.*, 1984); higher IQs and fewer medical, mobility, and visual impairments (Selzer & Krauss, 1984); and fewer behaviour problems (Borthwick-Duffy, Eyman, & White, 1987). Differential placement appears to occur despite evidence that individuals' institutional behaviours and medical conditions are not predictive of their success or failure in community settings (Baker & Salon, 1986; Karan & Gardner, 1984). Priority for placement also often is given to individuals "returning" to communities from target institutions. This occurs frequently at the expense of individuals who live in other institutional facilities or have never been institutionalized (Castellani, 1987; State of Connecticut Department of Mental Retardation, 1985).

Placement into a community-based facility does not safeguard against major medical or behavioural incidents that injure or pose the threat of harm to individuals (Spangler & Gilman, 1985) and abuse certainly occurs (Hewitt, 1987; State of Connecticut Office of Protection and Advocacy for Persons with Disabilities, 1990). Nor are there guarantees to family members who remain concerned about the permanency of community residences (Conroy & Bradley, 1985; Hearn, 1986). For example, Hill, Bruininks, Lakin, Hauber, & McGuire (1985) showed that community residential facilities, although more stable than typical living units in comparable neighborhoods, did close at annual rates ranging from a low of 5.6% for group residences to a high of 42.6% for foster home placements. There is higher turnover and less longevity among group home as compared to institutional staff, although rates of absenteeism are lower

(Baumeister & Zaharia, 1987). Despite research showing no decrease in either quality of life or property values following establishment of neighborhood community residences (Gelman, Epp, Downing, Twark, & Eyerly, 1989; Ryan & Coyne, 1985), public fear and uncertainty has led to difficulty in opening some facilities (Cnaan, Adler, & Ramot, 1986; Conroy & Bradley, 1985; Pedlar, 1990; Selzer, 1984; Selzer & Selzer, 1987).

Development of appropriate community services is hampered by self-perceptions of residential staff as providers of custodial care rather than as trainers (Slater & Bunyard, 1983); decreased family visits following community placement because the new residences were too far away (Grimes & Vitello, 1990); restrictions on the diversity and frequency of activities imposed by funding regulations (O'Neill *et al.*, 1990); and financial disincentives to states (Braddock & Fujiura, 1991).

From a public policy perspective, the claims that deinstitutionalization would be less expensive than institutional care (Howse, 1980) have not been substantiated because of the growth in spending on mental retardation and developmental disabilities services. National expenditures in the United States escalated from \$910 million in 1977 at the apex of the deinstitutionalization movement (Braddock, Hemp, & Howes, 1987) to \$5.64 billion in 1988 (Braddock & Fujiura, 1991). The reality is that individuals with more involved needs require more intensive services (Wieck, 1988), regardless of where the services are provided. Clearly, as these individuals have moved from no-service institutional settings into full-service community residences, costs have risen commensurately. Yet, Ashbaugh and Nerney (1990) have concluded that it is the model of residential program and facility characteristics, rather than client needs, that increase costs. Some facility characteristics are linked to client characteristics (e.g., higher staff-to-client ratios), it is unfortunate that substantial public resources have been devoted to more expensive alternatives such as ICF/MRs and public sector programs with higher personnel salaries and fringe benefits.

The traditional view of community placement requires matching an individual's level of functioning to a hierarchy of facility types such as group homes, community training homes, supervised apartments, and independent living arrangements. These presumably reflect increasingly less restrictive environments that correspond to increasingly higher levels of individual functioning. When we describe a taxonomy of services based on the concept of the least restrictive environment, however, we fall into what Steve Taylor has termed a "continuum trap" (Taylor, 1987) and we confuse segregation and integration with the intensity of services that an individual needs (Taylor, 1988). We also create niches into which individuals with highly idiosyncratic needs seldom "fit."

By starting with a different premise, the policy and empirical question changes dramatically from "What type of person fits into this type of setting?" to "What services and supports does this person need to live in this home?" Parallel shifts in policy and research questions occur when we apply the same line of reasoning to day programs. Such a shift removes us as practitioners from what essentially has amounted to victim blaming but puts the onus back on professionals to be creative in assuring the success of community placement.

Thus, the critical issues in addressing problems associated with community living pertain to the quality of the community residences into which individuals have been placed and the level of support and services they received post-placement. For example, increases in adaptive behaviour are associated with greater individual control over the environment, more resident-oriented care practices, and participation in programs (MacEachron, 1983). Transition planning to facilitate the individual's adjustment and to assure that appropriate resources are available is critical (Gardner & Karan, 1984; Wilcox, 1988).

For community living to be optimally successful, several things need to be in place. A qualitative analysis of the impact of the closure of Pennhurst in Pennsylvania suggests the need for quality assurance, monitoring, advocacy, case management, individualized planning, and leadership in maintaining the momentum established initially by the American judicial system (Conroy & Bradley, 1985). To avoid isolation and depersonalization within the community, rigid administrative practices must be abandoned and vigorous community-building activities undertaken (Jacob & Taylor, 1990). Quality assurance efforts need to shift from assuring that minimal health and safety standards are met to addressing quality of life outcomes that are driven by consumer needs, wants, and desires (Knoll, 1990).

Administratively, staff-to-resident ratios can be increased by reassigning staff duties so that certain staff have more comprehensive responsibility for working with residents (Byrd, Sawyer, & Locke, 1983). Staff also must receive adequate pre- and in-service training in relevant topics such as designing and implementing appropriate resident training programs (Fiorelli, 1982; Fiorelli, Margolis, Heverly, Rothchild, & Keating, 1982; Gage, Fredericks, Johnson-Dorn, & Lindley-Southard, 1982).

Rejecting the "goodness of fit" between an individual and a particular environment as grounds for determining eligibility does not negate the importance of applying the model to identify support needs (Schalock & Jensen, 1986). For example, if an individual cannot perform a certain important skill, support is needed. Depending on the individual's unique needs, that support may take the form of either training to the necessary level of independence or personal care services to perform the skill totally or partially on behalf of the

individual (Falvey, Coots, Bishop, & Grenot-Scheyer, 1989). As Taylor (1988) also suggests, community living can involve a phase-out of supports as individuals become more autonomous rather than requiring the individual to change and make transitions from one facility to another (Rudrud & Vaudt, 1986).

Conclusion

Webster's New Word Dictionary, in its definition of "home" includes "... a place where one likes to be; a restful or congenial place . . . ; the members of a family or a unit; a household and its affairs." Home is more than an address, and when we discuss deinstitutionalization, we need to begin with the premise that everybody needs a home.

Deinstitutionalization in the past decade has been moving beyond the notion that individuals must be matched to pre-existing services (Cone, Bourland, & Wood-Shuman, 1986). More and more services today reflect a model of independent living which presumes that all community residences should be homes for the people who live in them (Knoll & Ford, 1987). Support for independent living requires that assistance with housing, transportation, personal care, finances, and employment is modified and provided according to individual need with a focus on individual self-help and self-control (Budde & Bachelder, 1986).

The commitment to deinstitutionalization is not universal among human service professionals (cf. Crissey & Rosen, 1986). Yet, the messages we are hearing from individuals with mental retardation themselves are loud and clear. The outcomes self-advocates want for themselves include being treated like everyone else, getting the supports they need regardless in which community they live, being empowered to choose where and with whom to live and associate, living in typical and integrated neighborhoods, having control over their daily lives and their futures, and getting the jobs they want and the training they require (Campbell *et al.*, 1985; Kennedy, 1990; Williams & Shoultz, 1982). Contrast this to Maryann Crowley's description of institutional life:

"It was just like a jail. You couldn't do nothing. You couldn't make conversation like I'm doing now

They can just push you around They don't let us go home, they move us farther away. . . . I hadda share a room with 200 people You couldn't keep your own stuff. . . ." (Schweir, 1990, p. 110)

The story about deinstitutionalization is about human beings, some of whom I don't know and some of whom I do. It is about respecting what they say they want and helping them to achieve it. It is building on a solid foundation

of empirical research that shows the benefits of community living in comparison to life in an institution and that enables us to overcome the problems we encounter along the way. It is mindful of the substantial investment of public resources in community-based programs and commitment to expending those resources to the greatest good of the people they are intended to help. Deinstitutionalization is about the lives of other human beings and helping to assure that their lives are meaningful.

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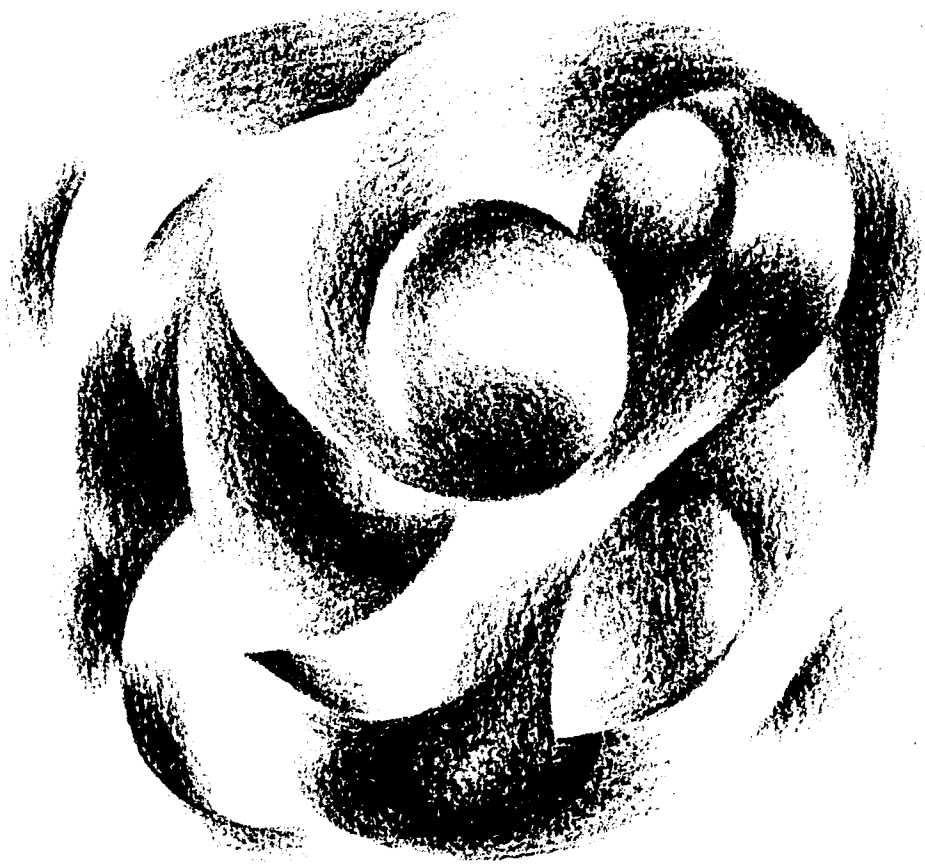
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Resource Networks for Community Settings: An alternative view of institutions

Abstract

Institutions, though declining in number and size, remain substantial components of services for people with mental retardation and other developmental disabilities despite rapid growth in community-based services. Vigorous debate has taken place between the institutional and community positions. This paper argues that an institutional capacity, envisioned as networks or regional resource centers, is still needed to support certain activities not readily available in the community. The term "institution" is explored and an alternative perspective is developed, suggesting that a softening of the strong anti-institutional position may be warranted. Examples of how regional centers can provide health care, specialized services, and research and professional training are presented to demonstrate the use of "institutional" components to support community-based services.

Résumé

Les établissements spécialisés, même si leur nombre et leur taille accusent un recul, demeurent une composante importante des services qui s'adressent aux personnes atteintes d'arriération mentale et d'autres troubles du développement, en dépit de l'essor rapide des services communautaires. La polémique est vive entre les partisans des établissements spécialisés et ceux des services communautaires. Les auteurs de cet article soutiennent que les établissements spécialisés, perçus comme des réseaux ou des centres de ressources régionaux, sont toujours nécessaires à l'appui de certaines activités qui sont difficilement accessibles au sein de la communauté. Ils analysent le terme «établissement spécialisé» et développent un autre point de vue qui préconise un assouplissement de l'opposition farouche à l'existence de ces établissements. Ils citent des exemples de la façon dont les centres régionaux peuvent offrir des soins de la santé, des services spécialisés en plus de mener des recherches et d'assurer la formation professionnelle afin de démontrer l'utilité des établissements spécialisés à l'appui des services communautaires.

During the last 20 years in the United States and Canada, remarkable growth has taken place in the development of community-based services for people with mental retardation and other developmental disabilities (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). Recently New Hampshire announced the closure of its state-operated facility at Laconia, making it the first state in the United States with no public institutional facilities for people with mental retardation. While New Hampshire had only one public facility to close, the trend is being echoed in larger states in the United States and in Canada as well. For example, officials in New York State have recently announced their goal to close all state-operated institutions for people with mental retardation by the year 2000. Nevertheless, future historians of the field may still refer to the 20th century as the era of institutionalization since institutions flourished during most of the century, peaking in the mid-1970s (Scheerenberger, 1987). Despite some shrinkage since then, institutions continue to be a widespread service option as the century comes to a close.

Thus, as the ideology of the field shifts toward community-based, integrated services, many institutional facilities remain. This has given rise to vigorous, often acrimonious, debate on issues such as residential size and type, quality of life, inclusion, rights, advocacy, treatment, mainstreaming, and public policy. This article examines several of the issues and provides an alternative view of certain elements from the institutional era that may have utility in the future—in a community-based service era.

Institutions and the Community: A Brief Overview

The continued existence of institutions does not mean that the movement toward community-based, consumer-oriented services is not substantial; indeed, in the last 20 years it has spread across the continent. Service systems in both Canada and the United States are becoming increasingly community-based. For example, in the United States, Braddock and his colleagues (Braddock *et al.*, 1990) showed spending on community services increased steadily from \$.58 per \$1,000 of the nation's wealth in 1977 to \$1.44 per \$1,000 in wealth in 1988, a 150% increase. Further, they found that changes in state funding that was supportive of community services were related to "advocacy activities" and the "political climate of the state," and not necessarily to the availability of funds (Braddock & Fujiura, 1991). Thus, the communitization movement produced important changes in public policy, funding priorities, and the actual mix of service providers (e.g., Borthwick-Duffy, Eyman, & White, 1987).

