

■ Preparing Professionals for the Challenge of Children who are Technology Dependent: Understanding and Meeting the Social and Emotional Needs of Families

■ La préparation des spécialistes aux exigences imposées par les enfants dépendants de la technologie: Comprendre les besoins sociaux et affectifs des familles et y répondre

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Abstract

Professionals are frequently unaware of the complexity of issues faced by families of children who are technology dependent. Caring for children who are technology dependent at home has become the preferred service choice of families and health care providers. The benefits of having these children at home come at considerable social and emotional cost to families who assume the bulk of their care. In some instances, this care occurs without adequate community support and funding. The service delivery system has been slow to transfer such supports for children from hospital to home. This paper discusses the unique situation faced by families with children who are technology dependent and provides suggestions for how professionals and policy makers may improve the social and emotional supports for families.

Abrégé

Il arrive souvent que les spécialistes ne soient pas sensibilisés aux problèmes auxquels les familles d'enfants dépendants de la technologie doivent faire face. Le soin à la maison des enfants dépendants de la technologie est devenu, en matière de services, la méthode privilégiée par les familles et les fournisseurs de soins de santé. Les avantages des soins à domicile imposent un coût social et affectif considérable aux familles qui prennent en charge l'essentiel des soins. Dans certains cas, ces soins sont offerts sans un appui et un financement adéquat de la collectivité. Le système de prestation des soins tarde à transférer ces appuis aux enfants, de l'hôpital à la maison. Le présent mémoire se penche sur la situation unique à laquelle font face les familles d'enfants qui dépendent de la technologie et offre des suggestions sur la façon dont les spécialistes et les décideurs peuvent améliorer l'appui social et affectif aux familles.

Keywords: Evidence-Based Practice, Clinical Process, Evaluating Research

Many professionals are unaware of the complexity of the issues faced by families of children who are technology dependent (TD). Children who are TD require a medical device to overcome the loss of a vital body function in addition to ongoing and complex medical care to avoid further disability or loss of life (Wayne, Power, & Fox, 1988). These children may be dependent on various types of technology, with some dependent upon more than one technology. Most children who are TD are being cared for at home or in foster homes. While families and professionals choose home care as the best environment for the child, families provide the majority of care, often with little support from the community (Noyes, Hartmann, Samuels, & Southall, 1999). In some cases, families provide complex medical care that would typically be performed in hospital by trained medical staff. The health and social services system has been slow to transfer funding from hospital to home and to coordinate services in the community. The issues created by the service delivery choice of caring for children on a long term basis in the home have only recently begun to emerge (Quint, Chesterman, Crain, Winkleby, & Boyce, 1990; Thyen, Kuhlthau, & Perrin, 1999). As a speech-language pathologist who conducts research with children who have undergone long term tracheostomies, it is increasingly apparent that many professionals lack

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information about the nature of conditions faced by children who are TD, as well as about the services for these children. A more distressing finding is the lack of awareness concerning the emotional impact on families with a child who is dependent on technology. Results of qualitative and quantitative studies have shown that although many families care for their children at home, they are not receiving adequate social and emotional support (Alexander, Rennick, Carnevale, & Davis, 2002; Leonard, Dwyer Brust, & Nelson, 1993; Lumeng, Warschusky, Nelson, & Augenstein, 2001; O'Brien, 2001; Wegener & Aday, 1989).

Children who are TD are likely to require numerous services in the communities where they live, now and in the future. The population of children who are TD will remain constant or increase as more children survive early life-threatening illnesses and require long term care (Dhillon, Frewen, Singh, & Speechley, 1996). Health and social service providers are beginning to recognize the needs of these children and their families and are beginning to put the necessary service supports in place. However, this process will take some time and will require an integrated effort from families, service providers, and community and government agencies in order to meet the long term health needs of this population (McCormack, Iacono, & Whittingham, 2000).

The provision of adequate health and social services for children with technology dependence and members of their families is contingent in part on increasing professionals' awareness to the needs of families. With knowledge of the issues faced by families of children who are TD, professionals can begin to help families and to advocate for better coordination of services. Therefore, the purpose of this paper is twofold: 1) to increase professionals' knowledge and awareness of children with technology dependence, as well as of the needs of and stresses placed on families who care for their children at home, and 2) to provide professionals with practical suggestions for supporting and interacting with families.

