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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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