Nonetheless, actual movement **into** the community may be occurring more slowly than many proponents would like. More resources are being devoted to community-based services than in the past, but spending for institutions still exceeds spending in the community (Braddock *et al.*, 1990). Also, more people with mental retardation still reside in institutional settings than in community settings (Braddock *et al.*, 1990; Cunningham & Mueller,

1991). And though fewer people presently reside in institutions, these facilities remain funded better than they ever have been.

These facts have not blunted the criticism of institutions. Despite richer funding, the view persists that institutional facilities are unfit places to live. Advocates armed with change strategies drawn from other rights struggles, philosophical concepts such as **normalization** and **social role valorization** (Wolfensberger, 1972; 1983), and accounts of institutional abuses have prompted substantial expansion in community-based services. Although concerns about possible negative effects of rapid deinstitutionalization have been voiced by parent and family groups (e.g., Louisiana Association for Retarded Citizens, 1984; Pennsylvania League of Concerned Families of Retarded Citizens, 1985), theoreticians and researchers (Crissey, 1975; Throne, 1979; Zigler, Hodapp, & Edison, 1990), and practitioners (Walsh & McCallion, 1987), it no longer seems reasonable to maintain that institutional facilities as we have known them in this century will continue far into the next. Many will close and the overall census in state-operated institutions will shrink (Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991). In short, despite the present numerical predominance of "institutional beds", the beginning of the end for large, central, public institutional facilities is at hand—even if the last one doesn't close until well into the next century.

As this century closes, the field of mental retardation and developmental disabilities finds itself characterized by a dual system – the coexistence of institutional facilities and community-based services. Everyone associated with the field—people with developmental disabilities and their families; advocates; researchers; service providers; allied professionals; educators; and state administrators—is struggling to redefine their roles at the end of a century that began with the certainty of institutions, encompassed a diversity of opinion, and approaches its end struggling with a dual system. As such, it is an ideal time to examine ways in which institutions have been successful and which may bear renewal.

Elsewhere (Walsh & McCallion, 1987) these ideas were presented in the context of "fluid" institutions functioning as "regional resource centres." The present paper extends this reasoning to the consideration of institutions becoming centres or network bases able to support such things as specialized habilitative services, professional development and training, and health care coordination. Before examining some of these in detail, however, a fresh perspective on what constitutes an "institution" is needed.

Institutions: Beyond Brick and Mortar

Words become prisoners of their usage. In the field of mental retardation the term "institution" usually refers to a facility, a brick and mortar **place**, for the congregate care of as many as hundreds (in the past thousands) of people, or as few as 16. Other connotations beyond this "brick and mortar" view are

possible. For example, in institutional research, the term has also been used to characterize **practices** within facilities along a quality of care dimension (Balla, 1976; King, Raynes, & Tizard, 1971; Zigler & Balla, 1977). Sometimes the word is avoided altogether by the use of "intermediate care facility" or "residential treatment centre." In general, the word "institution" has come to carry negative connotations in that institutions are viewed as detrimental to human development and happiness.

Unfortunately, problems of humaneness, rights, and quality of services are not automatically avoided in community-living settings (Landesman, 1988). Reviews of the literature centered on the institutional vs. community debate (e.g., Biklen & Knoll, 1987; Walsh & McCallion, 1987; Zigler *et al.*, 1990) have often reached different conclusions. Some call for additional research, viewing the issues as largely empirical and requiring more refined concepts and study (Landesman & Butterfield, 1987). Others conceptualize the issues as only involving "values" and "freedom" and not subject to empirical scrutiny (Blatt, 1987).

A strong anti-institutional view, however, ignores certain important referents or meanings of the term "institution". Dictionaries provide several meanings, only one of which conveys the notion of a place or facility with buildings and property. The word also refers to elements of **social organization or custom**—rather different than the "brick and mortar" emphasis. This connotation suggests numerous "institutions" exist within our communities, including public and higher education; political structures ranging from city councils and school boards to Congresses and Parliaments; health care systems and facilities; private ownership of property; and elements of social structure.

Institutions viewed as elements of social organization are known to change, being modified by the conditions of a particular historical period. For example, marriage and family life, as social institutions, have changed dramatically in the past half century. While the traditional nuclear family survives, numerous other arrangements flourish as well. This malleability, examined in the field of developmental disabilities, dramatically softens the dichotomy between institutions and the community, one that has fueled debate for two decades. Zigler, Hodapp, and Edison (1990) conceptualized strong anti-institutional sentiment as representing a fallacy of according too much importance to a social address. They argue, as have others, that **what** is done is more important than **where** it is done. For example, group homes, employing similar physical and programmatic regulations as institutional facilities and responding to traditional political, administrative, and fiscal pressures, may be quite similar to institutional units. This is not to argue for the continuance of large congregate facilities or to deprecate community residential services. Rather, the intent is to highlight the notion that services should be matched to the needs of individuals, regardless of setting (Zigler *et al.*, 1990).

In this way, too, it becomes clear that large bureaucratic systems designed to provide community-based services are, by nature, institutional systems – fraught with many of the perils of brick and mortar institutional facilities. In this context the words of Throne (1979) are unambiguous:

The distinction between institutions and communities is a false one. A human community is composed of people **and** their institutions. It is impossible to imagine a community of people without institutions. (p. 171)

Providing for Individual Needs: Regional Resource Networks

Institutional facilities are centralized systems—resources are located in one central place; community-based services, on the other hand, represent dispersed systems with resources flowing to several locations. Centralized facilities tend to provide all services required by a person, often in a less individualized manner; community systems tend to individualize more and access existing resources in the community. Thus, the efficiency (economy of scale) of the institutional model may be offset by its inability to individualize services. Similarly, although community-based systems tend to be more individualized, needed services are often inaccessible, incomplete, or simply unavailable. For example, at least in the United States, access to health care services has often been difficult for a variety of reasons (Crocker, 1989; Garrard, 1983).

Future service systems must be developed that avoid the drawbacks of both systems while preserving their benefits. Community-based services are here to stay (Janicki, Krauss, & Seltzer, 1988) and will be refined as we enter the next century (Braddock & Fujiura, 1991). The remainder of this article will focus on a few elements of the institutional model that should be preserved. Unlike previous efforts in this vein (e.g., Zigler *et al.*, 1990), however, the recommendations here do not argue for the maintenance of large institutional facilities. Rather a case is made for an **institutionalized capacity** able to (1) provide quality services in a variety of settings; (2) completely and adequately address the training and development of professionals and other practitioners; and (3) maintain adequate facilities to conduct discipline and policy-oriented research (Bruininks, 1990).

The task then becomes to determine ways of addressing problems in the field that bridge the gap between institutions and the community, and by extension between social policy advocates and researchers (Landesman-Ramey, 1990; Menolascino & Stark, 1990). "Institutions" of the future, then, might be thought of as organized systems of specialized resources, perhaps housed in regional centres but not necessarily, through which public policy can

be implemented. Sites for such centres could include universities, hospitals, established service providers, or sections of institutions that have closed or been reduced in size. In this perspective, an institution is best viewed as a network or a system rather than as a piece of real estate with residential buildings, classrooms, workshops, and administrative offices. In the haste to close centralized institutions, their potential, in altered form and reduced in size, as community support systems, resource banks, specialized service sites, and training and research centres has been neglected. While institutions gave rise to abuses, they also provided the foci for a "critical mass" of professionals who developed specialized treatment and service knowledge, conducted research, and developed additional specialists. Coordinated service networks will be able to continue certain of these functions as the following examples demonstrate.

Health care

As more people with developmental disabilities return to the community, problems arise in the provision of basic health care (Garrard, 1983; Luckhardt, Rupp, & Stevens, 1989), especially in meeting their specialized needs (Rubin, 1987). Consider a regional community medical centre that provides primary medical care to people living in the community, using staff of the centre (Ziring, Kastner, Friedman, Pond, Barnett, Sonnenberg, & Strassburger, 1988). While not an institution in the traditional "brick and mortar" sense, it is a centralized site providing quality services. Services are not rendered by the local community physician, but rather by professionals whose primary practice consists of people with developmental disabilities. While many health care issues of people with developmental disabilities are not unique and can be readily treated by community practitioners, certain problems require specialized services or, at least, specialized knowledge (e.g., Friedman, Kastner, Pond, & O'Brien, 1989). Further, such specialized systems or networks operating in the community have been seen as desirable in the provision of health care services (Crocker, Yankauer *et al.*, 1987; Kastner, 1991). Not only do such systems constitute essential health care services, they also serve an important coordination function among disparate members of the service provision scene. Although the primary goal of such systems in the future may be to support the delivery of primary care by local health care professionals, there may always be a need for regional centres as secondary and tertiary care providers based on the specialized needs of people with developmental disabilities.

Specialized services

The community movement rests on the assumption that the needs of people with developmental disabilities are best served in integrated settings. While this position does not deny the existence of individual differences among

people with developmental disabilities, the effect in practice is to minimize their differences from nondisabled people. However, a specialized field and specific body of knowledge has existed for well over 150 years (Scheerenberger, 1983). Although many of their needs are not different, some people with developmental disabilities do require special services. Controversial issues are encountered when considering specialized services. One is diagnostic labelling; another is segregated services; and sometimes congregate living becomes an issue. In the simplest model, specialized services begin by identifying specific needs in people (diagnostic labelling), and then bringing people with similar needs together for service (segregation). If the services require residential placement, some form of congregate living is arranged. Advocates have spurned the use of diagnostic labels (cf. Lilly, 1992) as inherently demeaning and too easily employed as a basis for devaluation of the person. However, from a scientific perspective, classification is essential before work can be carried out to explicate a phenomenon. Blurring aspects of the definition of mental retardation and disavowing diagnostic classification may well impede scientific advances (Burack, Hodapp, & Zigler, 1988; Zigler, Balla, & Hodapp, 1984; Zigler & Hodapp, 1986). From a clinical or treatment perspective, this may also not be in the best interests of people with specific disabilities (Hodapp & Dykens, 1992).

Specialized services and treatment are sometimes provided best in segregated, congregate living settings. For example, the author participated in a project that established a very structured group home treatment program for adults diagnosed with Prader-Willi syndrome, a syndrome that, among other problems, involves disordered eating patterns and, sometimes, associated behavioural problems (Omrod, Rose, & Walsh, 1985; Walsh & McCallion, 1987). In this program, adults with the syndrome lived in a group home and worked in the community. The program was designed to teach, among other things, appropriate eating and meal preparation behaviours. Individual choice was promoted within the structure (e.g., by allowing choice among dietary equivalents); routine tasks and daily discussion and therapy sessions afforded the mutual support of others who shared this rare disorder. It can be argued that the congregate life in this structured home of a small group of individuals with a similar genetic disorder, actually empowered them to succeed, in most cases, for the first time in their lives. In addition, a related benefit of this program has been the facilitation of a research program designed to systematically examine aspects of this syndrome (Dykens, Hodapp, Walsh, & Nash, *in press*). Most important, perhaps, is that anecdotal reports of the individuals themselves are generally positive; individuals appreciated the need for the structure employed. Indeed, the group dynamics of the program shifted such that the consumers themselves assumed control over the maintenance of structure. In short, they viewed the structure as "house rules" that applied equitably to everyone and had the advantage of helping everyone overcome the effects of their common syndrome.

Further, segregated residential treatment settings are not uncommon in other areas such as mental health, substance abuse, or cancer. Beyond treatment settings, cultural history is replete with examples of subgroups who share common needs, religious preferences, cultural background, or simply lifestyles affiliating in either existing neighborhoods or in specifically designed communities (Fitzgerald, 1981). Thus, if "congregate settings" refer to small home-like specialized living facilities, designed for specific therapeutic purposes related to developmental disabilities, offering individualized state-of-the-art treatment by knowledgeable staff, then in certain circumstances they may be quite appropriate. Given fiscal reality, it may also be that such settings could profitably employ the best small units of some larger, institutional facilities that are being reduced in size or closed.

Specialized services, of course, do not always imply residential living. Specialized community clinics are possible as are specialty treatment services within existing facilities. For example, although rarely encountered in the community, comprehensive physical management programs for multiply handicapped individuals can be efficiently arranged in more centralized settings (Smith & McFarland, 1991). A similar perspective has been articulated in relation to education (Gottlieb, 1990; 1981). Further, an argument can be made that special educators possess specialized skills quite applicable beyond the classroom (Rosen, Rice, Walsh, Hartman, & McCallion, 1991).

Research and professional training

As institutional facilities close and their resources are dispersed into the community, it is important not to lose the ability to conduct applied research in the area of mental retardation and developmental disabilities. While some community advocates have suggested that research into practical and service issues is less important than simply applying appropriate values (e.g., Blatt, 1987), others have recognized the need for continuing applied research efforts (Landesman & Butterfield, 1987; Robinson, 1987). Indeed, Brooks and Baumeister (1977) early on called for more ecologically valid research. Community research, however, has often lacked focus or been too narrowly defined. Allen (1987), for example, has described the identity crises that have plagued community-based research efforts, including lack of clarity in definitions and methodological problems. Research in this area has been reviewed extensively (see Landesman & Butterfield, 1987; Landesman & Vietze, 1987, for extensive discussions of these issues).

Institutional facilities have been good sites in which to conduct research. The community-based services that replace institutions often do not include the same "critical mass" of professionals specializing in the field. This fact remains a concern in the provision of quality services (e.g., health care), and represents a significant problem in the conduct of applied research. As institutions are

phased down, steps need to be taken to preserve the "critical masses" of professionals these facilities have traditionally maintained. In the past, professional departments in institutions provided a base for numbers of practitioners in a multitude of professions to work together, often with collaborations resulting in important research findings or the development of formal internship programs. Although the field is not totally devoid of opportunities, they are clearly more limited and dispersed. Nevertheless, the importance of a "critical mass" should not be underemphasized; professionals often are attracted to fields or subspecialties when opportunities exist to work closely with colleagues.

