

THE TECHNOLOGICALLY DEPENDENT/MEDICALLY FRAGILE AT RISK STUDENT

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This article considers our current technologically sophisticated educational system as it attempts to meet the needs of a school population that is more diverse, needy, and exceptional than at any other point in history. The very nature of the term 'at risk' is based on the perception that students may dropout due to their living situation which affects their academic lives. Within this at risk population there is a further level of need which includes students who are at risk of not only failure in school but also are identified as medically fragile/technology dependent (mf/td). It is this mf/td designation that is illuminated as these students require onsite complex medical care to manage 'multiple' risks via technologic support, multiple team member efforts, and coping mechanisms just to complete each day.

The current technologically sophisticated educational system attempts to meet the needs of a school population that is more diverse, needy, and exceptional than at any other point in history. Educators quickly realize the special needs of students as children encounter difficulties academically and socially. The very nature of the term *at risk* is based on the perception that students may dropout due to their living situation which affects their academic lives. Our at-risk population continues to grow daily as *an increasing number of young people live in conditions characterized by extreme stress, chronic poverty, crime, and lack adult guidance* (Parkay, Hardcastle Stanford, Vaillancourt, Stephens, 2005, p.185). Within this at risk population there is a further level of need and this level includes students who are at risk of not only failure in school but also are identified as medically fragile/technology dependent (mf/td). The mf/td label is most often due to medical conditions requiring complex care. To meet the needs of these mf/td students who are at 'multiple' risk requires technologic support, multiple team member efforts, and coping mechanisms just to complete each day (Rehm, 2002).

Educators have no choice when confronted with the needs of mf/td at risk students. These students rely on family, school and the community at large to meet both their academic and health needs. Educators must work within a team as the education of mf/td at risk students demands a modified environment which is complex yet *the use of technology should not drive the vision. The vision should drive the use of technology* (Surgenor, 1992, p. 137). Our human capacity to take and shape technology is foremost in deciding just how much inclusion may be possible for each student hence the most meaningful change in schools is that which comes from within. Education and the educators within undertake a personal journey that is influenced by many forces that are in some way related to technology which *is so deeply intertwined throughout our lives that it is sometimes hard to recognize, because of its pervasive nature* (Ortega & Ortega, 1995, p. 11). Educators reflect, create and improve learning for all students so if the mf/td student requires medical devices to aid function, avert death, and maintain life support during each school day (Winzer, 2002), teachers will work to meet or exceed these targeted outcomes.

Current State of Affairs

The current labels *technology dependent* and *medically fragile* can best be defined as circumstances that require technological health intervention(s) to support life functioning. A

medical device or health intervention is required to maintain body function and often life itself. In the United States, it is *estimated that between 11,000 and 68,000 children were reliant on technology* (OTA, 1987, p. 6), and it is plausible that given the requisite supports each person could attend their community school. Each year there has been a slow augmentation of these numbers as technologic and medical advances continue to increase the odds that a td/mf person can live longer and more fully than previously expected. The American Academy of Pediatrics (1999) has similarly noted that there have been *increases in the population of children who have serious chronic conditions, in part, because of improvements in survival rates for children with serious and/or life-threatening genetic, congenital, and postnatally acquired conditions (eg., cystic fibrosis, organ failure, cancer, human immunodeficiency virus, or severe prematurity)* (Rehm, 2000, p. 2).

In Ontario recent data compiled by the Ministry of Health – Long Term Care (MoHLTC) Office of Integrated Services for Children suggests a prevalence rate of .057% within the Ontario population (Waterloo Region District Health Council, 2001, p. 4). This Health Unit estimates that approximately 1700 children in Ontario are considered td/mf. Each of these students may have the opportunity to attend school if the essential supports, team efforts, and vision are created within the local school and community. However, the Provincial Health Planning Database (2000) suggests,

the number of children with disabilities living in a geographic area is influenced by the array of services available in that area. Therefore, more urbanized parts of the district may have larger numbers of children in need of services than in rural areas. (p. 14)

Parents are attracted to an area that has expertise, services, and community supports that are essential for their child's complex health and educational needs. Table 1 shows the number of children & youth with varying disability levels throughout a district and Ontario, in 1996.

Table one is summative yet lacks details of specific needs of individuals and the medical circumstances of each person. For instance, Td/mf students include many types of health exceptionalities such as, arthritis, cerebral palsy, clubfoot, hydrocephalus, limb deficiencies, multiple sclerosis, muscular dystrophy, scoliosis, and spina bifida. While there are many more health conditions that may be housed under the umbrella term of td/mf these seem to be most common in children and youth who attend school. Within our communities as this population of complex care students grows, they become more visible, known, and newsworthy in community planning. This leads to "activism by people with disabilities, their family members, and other advocates who have sought equal access to public services and facilities for all persons regardless of health or mobility status" (Rehm, 2000, p. 3).

