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Medical Procedures and Nursing in Schools

by Susan Agrawal

Many children with complex medical issues require medical procedures during the course of the school day. These may be as simple as administering a dose of medication or giving feeds through a feeding tube, or as complex as monitoring settings on a ventilator. As more children with medical technology are living longer and living at home, these children are attending school just like their peers. How to handle their medical needs is a somewhat tricky issue for many families, and definitely a source of fear for lots of parents.

Case Law

We are fortunate that court decisions and legislation over the past twenty or so years have made it possible for our children to attend school, even if they are very medically complicated. Cases such as *Tatro* and *Garret* have enabled even children who are extremely complex to attend school.

The first of these important cases is *Irving Independent School District versus Tatro*, a case that ultimately went to the Supreme Court and was decided in 1984.[1] In this case, brought on behalf of an eight-year-old girl with Spina Bifida, the school district refused to provide intermittent bladder catheterization to the child, despite the fact that the procedure could be performed by a layperson with less than an hour's training and the child could not attend school without receiving the procedure. The case went through multiple appeals and reversals and was ultimately decided in favor of the child by the Supreme Court.

The precedents established by *Tatro* are paramount. It sets up two stipulations that are vital: that medical procedures are "related services" under special education law, and that they are by definition school health services performed by a nurse, layperson, or another non-physician provider. "Related services," a category within special education that also includes things like transportation, physical therapy, and psychological services, are required to be delivered to children with special needs. In other words, related services are necessary provisions that allow a child to participate in school and receive the free education she is entitled to by law. By determining that health services can be provided by a nurse or layperson, this case also distinguished between the provision of medical services (by a hospital or physician), which do not need to be provided by a school, and the services of a nurse and ancillary staff, which do.

Over the next 15 years, there were multiple cases that clouded the law. As more children with complex needs began to attend school, several cases for children with substantial needs, including ventilator use, were decided in directly opposing ways. Some determined that schools did need to provide intensive nursing, including 1:1 nursing for certain students, while others found that these children's needs were simply too medical and placed an undue financial burden on the schools.

In 1999, the Supreme Court decided the case of *Cedar Rapids Community School versus Garret F.*, a case that settled this issue with certainty in favor of the child.[2] Garret F., a young child paralyzed from the neck down, required bladder catheterization, suctioning and tracheotomy care, ventilator monitoring, monitoring of his vitals, and emergency procedures due to ventilator malfunction or autonomic issues. Garret was cognitively intact, in a regular classroom, able to communicate, and able to drive his own powerchair.

In this case, Garret's needs required 1:1 nursing, and his school district believed his needs were so complex that they qualified as excluded "medical services" and not related services that could be provided as school health services by a nurse. In addition, his school district argued that continuous services that could not be provided by existing staff placed an undue financial burden on the school district. Despite the cost of the care required, the Supreme Court determined that Garret was entitled to any medical care that could be performed as a related service by a nurse under *Tatro*. This case guarantees that even children with the highest levels of medical complexity can attend school, as long as they can be cared for safely and appropriately by a nurse or layperson.

Implications of the Law

These two Supreme Court decisions require all school districts within the United States to provide health or medical procedures to children who need them in order to attend school. The district is financially responsible for arranging the appropriate level of care, whether that means having a trained layperson in the school, a nurse on site, or a 1:1 nurse with a given child.

These rulings encompass every procedure that can be performed by a nurse, including but not limited to bladder catheterization, tube feedings, tracheotomy care, suctioning, ventilator care, monitoring of vital signs, administration of Oxygen, administration and care of intravenous nutrition or medication, and administration of medications, including narcotics, by any standard method.

Any school-age child who receives one or more of these procedures and is deemed stable enough to attend school by a physician is entitled to nursing or lay health services in order to make school attendance possible.

Nurse or Layperson?

What these cases do NOT make clear is who must provide the services. Greater attention to this matter is definitely necessary. At this time, each state and district is allowed to determine the appropriate delivery of medical procedures, as long as they follow state, federal, and local laws. In general, most of these procedures are guided by state nursing acts and education acts, and not by federal legislation.

There are some procedures that are standardized throughout the United States for the most part. In almost all locales, tracheotomy and ventilator care must be provided by a nurse (LPN, LVN, or RN), or, in some cases, a respiratory therapist. Similarly, all children who require intravenous medication, nutrition, or care of an intravenous line must be cared for by an RN.

Apart from these standards, the majority of other procedures can be delegated to a layperson, depending on state guidelines. Many states require that a nurse determines a protocol for each child and then trains appropriate members of the staff, which may include a classroom aide, paraprofessional, welfare attendant, or even a teacher. In some cases, parents are permitted to train staff on certain procedures.

Because guidelines vary so much from state to state, it is difficult to outline what the correct procedure may be for a given child. In general, procedures such as bladder catheterization and monitoring of vital signs may be done by any trained layperson. Other procedures, such as suctioning, tube feeding, and distributing medication, are more likely to be performed by a nurse, but may be provided by a trained layperson in some locales.

In a brief survey of tubefeeding families, roughly half the children received feeding and care from a nurse, while the remainder were cared for by an aide or teacher (or both). Almost all children with trachs were cared for by nurses.

Problems with the Current System

The current system is fraught with problems. With no clear designation of who should be providing school medical care to children with complex needs, as well as the ongoing funding problems of schools and especially special education, schools are often shifting the burden of medical care to teachers and aides. These individuals, who have no formal medical training most of the time, are being asked to perform procedures that are well beyond their job descriptions and may even interfere with their ability to provide educational instruction.