Such groups of professionals will also usually spawn training programs and opportunities for students and younger professionals. As generic community services (those used by people who are not developmentally disabled) are increasingly utilized by people with such disabilities, it is imperative that professional training opportunities remain available. Indeed, the need for specialized training in the area of developmental disabilities will be heightened as more community practitioners from all disciplines begin to provide services to people who have developmental disabilities.

Conclusion

In this article I have presented the view that as large, centralized institutional facilities are replaced by services in the community, a specialized institutionalized capacity – conceptualized as systems, networks, or regional centres—is still needed. Such regional centres can continue to support professionals who provide specialized services, conduct research, serve as resource and consultation banks, and train young professionals. Zigler *et al.* (1990), Crissey (1986), and Walsh and McCallion (1987) have all suggested that these types of centres will be needed in the future. However, ardent proponents of community services have often espoused such a strong anti-institutional position that first, the institutional nature of many community services has not been recognized, and second, discussion of networks or regional centres such as those described herein has been precluded.

It may be that the foundations of such regional resource networks already exist in the form of large public institutional facilities that are shrinking and being closed. Service networks and resource centres as those described herein could support, supplement, and help coordinate community providers; they could also serve to organize knowledge, provide consultant assistance, and develop research and training programs. Without such centres, knowledge of developmental disabilities may become difficult to acquire as research activities disappear from service sites.

Without such centres, for example, a community physician, treating an individual with developmental disabilities living in the community, may have nowhere to turn for information about unfamiliar diagnostic or treatment

issues; or a psychologist working in the community, asked by parents to help them gain control over their child's behaviour, may not know how to design an individualized behavioural plan. Finally, without such centres, a young professional, of any discipline, seeking research opportunities or an internship or practicum site offering a broad range of experience with all levels and ages of people with disabilities, may search in vain for an opportunity.

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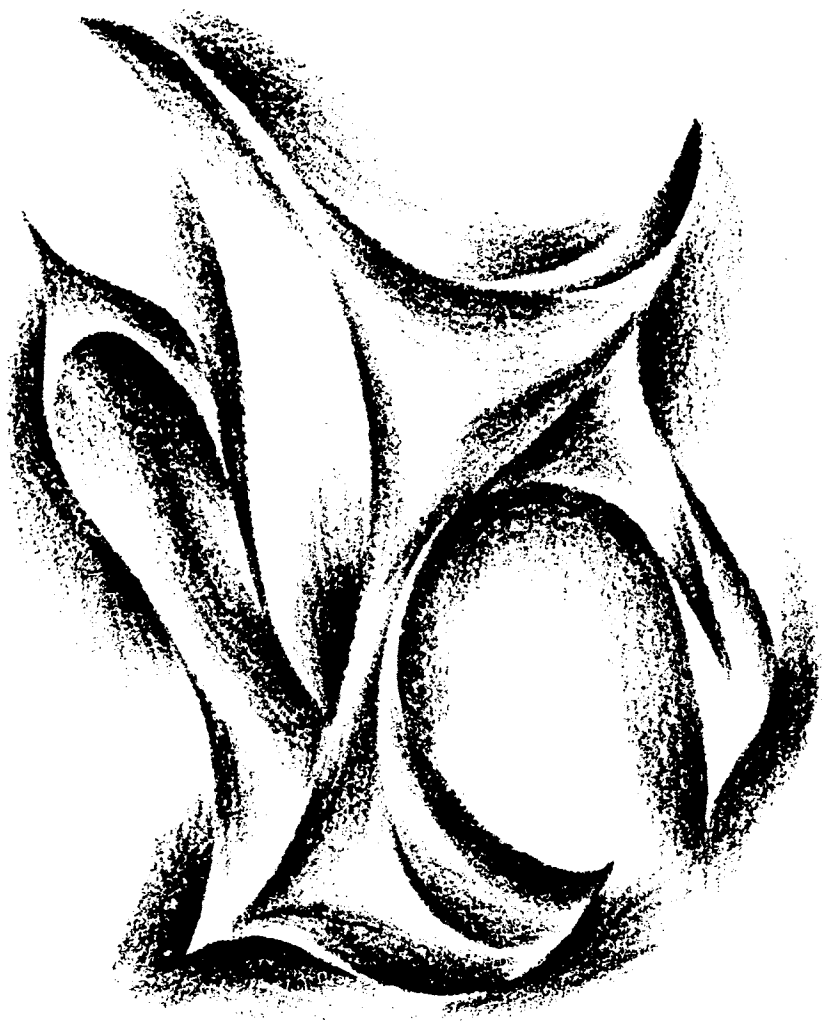
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Intervention Strategies for Families Having Children with Developmental Delays: Prospects for the 21st century

Abstract

A family systems model is presented for understanding, adaptation, and coping with children having a developmental disability. The importance of a systems approach, emphasizing reciprocal interactions, in working with children and families is stressed. These interventions provide the entire family techniques through which effective adaptive coping strategies, increased self-esteem, more positive parent-child interactions, and appropriate strategies for educating the child with disabilities are achieved. Centre-based child programs for children with developmental disorders can no longer function in isolation, rather emphasis and support for a family systems and social-ecological model is presented.

Résumé

Nous présentons un modèle de système familial cherchant à comprendre les enfants souffrant de troubles du développement, à s'y adapter et à traiter avec eux. Nous insistons sur l'importance de ce type de système et sur les interactions relatives au travail auprès des enfants et des familles. Ces interventions fournissent à toute la famille des techniques grâce auxquelles il est possible d'arriver à mettre en application des stratégies d'adaptation, d'accroître l'amour-propre, de rendre plus positives les interactions parent-enfant et de mettre en application des stratégies sur l'éducation des enfants souffrant d'invalidité. Les programmes des établissements destinés aux enfants présentant des troubles de développement ne peuvent plus fonctionner en vase clos et notre présentation met l'accent sur un modèle socio-écologique et un système familial.

Although past researchers have generally focused upon individual and dyadic relational patterns of adaptation, a family systems theory emphasizing reciprocal interactions, intersystem influences, and the complexity of relational networks form a natural conceptual bridge between developmental psychopathology and family systems theory (Cicchetti & Howe, 1991). Successful therapeutic interventions, by necessity, require a family-based organizational and transactional model. These interventions can provide the entire family with techniques through which effective adaptive coping strategies, increased self-esteem, more positive parent-child interactions, and appropriate educational strategies for educating the child with disabilities can be achieved. The importance of incorporating an intervention model considering both the spousal and parent-sibling subsystems remains crucial for the well-being of the entire family and is consistent with Minuchin's (1985) family systems theory.

The past two decades have seen a trend in research and clinical programs toward an emphasis and examination of the effects of childhood disorders on the entire family. This is in marked contrast to earlier efforts that traditionally focused on negative parental effects upon children, merely incorporating a dyadic (mother-child) model (Konstantareas, 1991). Five contributing, overlapping factors, may have accounted for the shift in paradigms: (1) a more systematic and widely accepted perspective of the transactional nature of interactions in family situations (Minuchin, 1985); 2) the growing body of research delineating the effects of children's behaviour on parents (Lamb, 1976); 3) a view of family functioning which perceives the child as an equipotential family member; 4) the absolute necessity for parental input for the long term treatment and education of children with disabilities and special needs; and 5) the recognition that many parents are frequently unable to meet the multiplicity of demands of having a disabled child (Konstantareas, 1991). This changing paradigm has influenced and had a direct impact upon service delivery models. For example, innovative intervention programs have begun to include the handicapped child, parents, and siblings (Caro, 1990).

Although numerous traditional home-based and centre-based clinical interventions are available for children with developmental disabilities and their families they remain problematic for a number of reasons. Many attempt to serve families with a multitude of psychological and medical needs, they remain atheoretical in orientation, and have staff with varying degrees of training. Nevertheless, most programs attempt to provide at least some modicum of parental training as well as individual treatment programs for the disabled child (Tjossem, 1976). While staff members may have different theoretical orientations and varying skills and sophistication in dealing with children with multiple disabilities, the programs themselves frequently subscribe to some general conceptual philosophical and/or psychological model (Derevensky, 1981).

While most intervention programs strongly advocate and incorporate parental training (e.g., Abidin, 1980; Caro, 1990; Caro & Derevensky, 1991; Derevensky, 1981; Derevensky & Wasser-Kastner, 1984; Derevensky & Baron, 1986; Tjossem, 1976) its efficacy has recently been questioned (e.g., White, Taylor, & Moss, 1992). More recent research efforts have begun to focus upon the entire family unit incorporating a family systems model.

The family's adaptation to the presence of a disabled family member is predicated upon the quality of the relationships achieved among all family members. An understanding of the family's communicative patterns with their disabled child remains critical to understanding family functioning and the potential efficacy of specific types of intervention strategies.

Family Systems Model

A family systems model represents a conceptual framework through which individuals can focus on the various subsystems within the family unit. The reciprocal effects of each family member's behaviours on the other members emphasizes the importance of examining marital (husband-wife), parental (parent-child), and sibling (child-child) interactions.

As a means of ascertaining the existing mental health status of the family unit, an essential starting point for clinical intervention may be determined by systematically observing interactions among its members, assessing the degree of closeness and communication skills, and examining both verbal and nonverbal behaviours (Skrtic, Summers, Brotherson, & Turnbull, 1984; Turnbull, Summers, & Brotherson, 1986). On a more pragmatic level family functioning reflects the nature of the family's ability to cope with cultural, environmental, economic, and psychosocial stressors (Fewell, 1986). Key factors found to influence the family's functioning revolve around basic needs, levels of stress, and perceived support. The individual's ability to deal effectively with each of these factors significantly affects their level of adaptation. The level of social support, and perceptions of this support, serves as a significant predictor of potential family crisis (Nihara, Meyers, & Mink, 1980). Not unexpected, specific resources, especially financial resources, have been found to mitigate the level of stress (Wikler, 1986). Similarly, close relationships with extended family members and religious groups serve as potential sources of support (Cohen, Agosta, Cohen, & Warren, 1989; George, 1988).

An understanding of both parent and child perceptions are paramount for the intervention team. Whether these perceptions are accurate or inaccurate, they continue to influence the manner in which parents respond to their children.

Relationship between parents and young disabled children

Central to the issue of the family's level of functioning as a unit is the quality of the relationships achieved by its members. This is particularly important for children with developmental disorders. Interactions between parents and children with developmental delays require an accurate interpretation of behavioural and nonverbal cues. Parental behaviours and interactions reflect an understanding of the cognitive abilities and affective needs of their children. Typically, nondisabled children demonstrate behavioural cues that are more easily and accurately interpreted, resulting in adult feelings of efficacy and self-worth (Goldberg, 1977). Conversely, young children with developmental delays frequently exhibit behaviours that negatively influence parental interpretation of their needs and, in turn, the quality of parent-child interactions. Children's passivity and lack of responsivity has been shown to elicit fewer positive parental reactions and behaviours (Brooks-Gunn & Lewis, 1984; Hanson, 1984). Interactions between parents and children with moderate to severe developmental disabilities consist of less enjoyment, pleasure, and reciprocity, when compared to parents having nondisabled children (Gallagher, Beckman, & Cross, 1983; Wasserman, Shilansky, & Hahn, 1986; Yoder & Farran, 1986). As well, the frequency of maternal and paternal responsivity has been shown to increase as a function of the children's enhanced repertoire of communicative skills (Frey, Fewell, & Vadasy, 1989). Increased communicative competence by children with disabilities is similarly indicative of their improved cognitive skills, resulting in higher frequencies of parental responsiveness and interaction (Brooks-Gunn & Lewis, 1984).

Although considerable research on parent-child interaction has centered upon maternal behaviour, the importance of paternal behaviour has recently received attention. Fathers have been shown to display varying levels of child care and emotional involvement with their nondisabled and disabled children (Bristol, Gallagher, & Schopler, 1988). In comparison to mothers, fathers are more effective in obtaining children's compliance to requests and present more socially interactive games (McCollum, 1988). Equally important is the essential role they play in supporting their spouse.

Interactions between nondisabled and disabled siblings

Within a family systems model the examination of sibling interactions becomes important. This becomes particularly acute when one of the siblings has a handicap. The sibling subsystem has characteristics that are unique, is influenced by family interactions, is dependent upon the developmental level of the children, and is reflective of individual differences and needs (Brody & Stoneman, 1986; Brody, Stoneman, & Burke, 1987; Dunn, 1988).

Research has generally focused upon a reciprocal interactional model, whereby each child influences the other. A number of critical factors seem to influence this relationship including birth order, gender, age, type and severity of disorder, family size, and socioeconomic status (SES).

Gender differences appear to be an important determinant. Older female siblings experience greater adjustment problems presumably because they are frequently required to assume many of the child-rearing roles for disabled children (Stoneman, Brody, Davis, & Crapps, 1988). Siblings of the same gender have been reported to be more adversely affected due to their close identification with their disabled siblings (McHale, Simeonsson, & Sloan, 1984). Still further, Pfouts (1976) concluded that nondisabled children displayed ambivalence toward their brothers with mental retardation, while disabled siblings remain more hostile toward their nondisabled brothers. Young male siblings seem to exhibit greater adjustment problems than females and assume a more dominant role in the sibling relationship (Crnic & Leconte, 1986).

Siblings from larger families appear to adjust better as parental expectations can be shared amongst all the children (Stoneman *et al.*, 1988). It has been found that children from low SES homes assumed greater child care responsibilities, while middle-class children exhibited greater concern with the negative stigma associated with having a disabled sibling (Seligman, 1983). The level of competence of the disabled sibling appears to significantly influence the perceived quality of the sibling relationship (Begun, 1989).

A common finding throughout these studies was that the adaptation and attitudes of the siblings greatly reflected parental attitudes (Brody & Stoneman, 1986). These attitudes are thought to be transmitted in an indirect manner through the roles they assign and the demands they place upon their nondisabled children (e.g., being a teacher versus a playmate) with the disabled child (Brody & Stoneman, 1986). Gallagher and Powell (1989) found that siblings' adjustment problems increased as they became more cognitively aware of the full extent of the effects associated with their siblings' handicapping conditions, regardless of the handicapped child's functional level.

Negative effects displayed by siblings include competition for parental attention and resources, compensation for the disabled child's limitations, confusion regarding parents' inconsistent behaviour and coping ability, exclusion from the parent-disabled child dyad, and being the recipient of "bribes" to compensate for diminished parental attention and time (McHale *et al.*, 1984).