School and Community Supports

Within the school community and the political make-up of most regions is a complex series of relationships that allow support agencies to exist in a collaborative manner. For example, in January of 2000 The Integrated Services for Children Division (ISCD) was put into place to direct the Long Term Care (LTC) services in Ontario which are provided by Children's Treatment Centres (CTC). CTC's in turn are responsible for in home support to children who are not able to access services outside of the home. In addition, the CTC also includes a School Health Support Services program. This vital program enables students to attend school while receiving Long

Term Care (LTC) services. Each Children's Treatment Centre offers LTC services to children and youth who are able to be moved to attend. Most often children's LTC services can be defined as

those community-based health and support services that are available for children with multiple special needs and/or complex care needs (Waterloo Region District Health Council, 2001, p. 5).

Table 1
The number of children & youth with varying disability levels throughout a district and Ontario, in 1996.

Geography / Age Category	Population	General Disability Rate (6.9%)	Multiple Special Needs Rate (2%)	Complex Care Needs Rate (.057%)
Waterloo Region				
0-4	30,433	2,100	609	17
5-19	88,588	6,133	1,772	50
Total (0-19)	119,021	8,212	2,380	67
%	(28.5)			
Total Pop.	418,334			
Wellington-Dufferin				
0-4	16,285	1,124	326	9
5-19	48,323	3,334	967	28
Total	64,608	4,458	1,290	37
%	(28.9)			
Total Pop.	223,745			
District				
0-4	46,718	3,224	934	26
5-19	136,911	9,447	2,738	78
Total	183,629	12,670	3,673	104
%	(28.6)			
Total Pop.	642,079			
Ontario				
0-4	756,053	52,168	15,121	431
5-19	2,221,814	153,305	44,436	12,66
Total	2,977,867	205,473	59,557	1,697
%	(26.8)			
Total Pop.	11,100,876			
<i>Sources: Provincial Health Planning Database, 2000 (Population Figures); Statistics Canada (1996).</i>				

An example would be a student with cystic fibrosis who requires percussion therapy, to extricate mucus from their upper body, medication, and a strict diet to compensate for inadequate (pancreas) organ function. In order to better understand the levels and groups of required care the The Office of Integrated Services for Children (1999) designed the following table. (Table 2 next page)

When faced with such complex care it is common for most educators to feel inadequate. Indeed, Rehm (2002) makes it clear that,

school personnel have regular and increasing contact with children with chronic conditions and that they often feel inadequately prepared to understand the nature of children's health concerns or to handle medical emergencies in the classroom (Krier, 1993). School nurses and aides deliver most routine health treatments in the classroom, including medication administration, respiratory treatments, diapering or catheterization, and tube feeding (Koenning, et al., 1995). Parents and school nurses provide most of the information educators receive about children's health care needs

(Koenning, et al., 1995). Practicing physicians are not often active participants in planning for health services and special needs for children with chronic conditions (Palfrey, Singer, Walker, Butler, 1986). Despite the importance of school nurses as on-site resources for educators planning services for children with special needs, nurses are often "shared" by several schools and therefore not necessarily included in evaluations and planning for special education services. (p. 6)

Table 2
Definition of Children who are MF and/or TD with Complex Care Needs

Group No.	Care Requirements
Group 1	Children dependent at least part of each day on mechanical ventilation
Group 2	Children requiring prolonged intravenous administration of: <ul style="list-style-type: none"> <input type="checkbox"/> nutritional substances <input type="checkbox"/> drugs
Group 3	Children with daily dependence on other device-based support for: <ul style="list-style-type: none"> <input type="checkbox"/> Tracheotomy tube care <input type="checkbox"/> Suctioning <input type="checkbox"/> Oxygen support <input type="checkbox"/> Tube feeding
Group 4	Children with prolonged dependence on other devices which compensate for vital body functions who require daily or near daily nursing care, including: <ul style="list-style-type: none"> <input type="checkbox"/> Apnea (cardio respiratory) monitors <input type="checkbox"/> Renal dialysis due to kidney failure <input type="checkbox"/> Urinary catheters or colostomy bags plus substantial nursing care
Group 5	Children with chronic conditions who are not technologically dependent but who require as great a level of care as Group 4, including: <ul style="list-style-type: none"> <input type="checkbox"/> Children who are completely dependent on others for activities of daily living; <input type="checkbox"/> Children who require constant supervision or monitoring resulting from the complexity of their condition and/or the quantity of oral drugs and therapy they receive.

(The Office of Integrated Services for Children, 1999)

In addition to the educators, special educators, nurses, teacher aides, administrators, and parents there could be several other team members in place to support a Td/mf student. These include Occupational Therapists, Physiotherapists, Speech-Language Pathologists, Social Workers, Psychologists, Psychometrists, Augmentative Communication Technologists, Recreation Therapists, Homemaking services, Personal Support Aides, Attendant Services, Dietetic services and Respite services for families caring for medically fragile and technologically dependent children. With larger teams there are points of tension, errors, and this only heightens the risk for the already at risk td/mf student.