What is Technology Dependency?

Children who are TD may require any number of technologies to sustain their lives. These may include a tracheostomy tube, gastrostomy tube, colostomy, intravenous care, monitoring for apnea, oxygen therapy, parenteral nutrition, dialysis, or mechanical ventilation (Fleming et al., 1994; Quint et al., 1990). Children who are TD fit into one of two major classifications based on whether the device sustains life (e.g. respirator) or compensates for the loss of a vital function (e.g. renal failure) (see Table 1). Children supported by either category of technology require ongoing care by a trained specialist or caregiver. Children can vary in the amount of technical support they need to survive; this may range from continuous support, to support only at night, to support in times of acute illness. The type and amount of support required will influence the child's ability to communicate, to move about, to socialize, and to engage in daily activities (Hamlett, Walker, Evans, & Weise,

1994; Kirk & Glendinning, 2002). These children comprise a subset of children who are chronically ill and disabled, but they are unique in the type of care that they require (Kirk, 1998). Like families of other children with disabilities, families of children who are TD need to find financial resources, to coordinate services, and to maintain healthy family relationships. Unlike other families, parents of children with technologies assume major responsibility for the ongoing, complex medical care of their children.

Table 1
Categories of Technology Dependency

Prolonged Dependence on Device Required to Sustain Life

Mechanical Ventilation
Intravenous Administration of Substances
Devices to Support Respiration or Nutrition

Prolonged Dependence on Device to Compensate for Vital Body Functions

Cardiorespiratory Function
Renal Function
Elimination of Body Waste

We might logically assume that families of children who depend on technologies to sustain life will be affected to a greater extent than families of children with technologies that support vital functions, and this assumption is supported by research (Fleming et al., 1994). Families of children dependent on technology to support vital functions typically did not experience financial burden, personal strain, or a social impact to the same extent of families of children dependent on technologies to sustain life. However, the impact of technology type on children and families is not always so straightforward. Children with technologies used to support vital functions lag behind children with other technologies in their development. Only 32% of children with technologies to support vital functions were reported to function like their same age peers (along with 37.5% of children dependent on intravenous support), while 74% of children dependent on mechanical ventilators functioned like their peers. While caring for a child with technologies in the home creates some financial burden regardless of the type of technology, families of children dependent on intravenous therapy (e.g., children with leukemia, children receiving intravenous administration of drugs or nutrition) or dependent on devices to monitor vital functions (e.g., cardio respiratory monitors, renal dialysis or urinary catheters) were most affected financially. These findings suggest that care is needed in planning for early developmental stimulation, home tutoring, and/or

schooling to help children who are TD keep pace with their peers academically.

How Many Children in Canada are Dependent on Technology?

It is difficult to determine the number of children who are dependent on technology in Canada. Because children require technologies throughout childhood and the types of technologies vary, there has not been a system established for documenting the incidence of technology use, or the duration of its use. A survey conducted in Toronto, Ontario in the late 1990s (McCormack et al., 2000) revealed that there were 249 children dependent on various technologies in the greater Toronto area. If we assume that there may be similar numbers in other large cities in Canada, there may be as many as several thousand children who are TD across Canada. Comparatively, Kirk and Glendinning (2002) speculated that there may be as many as 6,000 children dependent on technology in Britain. Children who are dependent on technology form a small set of the approximately 560,000 children aged 0-19 years with disabilities in Canada. Regardless of numbers, the important issues appear to be the complex and costly care needed to maintain good health in these children and the responsibility assumed by families in providing this complex care in the home. The unique health delivery situation created by home care requires the attention of professionals and policy makers independent of the numbers of children who will require such technologies.