School-age children and adolescents frequently experience difficulty in answering peer questions about their siblings' developmental delays and embarrassment from people's stares (Skrtic *et al.*, 1984). Similarly Grossman

(1972) found that adult siblings expressed fear about bearing a child with a disability and/or guilt concerning the burden of care that rests with the parents.

Without appropriate intervention, nondisabled children have been shown to engage in negative behaviours toward their disabled siblings (e.g., verbalizing or performing cruel or angry acts and statements) (Wellen & Brown, 1982). Siblings having a brother or sister with a disability report lower self-concepts and increased anger (Harvey & Greenway, 1984), anxiety, embarrassment, guilt, conflictual patterns with their parents, and decreased amounts of interpersonal relationships (Breslau, Weitzman, & Messenger, 1981; Skrtic *et al.*, 1984).

On a more positive note, siblings of children with cognitive handicaps have been shown to have large networks of friends (Stoneman *et al.*, 1988), indicating considerable sources of social support rather than social isolation (Crnic & Leconte, 1986). Although harmonious relationships between siblings may be difficult to establish and maintain, the incidence of interactional problems remains no more frequent than in other groups (Dunn, 1988). Sibling relationships in families with disabled children fail to maintain a consistent pattern. Their adaptations range along a continuum from inadequate coping to positive satisfactory adjustment (Simeonsson & Bailey, 1986). Nevertheless, within a family systems model an understanding of the sibling's perceptions, needs, and behaviours is paramount.

Prospects for the 21st Century

The more recent literature in early childhood special education has focused upon interventions with entire family units. A family-focused intervention model which emphasizes the parent-child relationship as well as relationships among other family members, has strong clinical support (Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986). The goals associated with this approach are to assist family members in (a) coping with the evolving needs of children having a disability; (b) comprehending the child's role both as a family member and as an individual; (c) establishing and maintaining mutually pleasurable and developmentally appropriate parent-child interactions; and (d) designing programs incorporating parental needs and priorities (Bailey *et al.*, 1986). Further, the past emphasis upon the parent-child relationship must be modified to include siblings, thereby ensuring the incorporation of the needs of all family members. Similarly, the family's perspectives, competing needs, and relationships between the various subsystems are included within a family system perspective. Families become empowered and perceived as having the capability to make responsible decisions concerning their children while professionals assume the role of facilitator of family change (Cohen *et al.*, 1989; Darling, 1989; Mahoney & Powell, 1988).

The proposed goals for the disabled child and family members must reflect the cultural, religious, ethnic, educational, and economic characteristics of each family. Ascertaining parental priorities, perspectives, and approval of the proposed intervention plan is stressed. A family-focused model of intervention consists of observations of the family's interaction patterns, the development of hypotheses regarding its needs, and the implementation of techniques to facilitate its growth (Bailey *et al.*, 1986). The success of such a model can only be evaluated by ascertaining the child's progress, the changing relationship patterns among members, and achievement of individual and family goals.

Inherent within this model is the assessment of the parent-child interaction. The strength of the parent-child relationship has a significant impact upon the entire family unit and serves as the basis from which parental feelings of effectiveness and child competence arise. The extent of the bond between parents and their children produces enduring emotions that help them sustain effective family functioning throughout their lives.

A systems perspective is recognized as a framework within which each family member's relationship influences the behaviours of its other members. Although centre-based programs can successfully enhance specific skills and cognitive growth in children with physical and mental handicaps, their potential to influence family functioning remains somewhat limited. Given the unique parameters surrounding family functioning, concomitant with the continued need to modify the handicapped child's program, a more holistic approach seems essential. The family-focused intervention model represents a promising avenue that conceptualizes its relationships as a foundation from which mutual pleasure, appropriate interactional behaviours, and increased child competencies emerge. When professionals are able to successfully facilitate change in all family members, there is an increased likelihood that positive behaviours will endure, more realistic expectations will have been achieved, and progress will continue after services and clinical interventions have been terminated.

Family members exhibit a continuum of both positive and negative reactions associated with living with a young child with developmental delays (Turnbull, 1988). Interventions aimed at improving children's competence and well-being should include explorations of effective coping behaviours and processes utilized by parents and children (e.g., family strategies, integration into community activities). The knowledge ascertained from successful interventions focusing on entire family units can provide a framework for future clinical practice. Centre-based child programs cannot function in isolation; rather they must redirect their efforts and focus upon the entire family.

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Intégration sociale à la garderie des enfants socio- culturellement déficients: Le rôle des habiletés cognitives et de l'attachement mère-enfant

Résumé

Les études sur l'intégration sociale des enfants déficients se sont limitées traditionnellement à la prédiction de l'adaptation au milieu scolaire à partir du niveau de fonctionnement intellectuel (QI). Deux critiques peuvent être adressées à ces études. Premièrement, le QI semble constituer un prédicteur insuffisant des difficultés d'adaptation scolaire. Deuxièmement, peu d'études ont cherché à vérifier si, dès l'âge préscolaire, des caractéristiques de nature sociale moins extrêmes que l'institutionnalisation interagissent avec le QI pour favoriser l'intégration sociale ultérieure des enfants déficients. A cet égard, les travaux sur l'attachement mère-enfant ont montré que, chez les populations d'enfants non-déficients, ce facteur joue un rôle important dans l'apparition de problèmes de comportements intériorisés ou extériorisés. Selon l'hypothèse des séquences similaires de développement, on peut supposer que l'attachement joue le même rôle chez les enfants déficients. Le but de cette étude est de comparer l'adaptation sociale à la garderie d'enfants socio-culturellement déficients à celle d'un groupe normatif, en fonction de la sécurité de leur attachement mère-enfant. Les résultats indiquent que les enfants socio-culturellement déficients éprouvent peu de difficultés à s'adapter à la garderie comparativement à leurs pairs non-déficients. Le rôle de l'attachement pour prédire l'intégration sociale du groupe déficient ne peut être interprété clairement, en raison de problèmes méthodologiques liés à l'utilisation de la méthode Q-Sort avec cette population particulière.

Abstract

Studies of the social integration of children with intellectual deficiencies have been limited by researchers' preoccupation with predicting adaptation as a function of level of cognitive functioning (IQ). This approach can be criticized since IQ alone is an inadequate predictor of problems in school adaptation. Few studies have verified if socio-affective characteristics of the child or the caretaking environment (other than institutionalization) interact with IQ in predicting adjustment. Moreover, there has been little focus on the preschool period. The quality of mother-child attachment has been identified as playing an important role in the development of externalizing and internalizing disorders for normal populations. According to the similar-sequence hypothesis of development, we can predict that attachment should play a similar role in the development of children with intellectual deficiencies. The objective of this study is to compare the adaptation of cultural-familial retarded children to the daycare setting as a function of security of attachment with mother. Results indicate that the low-IQ group is generally perceived by their teachers as having little difficulty with respect to social integration in the preschool setting. The role of attachment in predicting social integration could not be clearly interpreted from the results of this study owing to methodological problems related to the use of the Q-Sort Attachment procedure with cultural-familial retarded populations.

L'hypothèse des séquences similaires de développement met l'emphasis sur la similarité des stades développementaux que traversent les individus déficients et normaux (Weisz & Zigler, 1979). Bien que le rythme et le niveau ultime de développement puissent être différents pour ces deux populations, les tenants de cette approche soutiennent que la trajectoire développementale est la même. Plusieurs études empiriques appuient cette position, particulièrement pour les populations d'individus dont la déficience est d'origine socio-culturelle (Hodapp, Burack, & Zigler, 1990). Bien que la majeure partie des travaux qui supportent cette hypothèse concerne l'acquisition d'habiletés cognitives particulières (Zigler, 1969; Weisz & Zigler, 1979), la littérature actuelle suggère que le développement des comportements sociaux des enfants déficients et non déficients soit aussi organisé de façon similaire (Cicchetti & Ganiban, 1990). Par exemple, les résultats obtenus par Zigler et Balla (1972) indiquent que les enfants socio-culturellement déficients réagissent de façon semblable aux enfants normaux face à l'échec et à la privation socio-affective qui accompagne généralement l'institutionnalisation.

Selon la théorie de Bowlby (1969, 1973, 1980, 1982), ce type de problèmes relatifs au contrôle des émotions tire ses origines de l'organisation du système d'attachement. A cet égard, un nombre croissant d'études montre que les systèmes d'attachement, d'affiliation et de peur/crainte des jeunes

enfants affectés du syndrome de Down sont organisés de façon semblable à ceux des enfants normaux, et qu'ils produisent un effet similaire sur le contrôle des émotions (Cicchetti & Serafica, 1981; Thompson, Cicchetti, Lamb, & Malkin, 1985). Sur la base de ces similarités entre les enfants dont la déficience est d'origine organique et les enfants normaux, on peut s'attendre à ce que les relations entre l'attachement au donneur de soins principal et les comportements socio-émotifs suivent les mêmes patrons développementaux pour les enfants dont la déficience est d'origine socio-culturelle.

Plus récemment, plusieurs chercheurs se sont intéressés aux effets de l'attachement sur les habiletés autorégulatrices de l'enfant et sur son efficacité à utiliser ses pairs et les adultes de son entourage comme ressources cognitives. Un tel modèle offre des pistes potentielles intéressantes pour comprendre le rôle que jouent les problèmes socio-affectifs de la petite enfance dans la performance scolaire ultérieure. De la même façon, l'exploration de l'interdépendance développementale des fonctions cognitives et socio-affectives chez les populations déficientes pourrait contribuer à préciser leurs possibilités d'adaptation à un cadre scolaire particulier, ou à tout autre contexte social de résolution de problème au cours de l'existence.

D'un point de vue pratique, l'étude des interactions entre les niveaux de fonctionnement intellectuel et socio-émotif pourrait contribuer à éclaircir la problématique du choix de l'environnement éducatif idéal pour les enfants déficients. Dans cette perspective, une des explications possibles du peu de résultats significatifs dans les études ayant comparé l'adaptation scolaire des enfants déficients intégrés aux classes régulières ou à des programmes d'éducation spéciale (Gottlieb, Alter & Gottlieb, 1991) pourrait être que le QI à lui seul ne suffit pas pour prédire le succès de l'intégration. A QI égal, les individus qui sont capables d'utiliser leur environnement social pour répondre à leurs besoins tant cognitifs que sociaux pourraient réussir à s'intégrer aux classes normales mieux que leurs pairs dont le peu d'habiletés sociales constitue un handicap supplémentaire à leur déficience intellectuelle. Cette position émerge des études sur les populations d'adultes déficients qui montrent que des facteurs liés à la personnalité tels que la dépendance, la crainte et une faible estime de soi en combinaison avec le QI constituent de bien meilleurs prédicteurs de l'ajustement que le QI seul (Granat & Granat, 1973, 1978). Tel que le soulignent Merighi, Edison et Zigler (1990), une intégration réussie des individus déficients doit se concevoir comme étant le produit d'une interaction entre les facteurs de motivation, les expériences sociales et les capacités intellectuelles. L'importance de cette idée pour expliquer l'adaptation au contexte scolaire est illustrée par l'emphase que met Wood (1988) sur le fait de "savoir comment rendre son attention et ses actions contingentes aux requêtes, aux demandes et aux besoins des autres" (p. 215, notre traduction) comme l'une des principales habiletés sous-jacentes à la capacité d'apprendre à l'école. Meichenbaum et Biemiller (1990) résument ainsi cette position:

"Les composantes affectives et motivationnelles peuvent élargir ou interférer avec l'utilisation par un individu de ses connaissances et stratégies, avec son niveau d'expérience et de performance" (p. 10-11, notre traduction). De la même façon, la capacité d'un contexte enseignant à répondre aux besoins d'une population spéciale doit être évaluée en fonction de son habileté à tenir compte de l'interdépendance développementale des composantes motivationnelles et stratégiques et de la base de connaissances dans l'apprentissage.

L'interdépendance des fonctions socio-affectives et cognitives

Un élément fondamental du développement dans la théorie de l'attachement de Bowlby (1969, 1973, 1980) est le transfert graduel des fonctions exécutives sociales et cognitives d'un plan interpersonnel à un plan intrapersonnel. Selon Bowlby, les patrons de co-régulation établis dans le contexte des premières relations sociales constituent des modèles fondamentaux qui dirigent l'engagement ultérieur dans des activités de collaboration. Il décrit comment les premiers patrons d'étroite proximité physique, presque entièrement régulés par la mère durant la petite enfance, laissent graduellement la place à des patrons plus réciproques dans lesquels chacun des partenaires peut à distance attirer avec succès l'attention de l'autre. L'attachement de l'enfant au donneur de soins principal se développe dès la première année de vie et des patrons d'attachement individuels peuvent être identifiés vers l'âge de sept à neuf mois. Dans la deuxième moitié de la première année de vie, l'enfant qui a connu des soins cohérents, sensibles et attentifs à ses besoins parvient à un meilleur équilibre entre l'exploration autonome de son environnement et la dépendance. Une des manifestations de cet équilibre s'observe lorsque l'enfant initie un comportement de rapprochement physique avec le donneur de soins dans des situations où il perçoit un danger. La qualité de l'exploration des environnements nouveaux par l'enfant dépend également de ce que l'enfant a intériorisé un modèle de donneur de soins qui répond à ses besoins de protection et de régulation physiologique (Emde, 1989). L'enfant qui n'a pas cette "base de sécurité" (Bowlby, 1969) montre peu de motivation à s'engager envers les objets et à développer la maîtrise de son environnement.

Vers la troisième année de vie émerge un contexte de collaboration véritable pour la résolution de problème avec la transformation de la relation d'attachement en une relation de partenariat (Bowlby, 1973). Avec le développement du langage et des habiletés de prise de perspective, l'enfant devient capable de communiquer ses propres intentions et ses plans, il peut comprendre ceux de sa mère et s'engager dans des négociations qui visent à atteindre un but commun (Marvin, 1977). Cet établissement d'un contexte de collaboration efficace est conçu par Bowlby comme le résultat d'une relation d'attachement "sécure" et non strictement comme la conséquence de

changements cognitifs chez l'enfant ou encore d'un enseignement particulier de la part de l'adulte. Il s'agit selon lui d'une transformation des patrons comportementaux répétés de proximité et d'exploration en une représentation mentale généralisée. Ces représentations mentales, auxquelles Bowlby (1969, 1973, 1980, 1982) a donné le nom de "modèles opérants internes", sont construites par l'enfant et reflètent l'histoire des actions de celui-ci et des réponses parentales à ses initiatives. De plus, à partir du moment où l'enfant a atteint la permanence de l'objet, la formation des modèles opérants internes se poursuit dans les situations où le parent est absent et inclut les résultats des tentatives de l'enfant pour faire revenir son parent.

