

COORDINATION OF CARE OF MEDICALLY FRAGILE CHILDREN:
DEVELOPING A SOCIAL ECOLOGICAL APPROACH

by

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B.S., University of Tennessee-Knoxville, 2004

Submitted to the Graduate Faculty of
Behavioral and Community Health Sciences
Graduate School of Public Health in partial fulfillment
of the requirements for the degree of
Master of Public Health

University of Pittsburgh

2006

UNIVERSITY OF PITTSBURGH

Graduate School of Public Health

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Abstract

Although levels of disability among adults are relatively stable, the number of children with disabilities is steadily rising. It is increasingly the case that medically fragile children are receiving care in their homes due to early discharges from hospitals and other related service programs. These children and their families have needs that require interventions from many different services, such as health, education, social services, housing, transportation and benefits.

This thesis explores the present state of affairs by considering typical problems and decisions these families face on a day-to-day basis, family coping strategies, and local family resources. I propose a social ecological approach to addressing the special health care needs of children. The social ecology model explains the need for interventions to approach this complex problem on several levels—the individual, interpersonal, community, and policy. The model examines the inter-relationships between these levels and explains some of the barriers to care on each of the different levels.

The implications for public health educators and researchers are the possible collaboration with community-based institutions to assess, plan, develop, and evaluate interventions within the context of children with special health care needs and their

families. Based on my review, I propose strategies for intervention at four different levels—individual, interpersonal, community, and policy. My assumption is that if each of the proposed strategies is successful at its respective level, then children’s access to coordinated community-based social and health services would improve.

1. Introduction

A vitally important child health issue is the treatment of children with special health care needs (CSHCN). Although levels of disability among adults are relatively stable, the number of children with disabilities is steadily rising. These children and their families need a variety of resources that are often not readily available to them in their community. In 1994, 10.6 percent of children had limitations in learning ability, 6 percent had limitations in communication, 1.3 percent had limitations in mobility, and 0.9 percent had limitations in personal care [1, 2]. In 2005, the Maternal and Child Health Bureau reported that 12.8 percent of the children under the age of 18 in the United States met the criteria for their definition of children with special health care needs. This percentage translates to over 9.4 million children who are considered to have special health care needs[3].

CSHCN and their families need a variety of health and social resources that are often not readily available. The Maternal and Child Health Bureau describes children with special healthcare needs as” those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type or amount beyond that required by children generally” [4, 5]. This definition is broad and inclusive; however it was developed to assist States be able to provide community based services to a greater number of children. A child who is considered technology-dependent uses one or more medical devices, such as feeding pumps, suction machines, or ventilators on a daily basis [6]. Medically fragile

children are part of a growing population of children with special health care needs who are dependent on technology for survival [7]. The terms *technology-dependent*, *medically fragile*, and *children with special health care needs* are often used interchangeably in the literature to describe this particular community of children. In this thesis, the researcher will be addressing the needs of the broader population of children with special health care needs (CSHCN) as it relates to care coordination.

It has been estimated that about 10 percent of children with developmental disorders require access to a health care system and extensive caregiving throughout their childhood and into their adult years [8]. This new trend of integrating CSHCN into their homes and communities has many implications on the individual, interpersonal, community, and policy levels. In order for this new trend to be successful, an effort must be made by caregivers, health care workers, and policy-makers to understand what is required to care for these medically fragile children.

This difficult issue is extremely complex and therefore poorly understood by policy-makers, health and social service leaders, and most importantly the general public. Although funding is available, there are not well-developed infrastructures in the community to support the health care needs of this specialized group of individuals and their families. Some of the barriers reported by the families are differing eligibility criteria, duplication and gaps in services, inflexible funding sources, and poor coordination among service sectors [1].

The majority of these problems would be eliminated if the right infrastructure were in place in communities. The end goal should be an established community infrastructure through which collaborative efforts are made to establish a community-

based medical home for special needs youth allowing them to remain with their families. This thesis looks at present programs and research findings around children with special health care needs in the US and their families. The objectives of this paper are to (1) to explore the literature about children with special health care needs, with special attention to resources available to families and (2) using a social ecological perspective propose a health coordination model to assist children with special health care needs and their families in obtaining necessary health and social services in the Pittsburgh, PA area.

2. Theoretical Framework

2.1 History of Social Ecology Model

The multi-level complexity of this issue warrants use of the social ecology model as a viable theoretical framework for this particular intervention. Ecology is simply the study of the interaction of organisms with their environment. One's environment is simply the space outside of the individual. The term social ecological refers to the influence of social context on behavior, including institutional and cultural factors. In order to fully understand this concept, one must realize that "ecological" refers to models, frameworks, and perspectives and not necessarily specific constructs and variables [9].

