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ABSTRACT

An increasing number of children who are both medically fragile and profoundly retarded are living to reach school age due to advanced medical technology. The provisions of Public Law 94-142 the Education for All Handicapped Children Act, bring these children within the domain of public education. A major question concerns what service delivery models should be used to meet the needs of the target population; the answer to this question requires a closer look at Public Law 94-142 itself, while the law does not speak directly to the population of concern; it does offer two important features: (1) it provides the obligatory force to program for all children regardless of severity; and (2) it sets in place a framework within which such programming may be developed. Summarily, it can be said that the public education system is the central agency for services to school aged children. It has a value-positive place in the social structure; it eliminates stigma; and it represents the legally-mandated least restrictive environment. Hence it may be reasonably considered as the basis of a service model for the children under study. Another advantage is that it means that a source of monies and a method of dissemination are already in place. In developing new guidelines for the particular children of concern, attention must be paid to provision of funds to meet the "related services" needs of this population. The spirit of commitment to the education of all children and to early intervention expressed by Public Law 94-142 and 99-457 must be matched by policy, or the educational agencies and the population of concern will be left in a position of vulnerability. Following the text a framework for proposed system changes is presented in the form of an Individual Education Plan. Contains 24 references. (KM)

An Approach to Multi-Level Planning and Policy for Children Who Are Medically Fragile and Profoundly Retarded

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Introduction to the Issue

The coupling of current legislation with advanced medical technology has presented special education with a challenge for the future quite unlike any experienced in the history of public education. The challenge referred to is education for those children born with a multiplicity of profoundly handicapping conditions such that only the most subtle responses to the environment may be elicited. Under Public Law 94-142, these children are entitled to a free appropriate public education. With the additional passage of Public Law 99-457 public schools will be enticed, then mandated to provide special education programs for handicapped children under the age of five years. This legislation, which provides for education of children with special needs at a younger age, will increase the number of children receiving special services. Likewise, the number of children with profound disabilities needing special services will also rise. The identifiable population in need of early intervention will not be the learning disabled, the mildly mentally handicapped, or the hearing impaired child. It will be the one with clearly recognizable clinical signs.

This paper is interested in the population of children for whom cerebral development has been arrested at a level where functioning is basic to life processes and sensory awareness has not significantly evolved. These children will be referred to as those who are both medically fragile and profoundly retarded, for they frequently have physical handicaps, convulsive disorders, visual and auditory disorders, and a cognitive level that precludes learning. Medically fragile children are dependent on life-support equipment (Great Lakes Area Regional Resource Center, 1986, p.4). They may be distinguished from children with other health impairments by the level of acute care necessary to sustain life. Typical problems include children who are "...ventilator dependent, tracheostomy dependent, oxygen dependent, B.P.D., bronchial or tracheal malacia, nutritional problems requiring hyperalimentation or gastrostomy tube dependency, congestive heart problems, post-trauma children requiring long-term, high-tech care, apnea monitored children, and kidney dialysis" (Great Lakes Area Regional Resource Center, 1986, p. 4-5). Through advances made in medical technology, these children are now living to reach school age. As such, a redefinition of this population may need to be considered that would extend beyond the limit of care for health impairment or physical disability to acknowledge the need for educational support as well.

Prior to 1975, and the passage of landmark legislation known as Public Law 94-142, care of children who were described as medically fragile and profoundly retarded was not generally within the domain of public education. The issues of those concerned with public education of the disabled have changed significantly since the passage of Public Law 94-142, the

Education of All Handicapped Children Act. Most particular to the concern of this paper is how the responsibility of public education, as it is now promulgated in Public Law 94-142, translates to the population being addressed.

The issues surrounding programming for children who are both medically fragile and profoundly handicapped are complex and value-packed. Public Law 94-142 entitles all children to a free and appropriate education. It spells out the duties and obligations of state and local education agencies, regarding the rights of handicapped children. It assures these children the right to a free, appropriate, and available public education through the development of an Individualized Education Plan (IEP); that the provision of this program will be in the least restrictive environment; that on-going consultation will ensue with parents, guardian, or advocate appointed by the state; and that non-discrimination and confidentiality will be protected by an established set of due-process procedures.