La conception de Bowlby du développement pour la phase du partenariat (goal-corrected partnership) devient très complémentaire aux idées de Vygotsky (1978, 1986). Selon Vygotsky, la maturation des fonctions linguistiques, lesquelles sont alimentées par les interactions avec l'environnement socio-culturel, est accompagnée d'une différenciation croissante entre les fonctions de représentation et les fonctions interpersonnelles du discours. À l'âge préscolaire, les directives parentales ont été intériorisées par le jeune enfant et deviennent manifestes dans son discours social et privé (self-directed). Selon Wood (1988), le discours du jeune enfant remplit à la fois des fonctions de régulation et de communication. Le développement d'une plus grande expertise dans les habiletés langagières permet ainsi à l'enfant des progrès dans ses habiletés exécutives et un meilleur accès aux sources socio-culturelles d'information - il devient un participant plus actif dans les contextes de co-construction. Dans cette perspective, le développement d'habiletés de représentation plus complexes est relié au langage de deux façons: par le biais du discours d'autorégulation qui permet de diriger ses propres activités et par la compréhension du langage des autres, qui contribue à structurer et à diriger les processus de la pensée et de la formation de concept.

Comme Bowlby, Vygotsky met aussi l'emphasis sur la sensibilité de l'adulte pour ajuster son niveau d'interaction au niveau développemental approprié. En introduisant le concept de zone du développement proximal, Vygotsky met l'emphasis sur le rôle central de la médiation sociale dans la construction des fonctions cognitives. Il décrit la relation dialectique entre deux niveaux d'organisation mentale—le niveau actuel et le niveau potentiel—médiatisée par les échanges de l'enfant avec son environnement socio-culturel.

En résumé, la conception vygotskienne d'un contexte pédagogique cognitivement attentif et sensible est parallèle aux idées de Bowlby sur le développement d'une relation affectivement attentive entre le donneur de soins et l'enfant. Tel que l'ont noté van der Veer et van Ijzendoorn (1988), les deux requièrent une supervision attentive des habiletés de l'enfant, de ses signaux et de son état psychologique; les deux théoriciens conçoivent la

nécessité pour l'adulte de s'ajuster au point de vue de l'enfant pour parvenir à une compréhension mutuelle; et finalement, dans les deux cas l'adulte mène idéalement l'enfant à une plus grande autorégulation affective et cognitive en effectuant des demandes développementalement appropriées.

Les expériences socio-affectives et l'intégration à l'environnement scolaire

Un aspect fondamental des théories de Bowlby et de Vygotsky concerne l'idée que la qualité des expériences précoces de collaboration influence le développement ultérieur de relations tant avec les adultes qu'avec les pairs. Au cours de la petite enfance et de la période préscolaire, les connaissances sur la façon d'aborder les problèmes sont intériorisées de pair avec les modèles sur la façon d'utiliser les ressources sociales pour faciliter ses efforts cognitifs et les attentes concernant le succès de telles entreprises de collaboration. Ainsi, la qualité de la relation entre le donneur de soins et l'enfant aura des répercussions tant sur l'intégration sociale ultérieure que sur la réussite dans un contexte éducatif.

Les études sur les enfants d'âge préscolaire de niveau intellectuel normal appuient cette conception. Des travaux montrent que la sécurité de l'attachement dans la petite enfance est négativement reliée à la dépendance à l'éducateur et aux problèmes de comportements à la garderie, tandis qu'elle est reliée positivement aux compétences sociales des enfants d'âge préscolaire (Greenberg, Cicchetti, et Cummings, 1990; Lafrenière & Sroufe, 1985; Park & Waters, 1989). Erickson, Sroufe, et Egeland (1985) et Sroufe, Fox, et Pancake (1983) ont montré que les enfants dont l'attachement est insécure sont très dépendants de leur éducateur à 4 ans, et d'autres travaux relient directement l'insécurité chez les garçons à des problèmes d'anxiété et de retrait pendant la période préscolaire (Lewis, Feiring, McGuffog, & Jaskir, 1984).

Ces associations entre les états affectifs dans un contexte (la relation avec le donneur de soins principal) et les comportements sociaux dans un autre contexte (la garderie) peuvent refléter des représentations cognitives de son propre rôle et de celui des autres dans les situations collaboratives de résolution de problèmes. Nos propres travaux (Moss, Parent, & Gosselin, sous presse) indiquent que dans une situation de collaboration cognitive, les mères des enfants sécures de 3 et 5 ans donnent davantage d'informations, de feedback et de responsabilités à leur enfant dans la tâche, comparativement aux mères des enfants insécures de même âge.

En bref, à la période préscolaire, l'attachement affecte la nature des expériences de collaboration de l'enfant tant avec son donneur de soins qu'avec de nouveaux partenaires sociaux. Les habiletés autorégulatrices

supérieures des enfants sécures semblent être activement étayées durant la période préscolaire par un style maternel caractérisé par la modulation des interventions en fonction de la performance de l'enfant et de ses besoins de reconnaissance de ses compétences autorégulatrices émergentes. Ces patrons familiaux sont associés à une plus grande compétence sociale et à une meilleure intégration dans le groupe de pairs.

Selon les théories de Bowlby et de Vygotsky, il devrait être possible à la période scolaire d'étudier les différentes représentations cognitives des rôles et des fonctions de soi et des autres qui sous-tendent les différences comportementales entre les enfants d'attachement sécure et insécure. Cassidy (1990) explique ces différences en référence à la relation entre la conception de soi dans la relation d'attachement et des patrons plus globaux d'estime de soi et de sentiment de compétence. Maislin-Cole et Spieker (1990) ont obtenu des résultats qui appuient l'hypothèse du rôle médiateur de la motivation à maîtriser pour expliquer la relation longitudinale entre la sécurité de l'attachement et la compétence ultérieure (Bretherton, 1985). Nos propres résultats (Moss, 1992; Moss et al., sous presse) suggèrent une relation plus directe entre le style d'enseignement maternel et le développement de déficits de l'autorégulation, en ce que les mères des enfants insécures d'âge préscolaire exercent un excès de contrôle dans les activités dyadiques de résolution de problème, allouant ainsi peu d'opportunités aux enfants de pratiquer leurs habiletés métacognitives émergentes. En conséquence, les enfants insécures à l'âge scolaire présenteraient des déficits de l'autorégulation qui augmenteraient leur dépendance aux directives de l'adulte et qui, en retour, limiteraient leurs opportunités de développer davantage leurs habiletés autorégulatrices et de collaboration interpersonnelles (Cullen, 1985; Meichenbaum & Biemiller, 1990). A l'appui de cette hypothèse, plusieurs études ont montré l'influence du feedback et des attributions parentales dans des contextes d'apprentissage sur le développement des composantes motivationnelles dans l'apprentissage scolaire (voir par exemple, Bandura, 1986; Harter, 1978; Heckausen, 1987).

En résumé, l'ensemble de ces études suggère que les expériences précoces d'interaction des enfants avec l'adulte peuvent influencer le développement de leurs compétences tant pour s'autoréguler que pour utiliser les ressources sociales dans le cadre de leurs entreprises cognitives. Pour appliquer ces idées au développement des enfants qui présentent un retard intellectuel d'origine culturelle-familiale, il importe d'examiner dans quelle mesure les processus développementaux à l'oeuvre sont similaires et comment ces processus cognitifs et socio-affectifs interagissent dans le cas des populations intellectuellement déficientes.

L'interaction du QI et de l'attachement dans la prédiction de l'adaptation à la garderie

Plusieurs études ont examiné les effets de l'expérience sociale sur l'adaptation des populations déficientes (Balla, Butterfield, & Zigler, 1974; Butterfield & MacIntyre, 1969; Butterfield & Zigler, 1970; Clarke & Clarke, 1954; Elliot & McKay, 1971; Eyman & Call, 1977; Harter & Zigler, 1968;

Merighi et al., 1990; Richardson, Goulden, Koller, & Katz, 1990; Richardson, Katz, & Koller, 1986; Zigler, 1969; Zigler & Balla, 1972). La majorité de ces études cependant définissent l'expérience par des indices plutôt globaux tels que le type d'encadrement (par exemple, dans la communauté ou en institution) et utilisent les indices de fonctionnement socio-affectif exclusivement comme variable dépendante. On observe peu de tentatives pour comprendre comment les déficits précoces dans l'environnement éducatif contribuent au développement de patrons interactifs, ou comment l'internalisation de ces patrons affecte l'adaptation future. Cette tendance reflète à la fois une centration générale dans la littérature sur les déficits cognitifs comme prédicteur principal de l'ajustement et une conception des individus déficients comme jouant un rôle plutôt passif dans leur propre développement. La prise en compte des compétences sociales en combinaison avec les habiletés cognitives risque pourtant de contribuer à une meilleure prédiction du succès académique et social. Qui plus est, les compétences sociales requises pour une intégration réussie risquent de varier en fonction du type d'encadrement particulier. Tel que le souligne Simeonsson (1978), dans l'étude du développement des individus déficients, il est nécessaire de vérifier s'ils ont reçu à la fois la quantité et la qualité d'expériences nécessaires pour l'apprentissage incident des règles et des comportements socialement adéquats. De telles expériences optimiseraient les opportunités des individus déficients "d'assumer les rôles, de prendre les risques et de faire les choix qui favorisent les comportements socialement compétents" (p.163).

Etant donné les relations entre la qualité de l'attachement précoce et l'adaptation sociale et cognitive des populations d'enfants dont les habiletés cognitives sont normales, on peut supposer que la combinaison de l'attachement et du QI constitue un prédicteur plus puissant d'une intégration réussie dans les programmes réguliers que les habiletés cognitives seules. Cette hypothèse est d'autant plus plausible compte tenu de la plus grande dépendance à la situation d'apprentissage des enfants déficients comparativement à leurs pairs de QI normal. Dans ce contexte, leur capacité d'obtenir un étayage approprié de la part de leurs professeurs et de leurs pairs dans les classes régulières pourrait dépendre non seulement de la volonté de ces personnes à les accepter mais aussi de l'habileté des enfants déficients à prendre des initiatives sociales. Ce modèle interactionniste de la prédiction du succès dans le programme scolaire régulier est appuyé par les études qui indiquent qu'à l'intérieur de populations cognitivement homogènes d'enfants déficients, on observe une importante hétérogénéité en ce qui a trait aux compétences sociales individuelles telles que le concept de soi et les habiletés de prise de perspective de même qu'aux compétences interactives telles qu'indiquées par le statut sociométrique et par les habiletés de collaboration. Une compréhension plus précise des mécanismes par lesquels les relations antérieures facilitent ou interfèrent avec les processus cognitifs collaboratifs pourrait contribuer à clarifier les processus qui favorisent l'adaptation au contexte de la classe ou à d'autres situations sociales de résolution de problèmes au cours de l'existence.

Une deuxième raison nous incite à comparer l'intégration des enfants déficients d'âge préscolaire en fonction de leur attachement: nous souhaitons préciser l'origine des troubles reliés à l'anxiété qui caractérisent les enfants déficients d'âge scolaire. Lorsqu'ils atteignent l'âge de neuf ans, les jeunes déficients sont évalués par leur professeur comme significativement plus démunis et beaucoup plus sensibles aux feedback négatifs que leurs pairs non déficients (Baroff, 1974). Il n'est pas clair jusqu'à maintenant dans quelle mesure ces différences observées à l'âge scolaire sont fonction des expériences telles que les échecs répétés et l'attribution d'une étiquette de faibles habiletés, d'une plus grande prise de conscience due à des habiletés intellectuelles plus développées, ou encore de caractéristiques déjà présentes lors de l'entrée dans le milieu scolaire. Ainsi, une faible intégration des compétences sociales, émotionnelles et cognitives nécessaires à l'adaptation au cours des premières étapes du développement contribue à l'émergence de problèmes ultérieurs (Cicchetti & Schneider-Rosen, 1986; Sroufe, 1989). Il est possible que certains enfants déficients soient plus susceptibles de développer un sentiment d'impuissance dès leur entrée à l'école et que des précurseurs de cette vulnérabilité sont déjà apparents dans les évaluations que font les éducatrices de garderie du profil socio-affectif des enfants déficients. Si les enfants déficients qui présentent un attachement insécure se distinguent déjà de leurs pairs en ce qui concerne l'évaluation de leur adaptation par leur éducateur avant même leur entrée à l'école, ils pourraient alors constituer un sous-groupe à risque quant au développement d'un sentiment d'impuissance à l'âge scolaire. Cette information pourrait contribuer aux prises de décision concernant l'encadrement éducatif le plus approprié pour différents sous-groupes d'enfants déficients.

Méthodologie

Sujets

Les 46 sujets de cette étude ont été choisis parmi un échantillon plus vaste de 161 enfants qui participent à un projet de recherche longitudinale. Les sujets ont été recrutés parmi sept garderies de milieux socio-économiques divers à l'intérieur de la communauté francophone de Montréal. Tous les enfants fréquentaient la garderie au moins trois jours par semaine. Deux groupes de 23 sujets ont été formés sur la base du niveau de fonctionnement intellectuel des enfants. Un groupe d'enfants déficients (15 filles et 8 garçons, moyenne d'âge = 49 mois) et un groupe d'enfants normatifs (14 filles et 9 garçons, moyenne d'âge = 49 mois).