Home Care as the Preferred Service Location for Children who are Technology Dependent

Caring for children with technology dependencies at home has become the preferred choice of families and health policy makers. Families are afforded better opportunities to integrate the child with the technology dependency into the family and school than if the child is cared for in hospital (Faroux, Sardet, & Foret, 1995). The cost of caring for a child at home also is less than if hospitalization continued for extended periods of time (Andrews & Nielson, 1988; Fields, Hardy Coble, Pollack, & Kaufman, 1991). Developments in medical technologies also have improved considerably in recent years, thereby allowing families the option to care for their children at home. Further, children are given more opportunities to acquire developmental skills at home than while in hospital (Lumeng et al., 2001). Despite the preference of many families to care for their children at home, families acknowledge the stresses that come with home care (Faroux et al., 1995; Murphy, 2001a; Thyen, Terres, Yazdgerdi, & Perrin, 1998) and this area will be discussed subsequently.

Potential Stress Factors for Families

Families are likely to experience social, emotional, and/or financial stresses when they provide home care for

a child who is TD (Kirk, 1998). A common issue for families is the social isolation that occurs when they spend considerable time in the care of the sick child, while balancing care of other children (Kirk & Glendinning, 2002; Murphy, 2001a). Friends may feel uncomfortable with the child who is TD and limit their visits to the family. Similarly, transporting the child to social events in which the family would normally participate may not be easy or convenient (Mentro & Steward, 2002) thus creating significant social limitations.

Emotional stresses may evolve from a number of issues with which families of children who are TD must contend (Sharkey, 1995). Families are faced with providing complex medical care at home that would normally be provided by experienced nursing staff in an intensive care facility (Glendinning & Kirk, 2000). Anxiety may evolve from fears about the nature of the care family members have consented to undertake for their child (Baumgardner, 1999). Families also have fears about the death of a child while in their care (Jennings, 1990). Some children with respiratory problems require monitoring at night and families frequently experience sleep deprivation. For some families whose child has been in hospital for an extended period, bringing the child home involves integrating the new family member into the home routine under less than ideal conditions.

Families also encounter financial stresses (Patterson, Leonard, & Titus, 1992). The funding provided to the child in hospital may not extend to home, leaving the family to pay for expenses out of pocket (Spalding, Hayes, Williams, & McKeever, 2002) which may place an added burden on the family. Home care of the child who is TD often requires that one parent reduce the number of hours worked or quit his/her job (Thyen et al., 1999). The loss of income can create a financial crisis, especially when some children require expensive equipment or supplies. Caring for a child at home will frequently require the additional support of nursing or care giving staff. The number of hours of care and services covered by health insurance varies by community and by province.

There can also be confusion for families about the roles that they assume when caring for a child at home (Ratcliffe, Harrigan, Haley, Tse, & Olson, 2002). Families frequently share the care and responsibilities with professionals, but this can lead to conflicts about who the experts are. Families who care for their child daily become/are the experts in caring for their child. They are faced with training caregivers who will look after their child. However, caregivers may consider themselves the experts, in turn leading to conflicts. Parents need to feel empowered and supported in the knowledge that they can competently care for their child and negotiate the health care system. Families of children who are TD have been shown to experience more stress than families of healthy children (Leonard et al., 1993). However, families of children who are TD do cope in similar ways to families with healthy children (Stephenson, 1999).

Families Will Vary in the Actual and Perceived Levels of Stress

Leonard et al. (1993) suggested that the level of stress experienced by families is dependent on a number of factors. These include: an individual's reaction to stress, the severity and type of technology dependency experienced by the child, the characteristics of the family (e.g., number of children, marital status), and the home characteristics (e.g., type and intensity of care provided for the child, financial support). Wegener and Aday (1989) showed that these factors interact to predict family stress and that some factors were better predictors of the long term health of families. Financial problems, length of time since discharge from hospital, number of extended family members in the same home, and complexity of the health care system without a case manager all predicted family stress. Likewise, Petr, Murdock, and Chapin (1995) showed how family characteristics combined with lack of social support or incoordination in the health care system to create situations that threatened a family's ability to continue to care for their children at home. Finally, Fleming et al. (1994) reported that the level of stress experienced by families varied with the type of technology dependency. Families with children who were respiratory or intravenous dependent experienced greater personal strain and there was more social impact on the family than for families with children who were monitored for vital functions (e.g., sleep apnea, dialysis, colostomy bags, etc.). Thus, professionals should carefully assess and respond to the individual needs of families, as families with children who are TD are not a homogeneous group.