The tenets basic to Public Law 94-142, are further supported in the body of literature that strongly advocates deinstitutionalization and the inclusion of those with disabling characteristics into the community. Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, described the movement toward integration of those with severely disabilities as the "second stage of the revolution" (quoted from the forward to Proceedings of the National Leadership Conference 1987 on the Least Restrictive Environment: Commitment to Implementation p. vi). Implied in her comment is the concept that "...least restrictive environment is not simply an educational issue. Integration is basic to normalized work, living, and social opportunities as well. This holistic approach to least restrictive environment is apparent in recent initiatives developed by the U.S. Office of Special Education and Rehabilitative Services..." (Wilcox, 1987, p. vi). Other nationally known educators in the field of special education also speak strongly in favor of integration as the only way to achieve normalization, even among those individuals classified with severe intellectual compromise (Ford & Davern, 1989; Butler, Palfrey, Singer, Walker, & Raphael, 1988; Brown, 1987; Forest, 1987; Graylord-Ross & Peck, 1985; Stainback & Stainback, 1984; Sontag, Certo, & Button, 1979).

In contrast to those who maintain that all children with disabilities must receive the same services or opportunities as all other children, there are those who take the opposing position, that both law and society are "sacrificing the child to the concept" (Burton and Hirshoren, 1979, p. 599). The number of outspoken dissidents is far fewer. They posit the argument that the educational system is being driven by a mandate to serve a population of children for whom there is a noticeable lack of programming guidelines in both the legislation and the literature. Additional support for this position may be found in the growing body of litigation arising out of the confusion mitigated by the language and intent of Public Law 94-142. The issue is in its nascent stages now, but its potential to become problematic augers in the very near future.

Rationale for Change

In an earlier study, (Czaja, 1988), evidence of constraint on single agency planning was found to affect programming success in the educational domain. Related literature and litigation, together with the findings of this study, support the position that it is time to establish a case for the inclusion of legal guidelines in Public Law 94-142 that address the unique needs of medically fragile and profoundly retarded children who are eligible to receive public money for services. In response to these findings, this paper proposes a set of guidelines as a platform for system change. The potential effects of these guidelines on future practice, as well as the generalizable features of the format itself will be addressed.

In short, the issues presented in this paper address the needs of an emerging population of school eligible children, children who have substantial medical and developmental involvement, children who have not been identified, categorized or addressed under the Education of All Handicapped Children Act; and children who are entitled, under law, to receive the same rights and opportunities as other handicapped and non-handicapped children. The needs of the children addressed here are so unique, however, that to classify them non-categorically, and to serve them under the stipulations of the general legislative guidelines regulating education of the handicapped, is to overlook the significance of the issue.

The need for specialized service delivery to the new population of children who are medically fragile and profoundly retarded, is clearly evident. Identification of the need, however, is just the first step in the larger investigation of what a service delivery model should look like and how it should function. At the base of such a model should lie answers to four very important questions. They are concerned with issues that address the conceptualization of service delivery that satisfies standards of appropriate programming, including placement in the least restrictive environment and related services for children who are medically fragile and profoundly retarded. The questions are as follows:

1. Can existing models of service delivery be adapted to adequately meet the needs of the target population?
2. Who should assume primary responsibility for program coordination?
3. How should the issues around interagency planning and professional training be affected by the growth of school age children who meet the criteria of the target population?
4. Will there need to be amendments to the language in Public Law 94-142 regarding the definitions of appropriate education and least restrictive environment for the target population; and will the concept of related services need clarification in regard to the benefit clause, for children who are medically fragile and profoundly retarded?

Within each of these questions is a plethora of sub-issues critical to its response. Thorough investigation of each question must therefore be considered before a set of working guidelines should be accepted.

Considerations for New Guidelines

The first question asks whether there are current models to examine and adapt. Approaching the question in this way has two advantages. First, it addresses the issue of building on something that is already in place. Secondly, it implies avoiding the introduction of an unfamiliar structure. The latter concept could cause agitation and discomfort to an already stressful system of expensive and highly scrutinized programs for children with special needs.

The answer to the question of existing models first requires a closer look at Public Law 94-142 itself. While it does not speak directly to the population of concern, it does offer two important features: one, it provides the obligatory force behind the charge to program for all children regardless of severity; and two, it sets in place a framework within which such programming may be developed.