Mesures et procédures

Niveau intellectuel. Le niveau de fonctionnement intellectuel de l'enfant a été mesuré lors d'une visite au laboratoire. Deux instruments ont été utilisés: 1) *l'échelle de vocabulaire audio-visuel (EVA)* (Dunn, Dunn, & Whalen, 1984) qui est la version française du *Revised Peabody Picture Vocabulary*

Test (Dunn & Dunn, 1981) et 2) l'échelle verbale de la version française du *Weschler Preschool And Primary Scale Of Intelligence (WPPSI)*. Le EVA a été administré aux enfants âgés entre 30 et 53 mois tandis que les enfants de 54 mois et plus ont répondu au *WPPSI*. Le QI verbal moyen des 14 enfants du groupe déficient ayant répondu au EVA est de 83,2 et celui des 9 enfants ayant répondu au *WPPSI* est de 87,2 ; pour le groupe d'enfants normatifs, le QI verbal moyen des 14 enfants ayant répondu au EVA est de 111,3 et celui des 9 enfants répondu au *WPPSI* est de 123,9.

Qualité de la relation d'attachement. La qualité de la relation d'attachement a été évaluée à l'aide de la méthode Q-Sort sur l'attachement (Waters & Deane, 1985). Le Q-Sort est composé de 90 énoncés qui décrivent des aspects variés des comportements du bébé et de l'enfant d'âge préscolaire. Les comportements évalués sont ceux reliés à l'exploration, à la dépendance, à la sociabilité et à la sécurité. Les critères de Park et Waters (1989) ont été utilisés pour identifier les enfants sûres et les enfants insécures. Des points de coupure différents sont utilisés en fonction du sexe de l'enfant (pour plus détails voir l'étude de Park & Waters, 1989). Cette mesure a été complétée par la mère lors d'une visite au laboratoire.

Profil Socio-Affectif. Le Profil Socio-Affectif (PSA) (LaFrenière, Dubeau, Janosz, & Capuano, 1989) a été complété par les éducatrices à la garderie pour l'ensemble des enfants faisant partie de l'étude longitudinale. Le PSA est un questionnaire de type "likert" et compte 80 énoncés. L'instrument mesure la compétence sociale, les comportements interiorisés et les comportements exteriorisés de l'enfant, lorsqu'il est en interaction avec les pairs ou avec l'adulte. Ces trois dimensions sont réparties en huit échelles: dépression-joie, anxiété-confiance, irritabilité-tolérance, isolement-intégration, agressivité-négociation, égoïsme-prosocialité, résistance-coopération, dépendance-autonomie. Par la suite, le PSA permet d'obtenir une classification globale des enfants en quatre catégories: normatif, compétent, agressif et anxieux. Parmi les 161 sujets participants à l'étude longitudinale, 24% des sujets sont classés compétents, 43% sont classés normatifs, 21% sont classés agressifs et 12% sont classés anxieux.

Résultats et discussion

Dans un premier temps, deux analyses associatives ont été effectuées. La première concerne les relations entre le niveau de fonctionnement intellectuel de l'enfant et son adaptation en garderie et la deuxième porte sur les problèmes d'adaptation à la garderie, le niveau de fonctionnement intellectuel et la sécurité de l'attachement. Dans un deuxième temps, nous avons subdivisé les groupes d'enfants déficients et normatifs selon leur qualité d'attachement et nous avons comparé les scores de ces sous-groupes sur les pôles positifs et négatifs des huit échelles du PSA.

Selon la littérature, l'adaptation sociale des enfants socio-culturellement déficients est caractérisée par un manque d'intégration, par des compétences émotionnelles réduites et par une forte dépendance à l'éducatrice. La prise en considération de ces caractéristiques nous amène à postuler qu'au sein de notre groupe de sujets déficients la répartition du nombre de sujets en fonction des quatre classifications du PSA différera de celle du groupe normatif. Plus particulièrement, on peut s'attendre à ce que la proportion de sujets anxieux et agressifs soit plus élevée dans le groupe d'enfants déficients et qu'à l'inverse, la proportion de sujets compétents soit moins élevée comparativement au groupe normatif.

Le tableau 1 présente le nombre de sujets par groupes (déficient ou normatif) en fonction de leur classification au PSA. Nous avons vérifié la présence de relation entre le niveau de fonctionnement intellectuel de l'enfant et son adaptation en garderie à l'aide du test de Bartholomew pour échantillon ordonné qualitativement. Cette analyse permet de vérifier l'hypothèse selon laquelle la répartition des sujets déficients varie de façon ordonnée en fonction du niveau d'intégration sociale (dans l'ordre: anxieux, agressif, normatif, compétent). Le test de Bartholomew est une analyse plus puissante que le khi carré pour analyser ce type de données (Fleiss, 1981). Les résultats obtenus indiquent une association marginalement significative entre la déficience et l'adaptation à la garderie ($X^2(0,045 ; 0,34) = 3,51$ $p < 0,10$). Cette association indique que les enfants déficients ont tendance à être moins bien intégré à la garderie que les enfants non-déficients.

Tableau 1

Nombre total de sujets dans chacune des classifications du PSA et proportions de sujets du groupe déficient.

Classification au PSA	N Total	Proportions d'enfants déficients
Anxieux	5	0,80
Agressif	11	0,55
Normatif	20	0,50
Compétent	10	0,30
Total	46	0,50

Ces résultats obtenus avec le test de Bartholomew appuient partiellement l'hypothèse proposée d'une proportion plus élevée d'enfants anxieux ou agressifs et d'une proportion plus faible d'enfants compétents dans le groupe déficient. Cet appui partiel peut s'expliquer par l'insuffisance du QI pour mettre en évidence, à lui seul, les différences interindividuelles liées à l'adaptation sociale des enfants d'âge préscolaire. Tel que discuté, il est possible que l'adaptation sociale soit associée d'une part au niveau de

fonctionnement intellectuel de l'enfant et d'autre part à la qualité de l'attachement mère-enfant. Par exemple, une relation d'attachement insécure est caractérisée chez l'enfant par un déficit sur le plan des habiletés autorégulatrices, par une augmentation de la dépendance à l'adulte en situation de collaboration et par un répertoire limité d'habiletés interpersonnelles. À l'inverse, la sécurité de l'attachement favorise le développement des compétences autorégulatrices et la capacité de faire appel aux ressources sociales. Par conséquent, la prise en compte simultanée de la sécurité de l'attachement et du niveau de fonctionnement intellectuel de l'enfant devrait fournir des informations plus spécifiques sur l'adaptation sociale de l'enfant à la garderie que ces deux caractéristiques séparées.

Afin d'investiguer davantage la possibilité d'identifier un sous-groupe à risque en ce qui a trait au développement d'un sentiment acquis d'impuissance à l'âge scolaire, nous avons effectué une analyse log-linéaire pour vérifier l'existence d'une association entre l'adaptation sociale des enfants (en regroupant les enfants sans problème d'adaptation sociale (compétents et normatifs) et les enfants avec problèmes (agressifs et anxieux), le niveau de fonctionnement intellectuel (sujets déficients, sujets normatifs) et la qualité d'attachement (sécure, insécure). L'analyse ne révèle aucune correspondance entre les trois caractéristiques, c'est-à-dire qu'il n'y a aucun effet d'interaction significatif entre l'adaptation sociale et le QI, entre l'adaptation sociale et la qualité de l'attachement, ou entre l'adaptation sociale, le fonctionnement intellectuel et la qualité de l'attachement ($LR\chi^2(4) = 3,8$; ns). La non-correspondance entre l'adaptation sociale des enfants à l'âge préscolaire, le niveau de fonctionnement intellectuel et la qualité de l'attachement peut s'expliquer par le fait qu'il s'agit d'un indice trop global d'adaptation sociale et qu'il est nécessaire de procéder à l'examen des profils d'adaptation plus spécifiques. À cet égard, nous avons investigué l'hypothèse d'une trajectoire parallèle mais différée du développement social des enfants en comparant les pôles positifs et négatifs des huit échelles du PSA (dépression-joie, anxiété-confiance, irritabilité-tolérance, isolement-intégration, agressivité-négociation, égoïsme-prosocialité, résistance-coopération, dépendance-autonomie) en fonction du niveau de fonctionnement intellectuel et de la qualité de la relation d'attachement. En considérant les caractéristiques reliées à la qualité de la relation d'attachement, nous posons l'hypothèse que les sujets du groupe d'enfants déficients insécures seront évalués plus négativement par l'éducatrice à la garderie quant à l'autonomie et les habiletés interpersonnelles comparativement à l'évaluation des enfants déficients sécures. La même distinction devrait se retrouver au sein du groupe d'enfants normatifs.

Les tableaux 2 et 3 présentent les scores des sujets des groupes déficient et normatif pour chacune des huit échelles du PSA en distinguant le pôle positif du pôle négatif. Les deux groupes de sujets sont subdivisés en fonction de la qualité de leur attachement (sécure/insécure). De manière générale, on

remarque que les enfants déficients sécures obtiennent les scores les plus faibles sur les pôles positifs et ils sont aussi perçus plus négativement par l'éducatrice, tandis que dans l'ensemble, les enfants déficients insécures se comparent aux enfants du groupe normatif. Contrairement à l'hypothèse des séquences similaires de développement, ces résultats indiquent la possibilité d'une interaction entre le niveau de fonctionnement intellectuel et la sécurité de l'attachement.

Deux analyses de la variance multivariée 2(déficient/normatif) X 2(sécure/insécure) ont été effectuées. La première analyse concerne les scores des pôles positifs des échelles et indique l'absence d'effet global significatif de la variable groupe ou de la variable attachement et l'absence d'effet d'interaction. Toutefois, compte tenu du petit nombre de sujets par groupe et de la nature exploratoire de cette étude, nous avons procédé à un examen plus détaillé des résultats. On observe deux tendances marginales. Premièrement, les enfants déficients sont évalués comme étant moins bien intégrés que les enfants du groupe normatif ($F(1,35)=3,13$ $p<0,10$). Deuxièmement, on observe une interaction pour l'échelle de coopération, indiquant que les enfants du groupe déficient insécure sont perçus comme plus coopératifs que les enfants du groupe déficient sécure alors que c'est l'inverse pour le groupe d'enfants normatifs ($F(1,35)=3,54$ $p<0,10$). La seconde analyse de variance porte sur les scores des pôles négatifs des échelles du PSA. Les résultats ne révèlent aucun effet significatif du niveau de fonctionnement intellectuel et de la qualité de l'attachement des enfants, ni aucun effet d'interaction. L'examen détaillé des résultats n'ajoute aucune information supplémentaire.

Ces résultats sur les sous-échelles du PSA peuvent paraître étonnants puisque, contrairement aux analyses globales sur les relations entre le QI et le PSA et à la littérature sur les enfants non-déficients, aucun effet significatif n'a été obtenu pour le niveau de fonctionnement intellectuel de l'enfant ni pour la qualité de l'attachement mère-enfant. Cette absence de résultats significatifs peut provenir du fait que ces deux variables ont tendance à être en interaction et que la taille de nos groupes limite la puissance statistique des analyses. Toutefois, ces résultats se rapprochent de ceux obtenus par Baker et Cantwell (1984) et Cunningham, Siegel, van der Spuy, Clark, et Bow (1985). Ceux-ci montrent en effet que, bien qu'on observe une prévalence plus élevée de problèmes socio-affectifs chez les enfants qui présentent des déficits au niveau du langage, aucun patron particulier de symptômes ne caractérise cette population.

Les résultats montrent que la qualité de la relation d'attachement mère-enfant affecte de manière générale l'adaptation sociale de l'enfant à la garderie. En considérant le niveau de fonctionnement intellectuel des enfants, on remarque que la qualité de l'attachement n'affecte pas les enfants de la même façon. Les enfants du groupe normatif insécure tel que prévu (à l'exception

Tableau 2

Moyennes et écart-types des pôles positifs du PSA selon le niveau de fonctionnement intellectuel (déficient/normatif) et selon la qualité de l'attachement (sécuré/insécuré) des enfants.

Pôles positifs du PSA	Fonctionnement intellectuel	Qualité de l'attachement	M	E.T.
Joie	déficient	sécuré	3,94	0,58
		insécuré	4,61	0,99
	normatif	sécuré	4,59	0,58
		insécuré	4,50	1,30
Confiance	déficient	sécuré	3,83	0,72
		insécuré	4,33	0,86
	normatif	sécuré	4,37	0,67
		insécuré	4,31	1,18
Tolérance	déficient	sécuré	3,21	0,80
		insécuré	3,98	0,80
	normatif	sécuré	3,93	1,06
		insécuré	3,65	0,97
Intégration	déficient	sécuré	3,50	0,56
		insécuré	4,30	0,91
	normatif	sécuré	4,35	0,55
		insécuré	4,34	1,08
Négociation	déficient	sécuré	3,37	0,69
		insécuré	4,12	0,92
	normatif	sécuré	3,75	1,06
		insécuré	3,54	0,78
Prosocialité	déficient	sécuré	3,03	1,00
		insécuré	3,82	0,78
	normatif	sécuré	3,63	0,97
		insécuré	3,50	0,94
Coopération	déficient	sécuré	3,62	0,97
		insécuré	4,38	0,97
	normatif	sécuré	4,15	1,03
		insécuré	3,74	1,11
Autonomie	déficient	sécuré	3,63	0,69
		insécuré	4,11	0,90
	normatif	sécuré	3,82	0,62
		insécuré	4,10	0,76

Tableau 3

Moyennes et écart-types des pôles négatifs du PSA selon le niveau de fonctionnement intellectuel (déficient/normatif) et selon la qualité de l'attachement (sécure/insécure) des enfants.