The issues faced by families are not static, but change over time (Alexander et al., 2002; Mentro & Steward, 2002). For example, families may adjust to the daily routine of caring for a child with a technology dependency over a four to six month period, but the respite care they have come to rely upon may change, creating the need for adjustment to a new situation. Ratcliffe et al. (2002) described a model of family functioning based on four major stresses identified in the literature. The major stresses were role conflict, financial burden, care burden, and independence. This model is arranged as a matrix where the family, child, caregivers, and the health care system interact with the four stresses or themes. Families can experience extreme isolation in caring for their child (on the negative end of a continuum), or with proper social supports, care providers, and respite care, they can achieve some independence (on the positive end of a continuum). The health care system can present rigid boundaries or multiple access points for services, or little information about how/where to receive services. In contrast, a case manager can communicate regularly with families and help them to secure the services needed at home and in the community. Although the presence of a stress factor does not necessarily create ongoing difficulties for a family, a family's perception of the importance of the factor or the presence of social support can mediate the effects of the stress (Patterson, 2002; Stephenson, 1999).

Assessment of Family Stress

Burke, Kauffmann, Harrison, and Wiskin (1999) published a checklist for assessing stress in families with children with chronic health conditions. The *Burke Assessment Guide* includes 11 key areas of stress for families. These include: gaining knowledge, skills and experience, managing care of the child, managing physical resources and equipment, managing sibling issues, maintaining spousal and parental relationships, establishing and maintaining social support, maintaining health of family members, rearing a child with chronic conditions, maintaining good relationships with the health care system, and developing beliefs, values, and a philosophy of life. The components of this guide can be helpful to professionals in identifying a family's current needs and areas of stress.

Communicating with Families in a Family Centered Way

Family centered service is a philosophy and method of service delivery for parents and children. This service delivery approach highlights the formation of partnerships between professionals and families. Parents are seen as the experts in their child's needs and the family plays a major role in deciding what care their child receives (Rosenbaum, King, Law, King, & Evans, 1998). A family centered approach is especially important in the treatment of children who are TD (Brewer, McPherson, Magrab, & Hutchins, 1989). Families are asked to conduct complex medical procedures in their homes under the guidance of medical and social support personnel. This unique situation and the disruption to the normal family routine, as well as to parental and spousal roles, call for excellent communication between parents and professionals. Both professionals and parents need to recognize the reversal of normal roles in order to help the family provide the best care possible while the family ultimately assumes the major responsibility for the daily care of the child.

Communication with families ideally begins while a child who is TD is in hospital. Families who bond with their child, are involved in his/her care while in hospital, and show an ability to assume the care are more likely to make the transition to caring for their children at home when compared to families who are less involved (Cross, Leonard, Skay, & Rheinberger, 1998). Cross et al. (1998) found that family factors accounted for 20% of the variance in the length of time children remained in hospital once medical readiness for discharge was established.

Empowering Families

Working with families in a family centered manner has the ultimate outcome of empowering families. Empowerment is defined as an ongoing process in which individuals and/or families gradually assume more responsibility for their children's care and greater participation in the decision making about their children (Hulme, 1999). Gibson (1995) viewed empowerment as a

personal process by which frustration with the health care system serves as an impetus for parents to reflect critically on their situation and to start to take charge (i.e., advocate for the child and establish partnerships with professionals). Hulme (1999) showed that empowerment was an ongoing process and that the service delivery process moves from one that is dominated by professionals to one where parents begin to actively participate in the process. Parents begin to challenge professionals in the decision making and begin to negotiate with professionals about their child's care. Finally, parents and professionals collaborate in the provision of care to the child; parents assume more and more responsibility and rely less on professionals. Professionals need to be aware of the process of empowerment and recognize that as their role decreases, parents become empowered to take more and more responsibility in decision making for their child. Providing information so parents can make informed decisions is critical in the initial stages of a child's illness. Negotiating with families about the best services for their children is a healthy and necessary process and a signal that families see themselves as important partners in the decision making process.