In addition, schools have cut back on school nurses dramatically, meaning that many children end up in a school that does not even have a nurse on site. This can be an enormous problem for many families. For example, several parents of children with

feeding tubes have remarked that their schools will only allow a nurse to replace the feeding tube, but that the school does not have a nurse on site. Instead, schools are supposed to notify either the parent or Emergency Medical Services. Not replacing the tube immediately, which is as simple as replacing an earring, can lead to painful dilations or surgery for a child.

Other families have complained that only nurses are allowed to administer rectal emergency medications, such as Diastat to stop seizures, or give injections, such as insulin for children with diabetes. If a nurse is not present in the building, either the parent must come to the school or Emergency Medical Services must be called. In both of these cases, time is of the essence, and serious and life-threatening complications may occur if medication is not administered quickly. This lack of on-site nurses creates an unsafe medical environment for many children.

Finally, with schools perpetually short on money, some children who should be receiving nursing services simply are not, with these services provided by teachers or aides instead. Schools tend to set the barrier for nursing very high, and often do not feel the need to have a nurse on site. Similarly, children with very complex medical issues who should have 1:1 nursing often are deprived of this service due to high costs. This is medically unsafe for these children and puts schools, as well as teachers and aides, in a very dangerous situation liability-wise. It also places a burden on parents, who must fight for what level of care they believe their child requires, a difficult proposition when there are no state or federally accepted standards.

Least Restrictive Environment

Special education legislation, specifically the Individuals with Disabilities Education Act [IDEA], states that children must be placed in the Least Restrictive Environment that meets their needs. In general, this means that most children are included in regular classrooms for part or all of the day.

For children with complex medical issues, it is permitted that they be placed in a different school that may already have a nurse or established nursing protocols in place. As long as the school can provide the appropriate type of classroom and services, the law permits districts to transfer children in this manner from their neighborhood schools.

In addition, there have been case challenges about where medical procedures can take place within the school. Thus far, procedure placement has been left to the discretion of the nurse or layperson performing the procedure, meaning that a child may be removed from the classroom for suctioning, tubefeeding, and other procedures if the nurse feels it is in the best interest of the child's health.

Children in Preschool Settings

Preschool presents somewhat of a challenge when it comes to the laws described above. Because preschool is neither universal nor required and is governed in part by different laws than primary school, the cases cited above are not necessarily applicable to all preschool-aged children. For example, IDEA makes it possible for states to continue educating preschool-aged children through Part C or Early Intervention services.[3] If this is the case, these children are bound by the regulations of Early Intervention and not Special Education. Moreover, IDEA provides an exclusion for states whose state laws prohibit or do not authorize education for any children aged 3 to 5.[4] Similarly, private preschools, including some that receive federal financing, are also not required to provide extensive health services to a child, but rather only reasonable accommodations.

Because of these exclusions and vagaries, preschools have been known to refuse health services for some children. At this time, it is untested as to whether a child in a public preschool special education setting (or a child with a 504 plan) is entitled to a 1:1 nurse or other intensive health services. Many districts have their preschool programs follow the same rules and regulations as their primary schools, which means that most children in preschool programs are receiving the nursing they need. In addition, since many preschoolers only attend school for a half day, most children who do need 1:1 nurses and who are part of state Medicaid waiver programs have enough assigned nursing hours to provide them with nursing during school hours. But since this issue has not been challenged in court yet, it is unknown whether all public or federally-funded preschools are required by law to provide intensive nursing.

Recommendations

Here are a few recommendations to improve nursing and medical procedures in schools:

- Every school needs a nurse on site at all times. This nurse can meet the needs of the majority of children in any given school.
- Teachers should not be asked to perform medical procedures, except in emergency situations.
- Nurses may train an aide or paraprofessional to perform basic medical procedures. These procedures should be restricted to simple procedures determined by the difficulty and risks of the procedure.
- In an emergency, any trained staff member may administer medication (such as an Epi-pen).
- Children with complex medical needs, such as children with a tracheotomy, ventilator, central line, or physiologic instability, require 1:1 nursing.
- These requirements should be extended to the preschool level for children with special health care needs who attend public schools or other federally-funded programs.

[1] See http://www.wrightslaw.com/law/caselaw/ussupct.tatro.htm at Wrightslaw for an overview of this case.

[2] See http://www.wrightslaw.com/law/caselaw/case_cedar_rapids.html for the Eighth Circuit case and http://www.wrightslaw.com/law/caselaw/case_Cedar_Rapids_SupCt_990303.htm for the Supreme Court decision.

[3] "[C]hildren with disabilities who are eligible for services under section 619 [special education for children 3-5] and who previously received services under [Part C Early Intervention Services] until such children enter, or are eligible under State law to enter, kindergarten or elementary school, [may continue receiving these services] as appropriate, provided that any programs under this part serving such children shall include-- (I) an educational component that promotes school readiness and incorporates pre-literacy, language, and numeracy skills; and (II) a written notification to parents of their rights and responsibilities in determining whether their child will continue to receive services under this part or participate in preschool programs under section 619." IDEA section 632.

[4] "The obligation to make FAPE available to all children with disabilities does not apply with respect to the following....Children aged 3, 4, 5, 18, 19, 20, or 21 in a State to the extent that its application to those children would be inconsistent with State law or practice, or the order of any court, respecting the provision of public education to children of those ages." IDEA section 300.102.