Pôles négatifs du PSA	Fonctionnement intellectuel	Qualité de l'attachement	M	E.T.
Dépression	déficient	sécure	2,26	0,53
		insécure	1,86	0,71
	normatif	sécure	1,77	0,35
		insécure	1,81	0,72
Anxiété	déficient	sécure	2,19	0,18
		insécure	2,14	0,94
	normatif	sécure	1,85	0,48
		insécure	1,95	0,88
Irritabilité	déficient	sécure	2,68	1,01
		insécure	2,30	1,31
	normatif	sécure	2,42	0,84
		insécure	2,42	0,95
Isolement	déficient	sécure	1,98	0,70
		insécure	1,89	1,12
	normatif	sécure	1,69	0,51
		insécure	1,86	1,19
Agressivité	déficient	sécure	1,70	0,65
		insécure	1,80	0,92
	normatif	sécure	1,68	0,45
		insécure	1,94	1,05
Egoïsme	déficient	sécure	2,24	0,57
		insécure	2,36	1,19
	normatif	sécure	2,43	0,94
		insécure	2,48	1,00
Résistance	déficient	sécure	1,91	0,76
		insécure	1,84	0,90
	normatif	sécure	1,77	0,76
		insécure	1,99	0,54
Dépendance	déficient	sécure	2,21	0,50
		insécure	1,88	0,71
	normatif	sécure	1,92	0,51
		insécure	1,75	0,38

de l'échelle de dépendance) sont évalués comme étant plus déprimés, plus anxieux, plus isolés, plus agressifs et plus résistants. Le patron comportemental n'apparaît pas aussi clairement pour les enfants du groupe déficients. Pour le groupe d'enfants déficients, contrairement aux enfants normatifs, ce sont les enfants sécures qui sont évalués comme les plus dépendants, les plus déprimés, les plus irritables, les plus isolés et les plus résistants.

Concernant l'adaptation sociale des enfants déficients à la garderie, il importe de souligner que la mesure utilisée (le PSA) reflète davantage les perceptions des éducatrices que l'adaptation réelle des enfants déficients dans ce milieu. Une explication possible du peu de différences observées concerne les attentes des éducatrices. Il est probable qu'elles n'aient pas les mêmes attentes ni les mêmes demandes pour les enfants déficients que pour les enfants compétents sur le plan intellectuel. Cette distinction influence sans doute l'évaluation qu'elles font de l'adaptation sociale des enfants déficients.

Une seconde explication concerne elle aussi le domaine des perceptions, mais se rapporte cette fois à la perception des mères dans l'évaluation qu'elles font de la qualité de la relation d'attachement des enfants. Il semble possible que les mères ayant des enfants socio-culturellement déficients entretiennent des attentes moins élevées pour leur enfant. Pour expliquer ces différences de perception, les chercheurs ont invoqué à la fois des facteurs socio-affectifs et des déficits cognitifs chez ces parents d'enfants socio-culturellement déficients. Par exemple, les parents ressentent souvent des sentiments négatifs intenses envers eux-mêmes, envers l'enfant et envers la situation stressante que représente l'éducation d'un enfant intellectuellement déficient (Baroff, 1974). De plus, l'insularité qui caractérise souvent les familles d'enfants avec déficits intellectuels peut contribuer à la dépression maternelle et aux patrons associés de faible sensibilité et de distorsion des perceptions (Dumas & Wahler, 1983).

En ce qui concerne les déficits cognitifs des mères d'enfants socio-culturellement déficients, Bernstein (1967) a décrit leur style linguistique restreint, caractérisé par une sous-utilisation de concepts abstraits. À la base de ces déficits maternels, Baroff (1974) a souligné la présence d'une faible compréhension de la causalité et des séquences temporelles passé-présent. À cet égard, notons que la passation du questionnaire Q-Sort sur l'attachement exige de la mère des capacités de compréhension sémantique, de catégorisation et de mémorisation car elles doivent bien saisir le sens des 90 énoncés, parfois formulés négativement, avant de procéder à leur classement en trois catégories. Pendant l'administration de ce questionnaire, nous avons effectivement observé à quelques reprises que les mères des enfants du groupe déficients éprouvaient davantage de difficultés, comparativement aux mères du groupe normatif, à comprendre les consignes et les énoncés et à les mémoriser. À l'appui de ces observations, la comparaison des niveaux de scolarité des mères des deux

groupes indique que la majorité des mères du groupe d'enfants déficients n'ont pas d'études post-secondaires (61%) comparativement à seulement 23% des mères du groupe normatif.

L'adaptation sociale des enfants à la garderie telle qu'évaluée par le PSA ainsi que l'évaluation de la relation d'attachement à l'aide de la méthode Q-Sort ne semblent pas tout à fait appropriés pour mesurer les caractéristiques relatives à la déficience d'origine socio-culturelle chez l'enfant. En dépit de ces limites de nature méthodologique, il semble que l'étude de l'adaptation sociale en fonction de la qualité de l'attachement mère-enfant et du niveau de fonctionnement intellectuel des enfants d'âge préscolaire mérite plus d'attention. Lors d'une prochaine recherche, il serait intéressant d'utiliser des données observationnelles pour évaluer le comportement de l'enfant à la garderie et tout particulièrement, pour mesurer la qualité de la relation d'attachement mère-enfant.

Conclusion

La principale conclusion qui se dégage de nos résultats est qu'en général, au niveau préscolaire, les enfants ayant un faible QI ne présentent pas de problèmes majeurs d'intégration sociale. Ils sont généralement perçus positivement par leurs éducatrices et ne se distinguent pas des enfants normatifs par la présence de taux élevés d'anxiété ou d'agressivité et de dépendance à l'adulte. Ce type de problèmes, habituellement observés à l'école primaire, est probablement associé aux exigences académiques accrues de cet environnement, comparativement à l'environnement préscolaire. Compte tenu des limites méthodologiques déjà discutées, l'interprétation du rôle de l'attachement et de son interaction avec les habiletés intellectuelles pour prédire l'intégration sociale est pour le moins difficile. Toutefois, des recherches supplémentaires sont nécessaires pour examiner les effets de variables socio-affectives moins extrêmes que l'institutionnalisation sur l'intégration sociale des enfants à faible QI. Les effets de l'institutionnalisation dépassent largement la déprivation sociale; les enfants institutionnalisés sont aussi à divers degrés sous-stimulés sur le plan cognitif. Peu d'études jusqu'à maintenant concernant l'environnement précoce des enfants déficients ont distingué les effets du manque de stimulation cognitive, de ceux des styles d'affection et de contrôle des donneurs de soins sur le développement de fonctions cognitives et sociales particulières. De plus, il n'est pas clair dans quelle mesure les caractéristiques individuelles cognitives et socio-affectives des donneurs de soins et des enfants contribuent à la mise en place de patrons d'interaction dysfonctionnels particuliers (Sameroff, 1989). Les études futures devront s'efforcer d'identifier les facteurs socio-affectifs et environnementaux qui, au-delà des déficits intellectuels, favorisent ou nuisent à l'intégration sociale des enfants socio-culturellement déficients.

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Of Scarce Resources and Gilded Cages: A case study

Abstract

This paper examines the debate over whether persons with developmental disabilities can or should be served in the community or within larger facilities/institutions. The cases of two institutionalized persons are discussed, along with vivid descriptions of their institutional surroundings. This part of the paper is followed by the outcome of a court case brought by their advocates with regard to patient rights. Key legal cases involving the constitutional rights of institutionalized mentally retarded persons are also discussed.

Résumé

Le présent document traite de la question controversée des personnes souffrant de troubles du développement sous l'angle de la possibilité ou du devoir de desservir cette population au sein même de la collectivité ou dans de vastes établissements. On y présente le cas de deux personnes internées et on y donne des descriptions frappantes de ce milieu. Cette section du document est suivie de l'issue d'une affaire portée dans les tribunaux par des avocats, relativement aux droits des patients. On y traite également d'autres causes importantes touchant les droits constitutionnels des personnes souffrant d'arriération mentale et qui sont internées.

The debate among professionals and advocates over whether persons with developmental disabilities can or should be served in the community instead of large congregate facilities is largely over. Experience over the last two decades has demonstrated that people with disabilities can lead meaningful and productive lives in integrated settings if provided with the opportunity to do so. The question now is not whether the community is appropriate but whether special programs and facilities can be successfully replaced with supports and generic services so that true integration can successfully occur.

Recent data demonstrate that both Canada and the United States have made progress in the last decade in depopulating institutions and increasing available residential placements in the community (Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., & Mitchell, D. 1990).¹ That progress notwithstanding, the United States remains a country where in most states the primary treatment model for persons with mental retardation remains institutionalization. A recently published study [by the Institute for the Study of Developmental Disabilities at the University of Illinois at Chicago] reveals that in the fiscal year 1988, 51.9% of the total national mental retardation/developmental disability expenditures in the United States went for congregate residential services. Further, of that money spent for congregate residential services, 84.6% was spent for care in state institutions. In thirty states, more money is being spent to maintain persons with developmental disabilities in congregate facilities than in community settings. As of 1988, there were still some 91,400 people in state-operated institutions in the United States (Braddock *et al.*, 1991).

The continued institutionalization of persons with developmental disabilities remains inexcusable. Advocates argue that community placement is right; it is impossible for people to develop meaningful and full lives isolated from that part of the community where normal life activities take place. But advocates are increasingly being faced with the harsh reality that the political, legal, and social climate dictates that institutions will not soon vanish. They must choose between holding out for unavailable remedies and settling for available improvements. The dilemma for advocates then becomes whether they can morally and ethically accept, at least for the time being, a solution which falls short of complete community integration.

The Cases of A.B. and L.M.²

In 1971, A.B., a 28-year-old woman was transferred from a state training school for the retarded, where she had been confined since the age of seven, to a state psychiatric hospital, reportedly because of "unmanageable" behaviour. As a child she had been diagnosed as having infantile autism.

During her two decades of psychiatric hospitalization A.B. was never diagnosed as having a mental illness. Her only diagnoses were autism and mental retardation. She was "treated" with psychotropic medication, physical restraints, and seclusion. Hospital staff repeatedly stated that, in their clinical judgment, A.B. did not belong in a psychiatric hospital; was receiving only custodial care; was deteriorating as a result of her inappropriate confinement and treatment, and lack of behavioural programming; and should be discharged from the hospital to a small, specialized group home in the community.

The 1971 admission note in the hospital chart of A.B. read: "Therapeutic plans: Essentially this patient is going to be custodial." Twenty years later a belated evaluation by a speech and language pathologist from the department

of mental retardation confirmed that A.B. had received only custodial care, and concluded:

Placement for [A.B.] should be sought in an habilitative residential program in which the possible development of communication, social and daily living skills can be initiated. Her current placement in [name withheld] Hospital precludes the development of such an habilitative plan at present.

For two decades A.B. resided on a locked ward with thirty other female patients. Although the ward had a common sleeping area, A.B. had her own room because of her problematic behaviour, which involved self-mutilation behaviour that was manifested by striking herself, pulling her hair, vigorous rocking, agitation and restlessness, crying, rubbing and poking her eyes, running up and down the halls, spitting, vomiting, incontinence, assaulting others, taking off her clothes, repetitive changing of clothing, and stuffing clothing in the toilet.

The response of hospital staff to the behaviour of A.B. consisted of psychotropic medications administered on an "as needed" (*prn*) basis and the application of mechanical restraints. During a three-month period in 1990, A.B. received 298 *prn*'s (in addition to her regular dosage of medications) and was placed in four-point restraints on 72 occasions.

A visitor to A.B.'s ward described it in the following grim terms:

Upon entering the ward I saw a long hallway with a few single rooms each containing only a metal-framed bed without blankets. [A.B.] lives in just such a stark room. There was also the large, crowded room of small, partitioned sleeping areas. One woman was just getting up. . . from a bed next to the window - and was finishing dressing in full view of everyone standing in the hallway. The walls of the hallway have one or two small, plastic-framed pictures poorly replicating a real painting. The large room on the women's ward contained a few chairs and two-seated couches. . . made of black vinyl. . . The television room had chairs lined up against the walls facing each other, but not facing the television, which makes it very uncomfortable to watch television and difficult to carry on a conversation with fellow patients. One small couch towards the back of the room faced the television, but a patient was sleeping on it. Several other women on the ward were sprawled out on the seats sleeping as well. Empty bookshelves lined one wall and the paint throughout the ward, which is pink, was also dingy and peeling. Heavy, dirty screens obscured the view of the women's ward and there were

no rugs or carpeting on the hard, industrial-grey floors. . . . [T]he women's ward is barren, containing nothing other than a television to occupy patients' time. . . . [T]here were smells of urine and body-odor which followed us as we left the building.

A.B. spent most of her day "twirling a sock" while sitting on a sofa in the day room on her ward. On a typical day, in the early summer of 1990, A.B. was observed "sitting with her legs apart and rocking on a plastic couch wearing only a hospital gown and no underwear." A.B. rarely left the ward, taking her meals there, and leaving only for occasional medical appointments.

Repeated instances of self-injurious behaviour appear throughout A.B.'s hospital record. The most dramatic evidence of the unsafe conditions on A.B.'s ward and of the deterioration of her basic self-care skills is the fact that she lost her sight while in the hospital. Hospital staff did not notice or, if they did, did not act to correct A.B.'s declining eyesight until her blindness was irreversible. However, even before staff acknowledged that A.B. had lost her sight, they noted in her record that she would move "up and down the hall and bump against every other door and pat her hands against the back of the door."

In 1978, seven years after A.B.'s arrival at the hospital, L.M., a 29-year-old man with "moderate mental retardation", was admitted to the hospital from the same training school from which A.B. had come. Unlike A.B., L.M. had only been at the training school for a few months before his transfer. L.M.'s family learned of his hospitalization when they went to the training school to visit him. As in A.B.'s case, the only reason given for L.M.'s hospitalization was his "unmanageable" behaviour.

More than a decade later L.M. remains confined at the hospital, notwithstanding the fact that he has never been diagnosed as mentally ill. His only "treatment" (until very recently) has consisted of confinement on a locked ward, psychotropic medication, mechanical restraints, and seclusion. The question of whether the care and treatment available at the hospital was appropriate for L.M. was raised at the time of his admission. A staff psychiatrist wrote the following in L.M.'s admission note:

Admission of [L.M.] is appropriate only as an emergency action. Continued hospitalization . . . is inappropriate because there is no peer group, educational or recreational program available to maintain the very good adjustment [L.M.] has been able to make with his deficiencies.

Similar concerns were raised in a psychological evaluation five years later in 1983:

Mr. M. is moderately mentally retarded and does not possess the cognitive resources necessary to allow him to cope with the environmental demands he encounters in a living placement which is tailored for normal intelligence psychiatric patients.