What do Families Want in their Interactions with Professionals?

Families have specific ideas about the care they wish to receive from professionals. What families value in interactions with professionals is not unlike the values of many parents who depend on long term services for their children. Stubblefield and Murray (1999) interviewed 15 parents of children with chronic lung disease and found that families valued respectful care for them and their children, as well as the continuity of care over time. Parents also wished to be collaborators with professionals about their children's care. Sometimes this collaboration led to having negotiations with professionals and the health care system and parents sometimes had to give up some individual roles to work toward common goals for their children. Gibson (1995) has shown that encouragement from professionals contributed to the process of empowerment for mothers, with mothers gaining a sense of being connected with the outside world through these supportive relationships with professionals. Table 2 outlines some of the aspects of the personal and collaborative process that parents value. In summary, parents want an active, collaborative role with professionals. This collaboration involves give and take for both parents and professionals.

When Does the Child's Discharge Home Occur?

Children who are TD are discharged home when their medical condition is stable and when it is judged that their condition can be managed safely at home by family and support nurses. This decision occurs when the risk to the child receiving care at home is acceptable and the quality of life to be gained from being at home outweighs the medical risk (Cross et al., 1998). Discharge also is based on the

Table 2
What Families Value in Parent Professional Interactions

Personal Process

- To be treated as individuals
- To have a trusting relationship on an ongoing basis with the same professional
- To have children treated by professionals as if they really matter
- To have professionals act in the best interest of the family
- To be acknowledged for the efforts that parents bring to caring for their children

Collaborative Process

- To gain information about the health status of their children
 - To be part of planning children's plans of care
 - To be part of future plans for their children and to know what to expect about future development/progress
 - To be considered a contributing member of a team of professionals
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family's willingness and ability to assume a major portion of their child's care. There also need to be adequate supports in the community to assist the family prior to discharge (Storgion, 1996). This process requires strong and open communication between families and professionals. It also requires training of parents and support staff, as well as insuring that access to various community supports is put into place. However, not all families may be ready or able to care for their children at home. Realistic recognition of the skills and supports the family can bring to the care of their child at home must occur. Some children are placed in foster care temporarily, or in some cases permanently, to receive the complex care required. Families should not be made to feel guilty for not caring for their child at home if the prerequisite skills do not exist and supports are not available (Hamlett et al., 1994; Murphy, 2001a). By choosing the optimal care option, both the children and families are ideally served and supported.

What are the Critical Elements of a Discharge Plan?

A number of researchers have discussed the key elements of a discharge plan for providing complete and safe care of the child with technologies in the home. Many plans include preparation of the physical environment (e.g., beds, equipment, supplies, electrical outlets, etc.) and the training

and selection of caregivers (e.g., parents, nursing staff). Most plans also identify and align the key people who will contribute to the child's care (e.g., physician, hospital, equipment companies, home nurses, etc.). More recently, discharge plans include resources that enable families to receive emotional and social support (e.g., friends, family, other families with children who are TD, case manager, etc.). Table 3 presents the key physical, personnel, and social and emotional resources that should be incorporated into effective discharge plans.

Table 3
Key Elements of a Discharge Plan for
Caring for a Child with Technologies at Home

Communication

Development of discharge plan with family
Update plan to reflect changes in child's condition and needs within family

Identification of Key People

Primary caregivers (2)
Physician
Nurses
Case Manager or Service Coordinator

Identification of Community Agencies

Medical equipment supplier
Nursing agency
Provider of respite care
Hospital
Pharmacy and laboratories
School
Health unit
Government ministries

Physical Resources

Home environment able to support care and equipment
Equipment in place
Transportation/Van available

Training and Information Sharing

Training of parents
Training of nurses and other professionals in community

Emergency Services

Local agencies help in case of power outages
Transport in case of medical emergency

Personal Resources of Family

Social and emotional resources and contacts identified

The family is an essential partner in the development of the discharge plan and plans are more likely to succeed when parents and professionals work as a team (Bond, Phillips,