> Public Law 94-142 states that the term
> "...free appropriate" public education means special education and related services which (A) have been provided at public expense, under public supervision and direction, and without charge, (B) meet the standards of the State educational agency, (C) include an appropriate preschool, elementary, or secondary school education in the State involved, and (D) are provided in conformity with the individualized education program required under section 614 (a) (5) [20 USCS 1414 (a) (5)].

The law clearly identifies the state and local education agencies as the central structures for dissemination of all education and educationally related services. For students without handicapping conditions, the charge to public school systems is to provide quality standard education. This same system is charged with the responsibility to provide children with special educational needs all the opportunities available to students who are not disabled, plus provide a wide variety of related services including, but not limited to health, environmental, psychological and therapeutic adaptations. Summarily, it can be said that the public education system is the central agency for services to children of school age. It has a value-positive place in the social structure of a given community. The stigma attached to taking one's child to a medical facility, social service, or mental health agency as a primary source of intervention, is eliminated. The schools also represent the least restrictive environment as defined by Public Law 94-142, because they represent the normative expectation of all school age children. Given these considerations, the proposition that the public education system become the basis of a service model to children who are medically fragile and profoundly retarded should not be without serious consideration.

An additional argument, in support of the public schools assuming the role of intake and service coordination, is that they are the designated recipients of program funding. Under the provisions of Public Law 94-142, federally assisted schools must provide appropriate transportation; physical, occupational and speech therapy; interpreters; medical; support services such as clean intermittent catheterization, gastrostomy-tube feeding, suctioning and tracheotomy care; and psychological services to those children for whom such services are deemed necessary to allow them access to a free, appropriate education in the least restrictive environment. The vehicle through which services are considered necessary and appropriate is the Individual Education Plan (IEP). This is a team based approach to special education program development and was put into place through the Education of All Handicapped Children Act, of which Public Law 94-142 and its pre-school component, Public Law 99-457, are a part. Funding for the support services are the result of a federal, state and local formula designed to meet the obligatory regulations of the Law governing special education. In the exploration of a workable model, it can be said that under the existing system a source of monies and a method of dissemination for the same are already in place. This factor should not be overlooked. Commitment to educational support services for the handicapped is further strengthened by House Report 2470 under President Ronald Reagan. Dated July 1, 1988 the report reads:

> The conference agreement clarifies that Federal Medicaid matching funds are available for the cost of health services, covered under a State's Medicaid plan, that are furnished to a handicapped child or a handicapped infant or toddler, even though such services are included in the child's individualized education program or individualized family service plan. Under the Education for All Handicapped Children Act of 1975, P.L. 94-142, children with handicaps are entitled to a free and appropriate public education in conformity with an individualized education program

(IEP), which describes the educational and "related services" necessary to meet the child's unique needs. While the State education agencies are financially responsible for educational services, in the case of a Medicaid-eligible handicapped child, State Medicaid agencies remain responsible for the "related services" identified in the child's IEP if they are covered under the State's Medicaid plan, such as speech pathology and audiology, psychological services, physical and occupational therapy, and Medicaid counseling and services for diagnostic and evaluation purposes (Conference Agreement on H.R. 2470, Medicaid Catastrophic Coverage Act, pp. 268-269 of Report #100-661).

The implication of such legislation is the congressional affirmation of its intent to give federal support to more than the educational commitment of Public Law 94-142 and the new Early Intervention program, Public Law 99-457, parts B and H respectively of the Education of All Handicapped Children Act. Two clear components of a model are securely in place and supported by present day congressional legislation: money and legal mandates. These factors should not be overlooked. Issues implicit within these broad areas have not yet been addressed. In a very pragmatic sense they may become the key to resolving the dilemma of appropriate intervention planning, for they make up the direct service procedures fundamental to program success. Knowing what agency is responsible for intake and knowing that Public Law 94-142, Public Law 99-457, and Medicaid have provisions to pay for related services is satisfying, but it does not address the basic issue of how a child who is medically fragile and profoundly retarded effects a public system of education.