Virtually from the moment of his arrival at the hospital, staff members maintained that L.M. had received "maximum benefit" from his hospitalization, was experiencing deterioration in his condition and abilities because of his inappropriate hospitalization, and required a group home and day program in the community. Until very recently—and only then in response to a lawsuit brought on behalf of A.B., L.M., and more than forty others like them at the hospital—L.M. received no educational or behavioural programming appropriate to his needs.

When L.M. was first admitted to the hospital he was described as being clean, continent, and able to communicate his needs and follow instructions. He could feed, dress, and bathe himself, and care for his other needs, independently. On home visits L.M. rode a mini-bike, played basketball, made his own bed, and took out the garbage. Four years later, in 1982, L.M. was still able to feed, dress, and bathe himself, and to brush his teeth. However, the ensuing years witnessed a dramatic deterioration in L.M.'s basic self-care skills. A psychological evaluation in 1988 observed that L.M. "needed to take five or six showers a day and changes of clothes because of incontinence, behaving as though... not toilet-trained at all." By 1990 L.M. was no longer feeding himself on a regular basis. His case manager reported that "he wears a large sheet to cover his body because he spills things on himself." In early 1991, L.M. had regressed to such primitive behaviour as smearing his feces.

For more than ten years L.M. resided on a ward with some thirty other patients, half of whom, like L.M., were diagnosed as mentally retarded, the others suffering from chronic severe mental illness. The ward door was locked at all times and visitors could enter the ward only after a staff member unlocked it. The ward had a common sleeping area with each bed separated from the others by movable dividers. Areas within the ward that were accessible to patients, consisted of a long hallway leading from the door to the open nursing station, a large day room, and two large rooms off the day room, one of which served as a telephone room and the other as a television and smoking room.

A visitor to L.M.'s ward described it in the following manner:

After the door leading to Ward [name deleted], where [L.M.] resides was unlocked for us, we walked down a short hallway to the nurses' desk. The walls of the entire ward are painted blue. There are several rooms on each side of the hall, each containing

one metal-framed bed without blankets, and surrounded by bare walls. Directly across from the nurses' station was a large room, which we could view through a long window. The room was crowded with roughly six-and-a-half-foot-high partitions separating the patients' beds. One bed lay next to the window and a patient was still sleeping there, at approximately 9:15 a.m., in full view of everyone in the hall.

Ahead lay a large room, called the day room, empty but for three or four hard, orange, plastic seats, each situated across the room from each other. The floor is hard and cold without carpeting or floor rugs. Some of the male patients walked about the room bare-footed. The adjoining room, called the television room, also had several hard, plastic, orange seats situated across from each other on either side of the room, with a longer seat in the middle of the room facing the television. The seats are placed at such a distance from each other that it does not allow for casual conversation among the patients. Built-in bookshelves covered half of one wall of the television room, but they stood completely empty, adding to the austerity of the room. The view outside the windows is pleasant, however, heavy, dirty and aging screens obscure the view significantly. The dull, blue paint that covers the walls of the men's ward was dirty and the paint was peeling in many places. One of the patients kept pointing out to me the places where the paint was chipped and small chunks of the wall were actually missing.

There were no pictures or paintings on the walls. Only a few Valentine decorations, photos of some of the patients at a Halloween party and some cartoon figures with sayings that began with "Bullwinkle says. . . ." These decorations seemed a little too young for the patients.

[L.M.'s] ward was barren—there are no plants or flowers of any kind and there are no books or magazines to occupy oneself with. In fact, with the exception of the television, there is absolutely nothing available in the day room or television room which the patients can use to constructively pass the time each day. Harsh, fluorescent track-lighting covers the ceiling. Also, the smell of the air of the men's ward was stale with strong hints of urine and body-odor, which clung to our clothes even after we left.

L.M. existed in this grim setting for more than a decade. His life on the ward was one of frequent conflict with other patients involving repeated incidents of hitting, kicking, and biting. As L.M.'s condition deteriorated he

engaged in increasingly disruptive behaviour such as screaming, crying, removing his clothes, and stuffing toilets. His case manager attributed this behaviour to the fact that L.M. "is auditorially very sensitive and, when the noise level on the ward increases, [L.M.] becomes anxious and sometimes will lash out and hit someone or he will start to yell and scream." Trained observers concluded that L.M.'s conflicts and behaviours "appear to be his way of coping with the impoverished environment of the ward." Hospital staff have responded to L.M.'s "challenging behaviours" with the administration of psychotropic medications and the application of restraints. During a three-month period, in 1990, L.M. received 86 *prn*'s (in addition to his regular dosage of medication), and was placed in four-point restraints ten times.

The only service provided to L.M. by the department of mental retardation during a decade of hospitalization was "case management," which consisted of irregular visits by a case manager and periodic interdisciplinary team meetings at which an overall plan of services was developed and reviewed. At these meetings the team invariably concluded that L.M. was inappropriately placed and was deteriorating at the hospital, and that he required community-based group home placement and a day program, both designed to meet his special needs as a person with mental retardation and related behavioural symptoms. L.M.'s case manager from the department of mental retardation stated that when she visited L.M. at the hospital she would observe him walking around in circles or "just sitting, occasionally pacing, or in restraints." On the ward L.M. received weekly "music therapy" on Friday nights in which the male patients "just dance to the music or they sit and listen to the music. . . . It's meant to be like a party and it's just kind of a party sort of thing."

Mental Retardation and the Law

During the summer of 1990 a team of psychologists with extensive experience in the field of mental retardation visited the state hospital wards where A.B. and L.M. were confined. They observed the activities on the ward, spoke with patients and staff, and reviewed patient records. They reported that "what [A.B. and L.M.] experience is an anachronism—a service approach for people with mental retardation that existed almost a quarter of a century ago and has long since been abandoned."

What these observers saw were individuals with mental retardation confined on locked wards in a state mental hospital, together with patients suffering from chronic mental illness, being "managed" with psychotropic medication and mechanical restraints. There was no training to help these individuals develop or improve self-care skills, or to prevent the deterioration or loss of the skills they had; there was no training of patients and few other measures taken to ensure the protection of patients with retardation from their own self-injurious behaviour or from assaults by other patients; there was no

systematic process for assessing patients' needs, planning for addressing those needs, and providing appropriate services to meet those needs.

In its landmark decision on the rights of persons with mental retardation, *Youngberg v. Romeo* (1982), the United States Supreme Court held that persons with mental retardation in state-operated institutions have constitutional rights to safe conditions of confinement, freedom from unreasonable physical restraint, and training that is reasonably required to ensure their safety and to facilitate their ability to function free from bodily restraints. These basic constitutional rights have been held to include a right to training sufficient to prevent basic self-care skills from deteriorating (*Society for Good Will to Retarded Children v. Cuomo*, 1984); and, for those institutionalized at too young an age to have learned basic self-care skills, the right to such training as would match the improvement that they would have experienced if they had not been so confined (*Clark v. Cohen*, 1986).

Although the Supreme Court in *Youngberg v. Romeo* recognized these constitutional rights, it declined to articulate substantive criteria for assessing whether the rights have been violated. Rather, the Court deferred to the judgment of professionals, holding that state authorities must ensure that "professional judgment has been exercised" regarding treatment and conditions of confinement. In the Court's words,

[L]iability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such judgment.

Thus, the constitutional rights of institutionalized persons with mental retardation are violated either when treatment plans and the care provided fail to conform to accepted professional standards, or when treatment recommendations by qualified professionals that do meet accepted professional standards are not implemented.

While courts have held that institutionalized persons with mental retardation do not have a constitutional right to placement in the least restrictive environment appropriate to their needs, such as community-based group homes (*S.H. v. Edwards*, 1989; *Thomas S. by Brooks v. Flaherty*, 1990; *Society for Good Will to Retarded Children v. Cuomo*, 1990), individuals might be entitled to community placement if professional evaluators determine that habilitation in a community setting is necessary to provide adequate care in accordance with professional standards (*S.H. v. Edwards*; *Thomas S. by Brooks v. Flaherty*).

The Lawsuit and the Settlement

It was these rights that advocates for A.B. and L.M. sought to vindicate when, in the summer of 1989, they commenced a legal action against the departments of mental retardation and mental health on their behalf and on behalf of the others with mental retardation confined with them at the state hospital—the right to live in a safe environment, the right to be free from undue restraint, and the right to receive training to prevent the deterioration of basic self-care skills. The class consisted of thirty-nine other persons who shared the wards where A.B. and L.M. lived. Although all had "treatment plans," they consisted of little more than a recitation of major medical and behavioural problems with global statements regarding the ultimate amelioration of those problems. There were no assessments or behavioural management plans beyond tranquilizing medications and restraints. A few of the class members had day programs but most, like A.B. and L.M., spent their days wandering aimlessly around the wards.

It was clear to the attorneys that the conditions on the wards and the care and treatment of the class members fell woefully short of even the minimum required by professional judgement. The case on the merits seemed clear; what was unclear to the class attorneys was the question of remedies.

What the advocates really wanted for their clients was that they be discharged from the state hospital to small, supervised group homes and to appropriate day programs, where they might live more normal, satisfying lives and receive habilitation and training that would enable them to realize their potential for productive activity and the enjoyment of life. The advocates were committed to the ideal of normalization, an ideal that could not be achieved so long as their clients remained institutionalized. The hard reality, however, was that the state of Connecticut was in a serious economic recession and faced a multi-million dollar deficit. Short of a federal court order requiring the state to levy additional taxes—a prospect which was highly unlikely – it was clear that funds were not available to create residential placements in the community for all class members. On the other hand, the possibility of the court ordering the state to make improvements in the institution and to develop minimally adequate programs was real, but wholly unacceptable, to the advocates.

Despite the uncertainties, in May of 1991, the plaintiffs' attorneys filed a motion for summary judgment contending that they were entitled to a judgment as a matter of law without trial or further factual development. In the papers submitted, the plaintiffs requested that the court appoint a special master to oversee the treatment of the class. Concerned about the possibility of the appointment of a special master, the defendants immediately called for settlement negotiations. An interesting and creative proposal was presented. The commissioners proposed a series of individually-oriented, interdepartmental

case conferences for the class members, to be chaired by the commissioners of both agencies. The purposes of the conferences would be to provide: (1) the commissioners with information regarding the care and treatment of each class member and the interrelationship of the two departments relative to that care and treatment; (2) a means by which the service needs of each class member could be reviewed and strategies developed to meet those needs with the resources currently available; and (3) a forum in which a candid interchange of ideas and perspectives could take place among the professional staff of the departments in order to assure that the class members would receive appropriate care, treatment programs, and services. The information and strategies generated at the case conferences would serve as the basis for a consolidated treatment and service plan for each class member. Additionally, and of paramount importance, the commissioners reaffirmed an earlier commitment that the department of mental retardation would be responsible for placement in the community of all hospitalized individuals with mental retardation and that future admissions of persons with mental retardation to the mental health facility would be limited to those justified as a result of a psychiatric emergency. Finally, the commissioners agreed to place one-third of the class members in community residences within the current fiscal year, and the remainder within a "reasonable" period thereafter.

The Gilded Cage, and Beyond

By the end of the first six months of the settlement, every member of the plaintiff class was participating in a day program. The majority were leaving the hospital grounds to participate in sheltered workshops, supported employment, or social and recreational programs. L.M. is one of them. A small number are being served in an on-grounds program at the hospital where they are learning daily living and self-help skills, and engaging in recreational activities in the community.

During that same six-month period fourteen class members had either moved or been accepted into community residences. A.B. had moved into an interim placement at a department of mental retardation regional centre pending development of an appropriate community residence. L.M. has been placed in a group home near the home of his mother.

On the hospital wards, where the class members resided, their care and treatment improved significantly. Most had their medications reduced. The incidence of use of mechanical restraints plummeted. The staff became energized and "professionalized" by the attention being paid to their work by the commissioners at the weekly meetings, and by the advocates coming onto the wards to meet with them for the purpose of improving services for the patients.

Notwithstanding these positive developments in conditions and programs resulting from the settlement of the lawsuit, the majority of class members remain confined on locked wards of the state mental hospital. In effect, their advocates have settled for a "gilded cage" rather than holding out for what they knew to be right and in their clients' long-term best interests—the opportunity to lead more enjoyable, productive, "normal" lives in integrated settings in the community.

Conclusion

Fulfilling ethical and humanitarian obligations to institutionalized mentally retarded clients often calls upon the legal advocate to settle for incremental improvements in services and conditions of confinement, rather than holding out for major, costly changes in their programs, such as the development of group homes. In a world of scarce economic resources and political conservatism, large capital and program expenditures for group homes and other community-based services that would "normalize" the lives of institutionalized clients may simply not be economically or politically feasible.

We know that individuals with mental retardation can lead more productive, satisfying, and enjoyable lives in the community than in institutions. Yet, we must also acknowledge the reality that public funds in all likelihood will not be available, now or in the foreseeable future, to permit the movement of all institutionalized mentally retarded people into the community, with adequate supports and services to assure their successful transition from institutionalization to normalization.

People with mental retardation and their legal advocates live in the real world, not in an ideal world imagined by social and legal theorists. It is within the real world that advocates must struggle and make compromises to achieve improvements in the lives of their clients. The settlement in the case of A.B. and L.M. demonstrated the profound tension for advocates between their desire, and duty, to accept immediate measures to alleviate the suffering of clients, and social policy objectives that the advocates believe to be the best way to meet the needs of their clients in the long run, and the legal right of their clients to receive.

In attempting to address the immediate needs of their clients, legal advocates frequently are caught between meeting those needs and achieving long-term solutions to their clients' problems. In the real world advocates may find themselves agreeing to the expenditure of limited public funds to improve conditions and services within institutions, resulting in the expansion of programs, physical improvements, enhanced staff-patient ratios, reductions in the use of medications and mechanical restraints - in effect, the creation of a "gilded cage." At the same time, advocates must continue to push for the

eventual, and inevitable, closing of institutions for persons with retardation, and for their inclusion and integration in society.

NOTES

1. The number of persons with developmental disabilities residing in state-operated institutions across the United States dropped nearly 17% during the 4-year period between 1984 and 1988. Between 1986 and 1988 institutional expenditures increased only 10% while expenditures for community services increased by 38%. Braddock *et al.*, *The state of the States in developmental disabilities*, 1990, p. 13.
2. The case of A.B. and L.M. is an actual case.

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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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