& Rollins, 1994). Lewis, Alford Winston, Billy Kornas, McCaustland, & Tachman (1992) suggested that professionals must gain input on the family's needs, home routines, support systems, the assessment of their ability to care for their child at home, and the family's goals for their child's future. Communicating with families and developing a realistic assessment of the abilities and needs that the family will bring to the care of their child at home is essential to its success, and knowledge of the family's needs is essential. Additionally, knowledge of the family's routines assists with incorporating care within the structure of the family's activities. Families should always be asked about their perceived ability to care for their children and abilities should not be assumed (Parette & McMahan, 2002). Some families reported feeling obligated to care for their children at home when no other options for provision of complex care were available (Kirk & Glendinning, 2002).

Dokken and Sydnor Greenberg (1998) suggested that the best way to help families adjust to the care of a child at home is to help them organize their personal resources prior to discharge. By having families coordinate their resources with a professional's help, families are better prepared and emotionally ready for the realities of home care. This process first involves formulating a list with all areas that need to be considered at home and then providing a contact person who can provide assistance in each area (e.g., someone who can help with grocery shopping, provide parent to parent support, or accompany a sibling to a weekend soccer game). These authors recommend that families organize other family members, professionals or neighbors who can offer assistance in each of the following areas: housekeeping, cooking, care of siblings and their activities, transportation, information and support services, companionship, communication, and overall coordination of the family's schedule.

Throughout the literature the need for families to have a professional who serves in a coordination role predominates (Canadian Association for Community Care, 1996; Fleming et al., 1994; Kirk & Glendinning, 2002; Radford & Thorne, 2001). This idea is prevalent in articles based on services in Canada, the United States, and the United Kingdom. Lewis et al. (1992) outlined a coordinator's role as consisting of: (a) the assessment of a family's needs, (b) development and selection of support services directly with the family, (c) monitoring the child's medical care and health status on an ongoing basis, and (d) serving as a advocate for the family and/or collaborator with other professionals. Families can become overwhelmed with the care of the child, maintaining the typical family routine, and interacting with the health care system. The service coordinator can assist and guide the family through their navigation of the health care system and in finding resources for the family in the defined areas of need.

The case manager or service coordinator serves as a constant in a family's life and his or her role frequently spans several years. They play an important role in monitoring the care and support that a family receives from multiple

agencies in addition to serving as a neutral party (i.e., separate from the family or direct service providers) capable of assessing the quality of the care (Lewis et al., 1992). The case manager also coordinates all the services the family receives within a community and, as a constant contact with the family, can facilitate ongoing communication. The case manager also advocates for the family's needs (e.g., finding needed financial and/or social supports and adequate programming for the child). The use of case managers is viewed as the best method of providing an integrated program of emotional, practical, and information level supports for families (Petr et al., 1995; Spalding et al., 2002; Thyen et al., 1999).

Supports — What Families Want

Most researchers agree that the type of intervention provided for families of children who are TD should be one of family support rather than acute response to a crisis (Petr et al., 1995). Families require ongoing supports for several reasons. Children who are TD will be chronically ill and they and their families will need intervention, perhaps for years. The nature of the illness and the necessary adjustment to a family member who is TD is a dynamic process. Families will face numerous situations that require unique planning and problem solving to resolve (Mentro & Steward, 2002). These situations will occur over time and will likely only be resolved through the help of family members and various social supports. The specific types of support important to families have been described in the literature (Kirk, 1998; Kirk & Glendinning, 2002).

Kirk (1998) describes three levels or categories of support: emotional, practical, and the provision of information. Families report the important need of having a professional who will be there for them and whom they can trust. Families also benefit from professionals who advocate for them and their children by finding financial and social resources in the community. Knowing where to seek help and then navigating the service delivery system can be overwhelming for families; therefore support is essential. Finally, families need information about the nature of their children's conditions, care procedures, and service delivery options in order to provide the best care.