The history behind this particular framework for intervention began in the 1970s with a man named Rudolph Moss. Moss specified four sets of environmental factors relevant to health studies: physical settings, which include features of the natural environment as well as urban designs; organizational, the size and the function of the organizations, such as worksites, churches, in my case community-based agencies, human aggregate (sociodemographic or sociocultural characteristics of the people in your population), and social climate, perceived aspects of the social environment that relate to such influences as the supportiveness of the social setting.

In 1992, Dr. Stokols, one of the pioneers of this framework, proposed the idea that interventions must address environmental resources that may facilitate or hinder targeted health behavior changes [10].

2.2 Development of Social Ecological Model

The social ecological model is a comprehensive health promotion model that is multifaceted, concerned with environmental change, behavior, and policy that help individuals make healthy choices in their daily lives. The defining feature of an ecological model is that it takes into account the physical environment and its relationship to people at individual, interpersonal, organizational and community levels [11]. One must address variables at multiple levels to understand and change the problem. The variables are likely to interact thus an intervention must be aim to influence all levels.

In the case of children with special health care needs and care coordination, the intervention will look at Moss' four environmental factors relevant to the issue. The literature review will gather information on the physical settings, organizational, human aggregate, and social climate and then will be use to help inform the intervention for the Pittsburgh, PA area.

The philosophy behind this is the concept that behavior does not occur within a vacuum. This model will allow the researcher to form not only direct relationships between constructs of interest and outcomes, but also indirect relationships through intervening constructs. The proposed model builds upon the work of existing frameworks found in pediatric literature, in order to gain a more complete picture of care coordination than any one-tiered model might provide. Specifically, this means

- a) Focusing on both formal and informal networks with the community
- b) Incorporating specific findings in present research, such as the role of primary practitioner and key workers

- c) Taking a closer look at the constructs of family function and social support within the socio-ecological context
- d) Examining both physical and psychological health as outcomes in the model

3. Review of Relevant Literature

3.1 Background on Children with Special Health Care Needs

The increasing sophistication of medical advances in the care of preterm, congenitally impaired, and seriously ill infants and children has led to the emergence of a group of children with complex healthcare needs living at home [12]. When parents are caring for medically fragile children in the home, their lives are transformed even further than the average parent. The family's schedule revolves around the medical needs of the child. In addition, many of the monitoring and associated clinical procedures dominate the lives of the other family members [13].

The exact number of medically fragile children is unknown. As seen in Figure 1, the Maternal and Child Health Bureau [2, 3] reported 12.8 percent of the children under the age of 18 in the United States met the criteria for their definition of children with special health care needs. It was also noted that 20 percent of households have a child with special health care needs. However, all children who are sent home on ventilators, suctioning equipment, monitors, and the like are considered to be technology-dependent hence the uncertainty about the exact number of CSHCN.

In 2001, the National Survey for Children with Special Health Care Needs [13] was conducted. The National Survey of Children with Special Health Care Needs represents the first source of both national- and state-level data on the size and characteristics of the population of children with special health care needs.

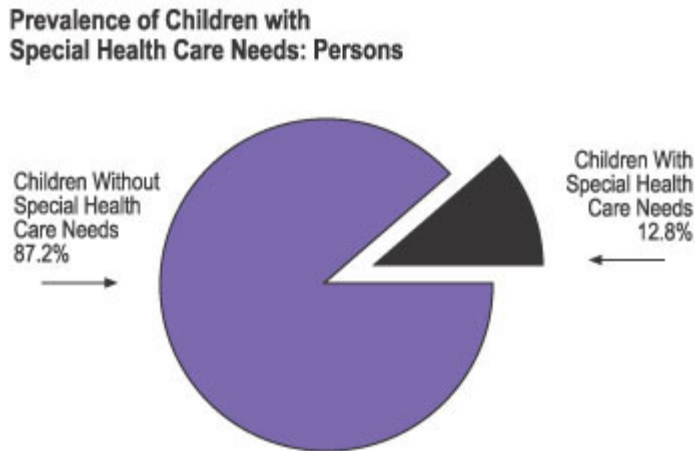


Figure 1: Prevalence of Children with Special Health Care Needs: Person

Adapted from National Survey of CSHCN et al. 2004

This survey was sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration and carried out by the National Center for Health Statistics of the Centers for Disease Control and Prevention. It provides detailed information on the self-reported prevalence of CSHCN in the Nation and in each state, the demographic characteristics of these children, the health and support services required for CSHCN and their families, and their access to and satisfaction with the care they receive. A total of 38,866 families of CSHCN were interviewed by telephone between October 2000 and April 2001 [14].

The National Survey of Children with Special Health Care Needs paints a positive picture of access to care for this population of children. Overall, 95 percent of children with special health care needs had health insurance at the time of the survey, 82 percent reported receiving all of the services they needed, and 89 percent had a personal doctor or

nurse. However, research findings found the following:

- Approximately 23 percent of children with special health care needs are usually or always affected in their activities by their conditions; 37 percent are sometimes affected; and 39 percent are never affected in their activities.
- Twelve percent of children with special health care needs were uninsured at some point during the year prior to the survey.
- Of those with insurance, the families of one-third say that their coverage does not meet their needs because of inadequate access to benefits or providers or unreasonable charges.
- Nearly 30 percent of parents of children with special health care needs report that they have had to cut back on work or stop working in order to care for their children [14]

Even though the initial picture painted by the National Survey of Children with Special Health Care Needs seems rosy, recent research paints a slightly different picture.