Recommendations

From the previous discussion it should be evident that this paper supports the basic educational model that presently exists under Public Law 94-142 and Public Law 99-457 as a viable option. However, revisions in the present legal guidelines must reflect a well articulated goal for the children of concern in this paper. They must further provide for family, professional and system wide service to help meet the medical, educational, social, and psychological needs of the population. To achieve this end, and address those remaining issues presented at the outset of this discussion, an alternative framework for system change is proposed (Figure 1). It includes components for comprehensive planning that are structured in a format not unlike that of an Individual Education Plan. A goal is stated, the present level of functioning defined, strategies for change proposed, and standards for measurement of change articulated. In this case the goal states the intent and rationale behind program change for children between the ages of 3 and 21 years, who are both medically fragile and profoundly retarded. The present level of functioning is defined relative to what is appropriate education for the population of concern. Strategies for change are proposed to support appropriate programming that will be least restrictive medically, physically, socially, and emotionally to the children who are both medically fragile and profoundly retarded. Standards for measured change are articulated relative to educational benefit from related services for those affected by the complexity of the prevailing disability.

The goal states clearly to whom the program is designed, the program's purpose, and the conditions necessary to achieve that purpose. It further reflects the spirit of Public Law 94-142, in its focus on programming that encourages children between the ages of 3 and 21 to function at their capacity. The goal concludes with a statement focused on the ability of the primary care giver (parent, guardian) to use resources effectively or receive community support necessary in this endeavor. This is where the family component of Public Law 99-457 can be drawn in and adapted to Public Law 94-142, for the purpose of strengthening the existing models while keeping an eye toward future planning for children who are both medically fragile and profoundly retarded.

The objectives in Figure 1. track the progression of programming from initial assessment through the stages of service and resource acquisition. As written in the guidelines of Public Law 94-142, an interdisciplinary team is coordinated by the education agency. Looking once again at the model provided by Public Law 99-457, the team should reflect representation from the family as well as the delivery system(s) best qualified to clarify the non-educational issues for the population of concern. The need for interagency cooperation and family support is corroborated in the data presented from the field study. It is at this point that the model addresses the second of the four fundamental issues, positing that coordination of services can remain within the structural guidelines of Public Law 94-142, with the local education agency working toward collaboration of services and determination of the least restrictive alternative for each child within the target group.

As the population of school age children who are both medically fragile and profoundly retarded increases, programming issues become more complicated at the agency level. Thus the third of four presented issues is discussed. The situation exists because it has not been addressed at the statutory level. Support for this argument may be found in the number of court cases over related services to children who are medically fragile (Timothy W. v. Rochester School District (1987-1988), Christopher C. v. Weston Public Schools (1987), Bevin v. Wright (1987), Department of Education v. Katherine D. (1983), Irving Independent School District v. Tatro (1983-1984), Detsel v. Board of Education (1986)). It is apparent that attention must be given to the appropriation of funds necessary to address the diverse and complex needs of the target population. Dispersal of funds would need to span social services, staff training, consultation, medical care services, nurses, aides, transportation, and a range of possible therapies. Such a model of education is not now reflected in the language of Public Law 94-142 and would require the state and national system of special education to change the general status of service, to more specifically adapt itself to the functional needs of the target population. "Because P.L. 94-142 has provisions to pay for certain related services, agencies that had hitherto assumed provision of those services are now shifting them back to the schools" (Baird & Ashcroft, 1985, p. 662).

This unsystematic shifting of responsibility has to stop. For this change to occur there must be clarification of intent and guidelines to support a change. Such clarification would obviate the need for new language at the federal level. This brings the scope of this study to the fourth and final issue: that of amendments in the statute that would target the terms appropriate education, least restrictive environment and related services as they apply to the benefit clause.

The spirit of commitment to educating all children with disabilities, regardless of severity, is clearly expressed in Public Law 94-142. Expansion of this commitment translates into the support for early intervention under Public Law 99-457. For those educational agencies facing the responsibility of programming for children who are both medically fragile and profoundly retarded, the match between spirit and policy is not apparent. For that reason both the educational agencies and the population of concern are left vulnerable; the system to the financial, legal and professional absence of support, and the children to the fulfillment of their statutory rights.

Conclusion

This paper has investigated the issue of growing change in the system of serving children with very specific medical and educational needs. It has considered the implications of change from a legislative, litigative, and single agency service delivery perspective and disequilibrium when support within the system is unbalanced. The best feature of Public Law 94-142 is that it forces society to serve all children. Social policy must now live up to that commitment, commensurate with the level of care necessary to provide for the emerging number of medical wonder babies. Societal obligation may be "identified as the point where... quality care and economic support respond to changing needs for resources enhancing to social functioning in daily living situations as a basic right in each life phase" (Butler, 1988).