Kirk and Glendinning (2002) interviewed 24 families with children who were TD. Families expressed the importance of receiving emotional support. Several specific types of emotional support were reported as beneficial to families: having professionals be there when needed, having professionals listen and counsel, and having professionals who promoted self-confidence. Families noted the importance of being able to contact a person who was familiar with their child and the security of knowing that the professional was accessible when needed. Parents also expressed the importance of having someone to talk with who understood their needs and concerns. Finally, parents served as the experts, yet wished to get reassurance from professionals that they had made the correct decision or were following correct procedures. Although families have

articulated their needs to professionals, these needs are not always met.

Critical, Yet Overlooked Areas of Support

Support for the Primary Caregiver

Several areas related to providing social and emotional supports for families have been frequently overlooked or not adequately addressed. For example, because mothers frequently provide the bulk of the direct care for a child who is TD, they may need to give up employment to care for their children and in doing so eliminate an outlet for time away from constant care. The mental health of some mothers may be affected (Leonard et al., 1993). Therefore, professionals should work closely with families to seek solutions to balance provision of care with financial needs of families and with emotional release from constant care. Mothers may benefit from working outside the home for part of the time, not only to improve family financial resources, but also for the emotional wellbeing of the primary caregiver (Thyen et al., 1999). However, poorly trained caregivers may provide additional and unnecessary stress for parents who worry whether their child is receiving proper care while the parents are working outside the home (Leonard et al., 1993). Thus, putting quality caregivers in place is essential for parents to be able to work without significant stress.

Finding Appropriate School Placements for Children with TD

Educational placements for children with technology dependence may not always be adequate or accessible. Professionals can play an important role in bringing families and school personnel together to develop appropriate programs for children who are TD. Transportation to school also may need to be arranged. Those children whose technologies include prolonged dependence on devices that support vital body functions (e.g., cardio-respiratory monitors, renal dialysis, colostomy bags, etc.) were shown to perform the poorest academically of children who are TD (Fleming et al., 1994). Therefore, some children who are TD will need individualized educational programs beginning with developmental stimulation at home to keep pace with their peers.

Finding Opportunities for Family Recreation

Families of children who are TD have fewer opportunities for recreation than families with healthy children (Thyen et al., 1998). Professionals need to assist families with arranging recreation activities as a family or individually. Community agencies may also need to be aware of the challenges faced by families in using their facilities for recreation. Ramps to swimming pools or wheelchair access to buildings can improve access for these individuals. Staff who supervise recreational activities may require additional training in how to include those with

technologies in recreational activities, sporting events, or public entertainment. Participation by those with technologies, as well as by members of their families, is important for their acceptance as part of the community, engagement in activities other families perform, and expanding social interactions with others. For example, Lumeng et al. (2001) showed that participating in a variety of activities was associated with greater life satisfaction for children who are ventilator assisted.

Obtaining Respite and After School Care for Children who are TD

It is always difficult to find quality childcare, respite care, and after school care for children who are TD (Thyen et al., 1999). Professionals can help families to know what resources exist in communities for child and respite care. Respite care may be available through hospitals, through residential facilities, or within the home (Miller 2002). Ample respite care is not available in many communities (Murphy, 2001b). Professionals and families also must advocate for adequate respite services, particularly for those children requiring constant medical care. Respite care is critical to families being able to care for their children with technologies on a long-term basis. Without periodic breaks from care, families, especially the primary caregiver, experience considerable stress (Beale, 2002). It is not realistic for a family to provide all the care for the child all the time (Petr et al., 1995).

Does Service Delivery Differ for Children with Technology Dependence in Canada from Services in the United States or Britain?

While much of the research about the issues faced by families of children who are TD has been performed outside of Canada, it appears that Canadian families face the same challenges. Further, although the provision of services varies with the structure and funding of health care in various countries, the literature suggests that service providers everywhere face similar challenges in adequately meeting the needs of families. Several recent reports about services for children with special needs and children who are TD in Canada support common themes found in caring for children with technologies and their families in various countries (McCormack et al., 2000; Spalding et al., 2002).

