



September 2005

Medically Fragile: State Policies and Procedures

by *Eve Müller*

The purpose of this document is to provide information on how states handle issues related to children who are medically fragile. Project Forum conducted this analysis as part of its Cooperative Agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP).

Little is known about state policies and procedures regarding medically fragile students. Although the term *medically fragile* is frequently used by special educators and policy makers to refer to students with serious health conditions (See section on *Definitions* below), data collection on the prevalence of medically fragile students and/or the services they receive is not required under the Individuals with Disabilities Education Act (IDEA). An Internet search of this topic revealed that while several states have collected data on the numbers of medically fragile students, these data are for the most part out of date and/or pertain to only a small subset of medically fragile students (e.g., children ages birth to four).

Data Collection

Project Forum developed a survey on how states address issues related to students who are medically fragile. Survey responses were

collected during the months of June and July of 2005. A total of 37 state education agencies (SEAs) completed surveys and findings are reported in the following section of this document.

Findings

Definitions

Only eight SEAs reported having specific definitions of medically fragile children. Of these, two noted that the definition was generated by community-based services or other outside agencies as opposed to the department of education. A third SEA noted that different agencies in the state use different definitions for medically fragile (e.g., its department of education uses a different definition from its department of human services). Most commonly, definitions include criteria regarding the frequency and/or intensity of medical interventions required (e.g., involvement of a doctor, nurse or other appropriately trained personnel), intensity of symptoms (e.g., an unstable life threatening physical condition), expected duration or symptoms (e.g., at least 12 months) and/or need for a medical device or assistive technology. Twenty-nine SEAs reported that they do not have definitions for medically fragile. See Appendix A for state definitions of medically fragile.

Use of Descriptor in Special Education

Of the 29 SEAs who reported that they did *not* have a specific definition for medically fragile, nine reported that they use the term, “medically fragile” in special education. Most commonly SEAs reported using the term informally to describe students with significant health conditions (e.g., requiring medication, catheterization, tracheotomy, respiratory assistance or other medical procedures and usually intermittent or constant monitoring). Other uses of the term include:

- publications relating to school health services;
- data collection;
- medical evaluation and possible eligibility for the “other health impairment” category under IDEA; and
- description of the level of educationally relevant medical services required by a student in order to benefit from education.

Three of the 20 SEAs that reported that they did *not* use medically fragile as a descriptor within special education noted that they did use similar terms (e.g., students assisted by medical technology, students with special health care needs).

Classification

Most of the SEAs reported that medically fragile students are classified using a range of disability categories. Twenty-five SEAs reported using the category of other health impairment (OHI); 15 reported using the category of multiple disabilities (MD); and six reported using the category of orthopedic impairment (OI). Other categories reported by only one or two states included: multiply

disabled, severely sensory impaired, mental retardation (MR) and severe/profound intellectually disabled. A total of seven SEAs reported only that state or federal disability categories were used and three SEAs reported that classification was determined by the individualized education program (IEP) team. Two SEAs noted that medically fragile students are not always eligible for special education services, in which case they may be eligible to receive services under Section 504 of the Americans with Disabilities Act (ADA).

Classification of Younger Children

Fourteen SEAs reported that they use different disability categories to classify younger children who are medically fragile (e.g., children eligible for Part C and/or Section 619). Eight SEAs reported using the category developmental delay (DD) and eight SEAs reported using other categories for younger children including preschool severe delay, established medical disability, established conditions program (0-3), preschool disabled and specific medical condition.¹ Two SEAs described using different categories for children eligible for Part C and those eligible for Section 619. Two other SEAs described using DD for children eligible for Part C but using the same disability categories for Section 619 as for the rest of Part B. Twenty-four SEAs reported that they do not use different disability categories to classify younger children who are medically fragile.

Formal Guidance

Nineteen SEAs reported providing formal guidance related to children who are

¹ These numbers do not sum to 14 because two SEAs reported using more than one disability category for younger children who are medically fragile.

medically fragile. Most commonly, SEAs described guidelines and procedures for meeting the specialized physical health care needs of students (10 SEAs). Other formal guidance mentioned by only one or two SEAs included guidelines for health screenings; physical therapy (PT) in educational settings; management of chronic infectious diseases in school children; parents of students with special health care needs; administration of medications; first aid for school emergencies; managing asthma in schools; and training public school employees in the administration of insulin and glucagon. Eighteen SEAs reported that they do not provide formal guidance related to this population.

Educational Placements

Fifteen SEAs reported that they provide a full continuum of educational placements for students who are medically fragile (e.g., inclusive classrooms; pull-out; self-contained classrooms; home; and hospital). Fifteen SEAs reported that educational placements were determined by the IEP team and/or based on the educational needs of students. Several states noted that the most common educational placements were either self-contained classrooms and/or specialized health care residential facilities. One SEA noted that educational placements for a given student might change due to improving or deteriorating medical conditions. Seven SEAs reported that data on the educational placement of medically fragile children are unavailable.