Looking at Figure 1. as a guideline for change, there are definite levels at which educational policy and program planning coordinate: the child, the family, the agency, and the broader legislative system. The framework for comprehensive planning is in place. The guidelines for interagency cooperation, through related services to children with handicapping conditions, are laid out in Public Law 94-142. Provisions for interdisciplinary planning are fundamental to Public Law 99-457. The key to implementing a model of service delivery, that addresses the unique needs of children with severe medical and developmental complexities, is to go back to the legal mandate; look at the language; evaluate the discrepancy between intent and content; and amend the guidelines to acknowledge the emerging population. It is unconscionable to imagine the strength of special education turning its back on itself. Perhaps the issue is one of awareness. Above all else it is the intent of this paper to provide that awareness and to charge those with professional commitment to move from this level into action.

FIGURE 1. A Multi-Level Approach to Policy and Planning for Children Who Are Both Medically Fragile and Profoundly Retarded.

Goal: That all medically fragile and profoundly retarded children in the 3-21 year age group function at their capacity physically, socially, emotionally, cognitively; and that their primary caregiver (parent, guardian) be able to use resources effectively, or receive community support necessary in this endeavor.

Present Level of Functioning (Where we are now)	Objectives (Methods and Strategies)	Measurable Results
Level: Child		
1. Many medically fragile and profoundly retarded children are served by a larger system of programming for children with special educational needs. Under such a system services are delivered with little regard for the limited level of functioning, and considerable medical support required by these complex children.	1a. The established traditional interdisciplinary school team will prepare a basic assessment. 1b. Extension of assessment team to include a representative from the delivery system best qualified to clarify medical issues for children of concern. (Handicapped services, rehabilitation services, primary physician).	1a. Based on the children's comprehensive assessment, they will be receiving services promotional to their highest level of competency in each domain (reflecting positive affect such as joy, pleasure, absence of crying).
Level: Caregiver		
2. Caregiver's understanding of child's condition is based on facts and myths provided by a variety of resources - primary physicians, educational system early intervention, extended family, newspaper articles, advocacy groups. Guilt, stress, depression, and false hope sometimes prevail.	2a. Parent education through school resources, presented in a formal and informal manner. 2b. Access to: -parent support groups that fit with their needs -parent advocates -conferences with recognized authorities -reading material geared to their level of understanding 2c. Assist in making connections with social agencies for family counseling related to child development, parental stress, guilt, etc.	2a. Primary caregivers will be able to describe their children's needs and participate in the management of their child's program with or without parent advocate assistance.

(continued)

Present Level of Functioning (Where we are now)	Objectives (Methods and Strategies)	Measurable Results
	2d. Provide an environment where parents are considered co-members of decision-making teams and encouraged to participate in decision making.	
Level: Educational Agency 3. Confusion in mission at the agency level. The on going need for full service. Medical support outweighing the value of an educational plan.	3a. Establish full range of social services . Funds necessary to pay for medical care system include: -training and consultation for staff, nurse, medical doctors, aides, LPNs, etc. 3b. Early identification of population through more specific child-find procedures. Define the limits of service as an educational agency. 3c. Identify additional community services needed for the on-going comprehensive assessment and programming of children (medically fragile and profoundly retarded) eg., social service component, mental health, rehabilitation, medical and nursing. 3d. Establish a system of payment for these services. 3e. Selection of site alternatives based on home and other levels of care. 3f. Establish a system of training and consultation to caregivers carrying out the Individual Education Plan.	3a. School system will develop collaborative programs where knowledge and skills are necessary for services to the medically fragile and profoundly retarded population; and will assist in the determination of the least restrictive alternative.

(continued)

Present Level of Functioning (Where we are now)	**Objectives** (Methods and Strategies)	**Measurable Results**
Level: Policy		
4. Lack of clarity at the statutory level; does not address the population of concern.	4a. Establish action group geared to a change in statutes to expand the services necessary for the target population. -parent groups -state education agencies -professional advocacy groups: Association for Retarded Citizens, Council for Exceptional Children	4a. State and National system will change the general status of services to more specifically adapt to the functional needs of the target population eg., Constitutional Law Legislation Administration
	4b. Appropriations at the federal, state and local level, to support change.	

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