Locally, a Central Ontario Board of Education has put in print a document entitled: *Building the Future Together: Strategic Planning Toward the Year 2000*. The resource suggests educators must be *committed to providing the best possible educational opportunities through which each student may develop the necessary knowledge, skills and attitudes to become a responsible, contributing participant in a changing global society* (Muskoka Board of Education, 1999, p. 48).

This inclusive vision is proactive yet when faced with the complex care and educational needs of a Td/mf at risk student the entire team needs to develop and embrace similar values, expectations, and outcomes in order for the team strategy to succeed via careful planning, application and maintenance. As well, there needs to be community support such as the Parents of Technologically Dependent Children (PTDC) of Ontario Kids Country Club with organizations in London, Guelph, and Cambridge, Ontario as these vital community supports *strive to create a community where all children are cherished through advocacy, support and respite services* (Parents of Technologically Dependent Children, 2003).

This organization of stakeholders includes parents, advocates, and the community at large who work closely with the Ministry of Community, Family and Children's Services and other professionals who often provide services in a volunteer mode. The vision of this community support group is to,

value each other and our friendships. Together we can hope and dream. Give us tomorrow but give us today where people have value and belong and the only label is their name. Together we will open doors that once were closed. Our needs may be different we can ensure the building of a caring community. Our children will live quality lives. But with respect for each other. (Parents of Technologically Dependent Children, 2003)

To attain some of these goals requires practical and assertive movement from educators who need to accept several contemporary realities:

Technology is an inseparable part of our daily existence.

Technology is with us from the moment we wake up until the time that we turn in at night.

Technology is even with us while we sleep.

Technology is at the heart of our buildings and structures.

Technology assists us in coping with the environment outside.

Technology is vital in transporting us from place to place.

Technology allows us to solve many of the challenges that face us.

Technology is something that strikes fear in the hearts and minds of people.

Technology intimidates.

Technology is complicated

Technology is advancing at ever-increasing rates.

(Lambton county Board of Education, 1994, p. 2)

Uncertainty can cause educators to put forward thoughts that all educators can and need to address. For instance, Wadsworth (1993) asks, *Help! Is this an Intensive Care Unit or a classroom?* Her paper offers practical suggestions for educators working with Td/mf students. Educators need to manage the physical environment (field trips, classroom layout & equipment), specialized equipment (modified desk, wheelchair desk, computer, audio, video), staff training, emergency response team & plans, student/family needs (peer relationships), counseling liaison, regular meetings (IEP, IPRC) for communication and monitoring (Wadsworth, 1993). What is implied is that there is a need to go beyond the Individual Educational Plan (IEP) and develop a written health care plan. The Health plan includes such items as monitoring and backup systems and schedules that detail frequency and duration of care at school. As well, the Td/mf students in regular classes (rather than special education classes) require more time to function, and transition. Health plans explain how nurses, aides, and caregivers will provide required follow-up activities.

Educators in Canada who work within Special Education attempt to do what is necessary to fulfill their obligations and comply with such imperative documents as the Canadian Charter of Rights and Freedoms, the Provincial Human Rights Code, the Provincial Education Act and regulations made under the act, and other relevant legislation. Most Boards strike committees such as the Special Education Advisory Committee (Ontario) to oversee the special education programs however, the hierarchy and number of stakeholders can slow a process and impinge on its effectiveness. An average Board of School Division would have a Special Education Superintendent, Manager of a Individual Placement and Review Committee, Coordinators of Special Education, Supervisors of Special Services, Office Supervisor/Administrator, Assistant Secretaries, (secretary IPRC/Psych/general secretary Special Ed), Psycho-educational Consultants, Speech & Language Pathologists, Child and Youth Counsellors, School Social Workers, Secretaries (MASS, OCTU), Regional Coordinator, and finally, the local school with its own stakeholders. What can happen, and usually does, is that information is mislaid and communication is deficient hence we then enter into a problem solving process that is often nicely laid out by the Board yet takes a great deal of time and energy to move through. Meanwhile the needy at risk Td/mf student attends school daily as stakeholders attempt to untangle themselves. Fortunately, the front line teacher is on the job each day unencumbered and taking care of the needs of all students.

Conclusion

Students have a right to an education and educators have a legal responsibility to educate all students including those who may be labeled Td/mf. Most Boards in Ontario have an integrated services delivery model for professional support services. Most often, the support is via the Special Education Advisory Committee with extended partnership agreements with community agencies that aim to enhance and expand the level of professional support services in its schools. By combining staff from each Board and the community agencies, three levels of professional support are most often offered throughout a region: clinical, targeted and universal. For example, universal programs target the student population as a whole while targeted programs focus on small groups of high-risk students and clinical programs provide interventions for individual symptomatic children. The complex care required for a Td/mf student would be considered clinical and as such be addressed on an individual case-by case basis. With rising numbers in Canada, it is only a matter of time before the training, support and expertise is more common, mainstream and available in all larger urban areas.

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