Related Services

Fifteen SEAs reported that medically fragile students receive school health services and/or nursing, 14 reported that medically fragile students receive occupational therapy

(OT) and 14 report that medically fragile students receive PT. Less commonly, SEAs reported that medically fragile students receive speech and language therapy, audiology, therapeutic recreation, specialized transportation, case management, family counseling and supports, assistive technology (AT), adaptive physical education (P.E.), preschool services, medical services for assessment and diagnosis, respiratory therapy, respite care, in-home supports, supported living and rehabilitation. Twelve SEAs reported that related services are based on IEP team decisions and/or the educational needs of students. Several SEAs said that the range of personnel who would most likely deliver services to medically fragile students include school board employed nurses or contracted nurses, home school staff and personal/health care assistants. One SEA noted that rural areas frequently contract for services through a special education cooperative, whereas larger urban districts provide their own staff. Eight SEAs reported that data on related services for medically fragile students are unavailable.

Nursing Services

The new IDEA 2004 has explicitly added nursing services to the list of related services. Thirty states reported that they included nursing services as a related service prior to the reauthorization of IDEA, frequently under the rubric of school health services. Several SEAs noted that nursing services would be provided under IDEA only if they were included on the IEP. Another SEA noted that nurses are core members of early intervention services teams. Six SEAs reported that they did not include nursing as a related service prior to the 2004 IDEA reauthorization.

Challenges

Most SEAs described one or more challenges to serving medically fragile children. Most commonly, SEAs reported the challenge of balancing least restrictive environment (LRE) and safety needs (15 SEAs), lack of funding and/or increasing costs of services and equipment (12 SEAs), difficulty accessing Medicaid funds to offset costs of services to medically fragile students (11 SEAs), providing necessary accommodations during transportation to and from school (11 SEAs), provider shortages – particularly the lack of availability of specialized nursing staff (10 SEAs) and providing services in rural or remote areas (6 SEAs). Other challenges reported by no more than one or two SEAs included the following: determining medical versus educational services; handling do-not-resuscitate (DNR) orders; coordinating/accessing varied funding sources; liability issues for teachers; ensuring free appropriate public education (FAPE); measuring progress on goals and objectives for students with degenerative conditions; communication between medical and educational fields; providing appropriate AT and lack of air-conditioned transportation options. Three SEAs reported that there were no challenges to serving medically fragile children within the state. An additional four SEAs reported that data pertaining to challenges in serving this population are not available.

Concluding Remarks

Although only eight out of the 37 responding SEAs reported having a specific state definition for medically fragile, almost all responding SEAs appear to use the term informally and the majority (19 total) reported offering some type of formal guidance for providing appropriate services to this population. Most SEAs appear to use similar disability categories for classifying students who are medically fragile, as well as similar ranges of educational placements and related services. SEAs also appear to be in agreement regarding the types of challenges faced in serving medically fragile children. Furthermore, although states are not formally required to address this population as a separate group, most tend to have a good grasp of what is happening to serve them at the local level.

Because medically fragile is not a federal disability category, data collection regarding numbers of students and types of services received is virtually non-existent at the state level. However, based on the fact that IDEA 2004 explicitly added nursing services to the definition of related services as “school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child” [§602(26)], states should begin to pay even greater attention to the issues related to medically fragile students. This is an issue that deserves extensive and formal consideration on the part of states.

Appendix A – States’ Definitions of Medically Fragile

Alaska – “Children who receive long-term care in a facility for more than 30 days per year who have a severe chronic condition which results in a prolonged dependency on medical care or technology to maintain health and well-being and who: (1) experience periods of acute exacerbation or life-threatening conditions, (2) need extraordinary supervision and observation and (3) need frequent or life saving administration of specialized treatments, or dependency on mechanical support devices.”

Arkansas – “A condition in which the absence of immediate, health-related special-skilled care threatens the life or health of the student. A medical protocol is required to ensure a person’s safety. There is no foreseeable end to this condition.”

California – “Pupil who has an unstable life threatening physical health disability that requires monitoring and interpretation of signs and symptoms and interventions.”

Hawaii – “A student receiving special education services and requiring specialized healthcare procedures during the school day in order to receive a free appropriate public education (FAPE).”

New Mexico – “Those students whose health impairment is severe enough to require prolonged dependency on medical care or technology and require intense nursing services at school in order to maintain health and well-being. The health impairment will be characterized by periods of acute exacerbation or potentially life-threatening episodes and may require frequent hospitalizations or prolonged recuperation periods in home.”

Ohio – “A child to whom all the following apply: (1) requires the services of a doctor of medicine or osteopathic medicine at least once a week due to the instability of the child’s medical condition; (2) requires the services of a registered nurse on a daily basis; and (3) is at risk of institutionalization in a hospital, skilled nursing facility, or intermediate care facility for the mentally retarded.”

Texas – “A student receiving special education and related services who is: (1) in the age range of birth to 22 years; (2) has a serious ongoing illness or a chronic condition that has lasted or is anticipated to last at least 12 or more months or has required at least one month of hospitalization, and that requires daily, ongoing medical treatments and monitoring by appropriately trained personnel which may include parents or other family members; (3) requires the routine use of a medical device or of assistive technology to compensate for the loss of usefulness of a body function needed to participate in activities of daily living; and (4) lives with ongoing threat to his or her continued well-being.”

Virginia – “Children with a chronic condition and/or who require technology or ongoing support to prevent adverse physical consequences.”

This report was supported by the U.S. Department of Education (Cooperative Agreement No. H326F000001). However, the opinions expressed herein do not necessarily reflect the position of the U.S. Department of Education, and no official endorsement by the Department should be inferred.

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