A unique aspect to the care of children at home in Canada is the lack of mandated services for children requiring medical care in the home. The Long Term Care Act (1994) was enacted in Ontario to guide the delivery of community services in the home and community for seniors, not children. Service providers struggle to modify the home services developed for older adults to the delivery of services for children, and obvious gaps have occurred. Some of the barriers to care include the costs of care that go beyond the care funded by the government, costs incurred when schools are closed or the child with technologies is sick, access to care

at nighttime (hours of care at night that are funded vary widely), access to and availability of respite care (sometimes restricted to one 8-hour period per month), and inconsistency in the delivery of supports and services across children and communities (McCormack et al., 2000). Children who are TD are transferred from hospital to home under care contracted by Community Care Access Centres in Ontario and by Centre Locales de Santé Communautaire in Quebec. In Alberta, Children's Home Care Teams assess children's needs and organize services (Spalding et al., 2002).

At this time, families in Canada provide the bulk of care at home for their children dependent on technology with varying amounts of paid nursing care and varying support from community agencies. There are wide variations in community supports with variations based on rural versus urban location, by province, and within and across ministries. For example, across Canada, families of 82 children with dependence on mechanical ventilation received varying funding for equipment and personnel (Dhillon et al., 1996). Families in British Columbia and Manitoba receive 100% funding while the other provinces vary in the amount of funding provided. The coordination of services also varies across provinces. Although coordinated services appear to be a desired outcome by families, it is achieved inconsistently and not in most locations currently in Canada. A case management model is used in some locations and most consistently when a child first requires services. Children's conditions and needs are likely to change, sometimes requiring long term care coordination that many children are not receiving. Further, service coordinators often carry heavy caseloads with a specific agency or ministry and frequently do not have the authority to access necessary services for families mandated by other agencies or ministries (Spalding et al., 2002).

Summary

Children can be dependent on technology to sustain life or to compensate for a loss of a vital function. Families are providing the bulk of the care for their children at home. Communities vary in the availability of trained personnel, services, and funding to support families in caring for their children. Because it is estimated that nearly a third of children dependent on technology to support vital functions or on intravenous support are not keeping up developmentally with their peers, these children will need developmental stimulation and schooling to optimize their development. Further, families experience social, emotional, and financial strains from caring for children at home. Professionals need to attend to these needs along with the provision of speech, occupational, physical, or respiratory therapies. Particularly important is the provision of information about each child's development and condition, expectations for progress, and community programs and therapies. Taking time to listen to families and involving them as partners in the care plan is crucial. Professionals can begin by assessing the stresses of families and matching their

needs with services in the community prior to discharging the child to his/her home. Families will need help in organizing a personal plan of supports from family, friends, neighbors, and community agencies to help with day to day routines and activities. Identifying and obtaining a service coordinator who can follow the family is essential in order to provide excellent care to the child and family. Provision and availability of daycare and respite care for children who are TD is problematic in many communities; however, these services are important in helping families to balance care of the child who is TD with regular family routines and to provide opportunities for families to participate in community activities.

Implications for Professionals, Service Providers and Policy Makers

Knowledge and Personal Training of Professionals

- Learn more about children who are dependent on technology.
- Help train professionals in the community to care for children who are TD (those professionals who work in ICUs are more knowledgeable than community professionals with less exposure to these children).
- Learn about the services for children who are TD in your community and province.
- Consider ways to develop a database of services in the community or province for families with children dependent on technologies.

Interactions with Families

- Recognize the strengths and perceptions of families about caring for their children with technology dependency (families will vary in their approach to the situation and will balance demands and capabilities to adapt over time).
- Provide families with information about the conditions and developmental progress of their children.
- Involve families in the decision making for the child from the beginning and empower them to gradually assume responsibility for their child's care and to interact with the health care system.
- Provide families with information about community services and how to access them.
- Recognize that the family's situation will change and the supports they need will also vary over time.
- Help families with securing a key person to coordinate services.

Interactions with/Involvement of Policy Makers

- Advocate for a national system of care for children, including children who are TD, with provision of standard services for all children.

- Help families to obtain service coordination.
- Increase flexibility in accessing services and in eligibility for services.
- Coordinate services for children who are TD across agencies and health, social, and education service sectors, as well as across government ministries.
- Develop a national registry of children requiring technologies in order to help with planning and services for these children in the future.

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