3.2 Prevalence Rates of Children with Special Health Care Needs

To identify CSHCN, the survey asked parents whether their child used more medical care, mental health services, or educational services than is usual for most children of the same age; whether the child used specialized therapies, mental health counseling, or prescription medications; and whether the child was limited or prevented in any way in his or her ability to do things most children of the same age can do, because of a medical, behavioral, or other health condition that is expected to last at least one year [14].

Prevalence of Children with Special Health Care Needs: Age

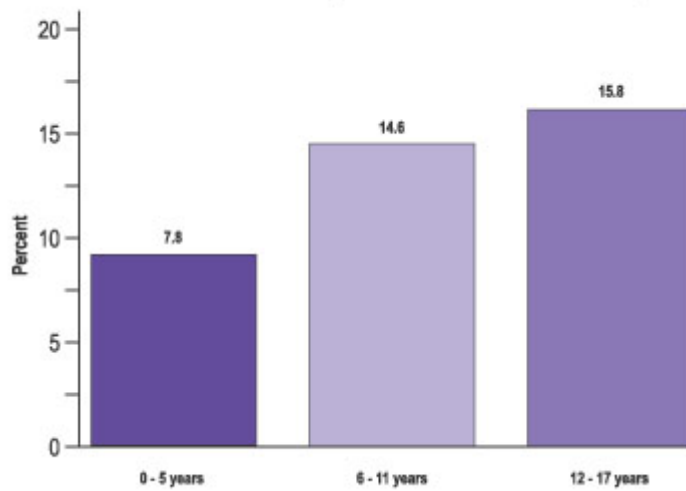


Figure 2: Prevalence of Children with Special Health Care Needs: Age

Adapted from National Survey of CSHCN et al. 2004

Graph 1 illustrates the prevalence of special health care needs in children increases with their age. This is consistent with other research findings in other studies[15]. The higher prevalence of special health care needs among older children is likely to be attributable to conditions that are not diagnosed or that do not develop until later in childhood [14, 16].

As seen in Graph 2, special health care needs are more prevalent in boys than girls. Fifteen percent of boys have special health care needs, compared to 10.5 percent of girls. This may be related to the higher proportion of boys who are diagnosed with behavioral disorders.

Prevalence of Children with Special Health Care Needs: Sex

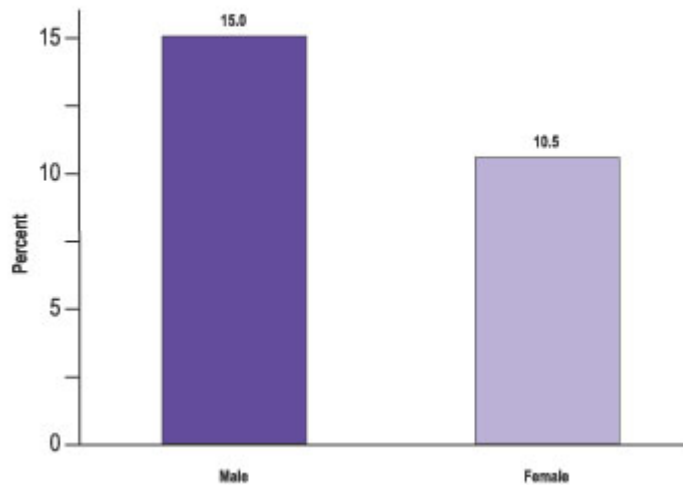


Figure 3: Prevalence of Children with Special Health Care Needs: Gender

Adapted from National Survey of CSHCN et al. 2004

3.3 Health Care Policies Concerning CSHCN

Supplemental Security Income (SSI) was created in 1972 through the enactment of Public Law 92-603 administered by the Social Security Administration. The SSI program replaced state-administered aging and disability assistance programs of needs-based cash assistance [17]. Qualifications for SSI are based on financial need, as determined by asset limits of \$2,000 for single-parent households and \$3,000 for couples. Persons are able to receive SSI as long as they are considered disabled. Children who are eligible to receive SSI often qualify the child for state administered Medicaid [7, 18]. Medicaid benefits

differ from state to state, however , all states provide payment for physician visits, hospitalizations, and medication [19].

In February of 1990, the Supreme Court of the United State ruled in *Sullivan v. Zebley* case that the Social Security Administration was improperly determining children's eligibility requirements for SSI. After this legislation, the Social Security Administration reviewed more than 450,000 claims that had been previously denied. The number of children receiving SSI benefits in the 1990s more than tripled, increasing from 297,000 in 1989 to nearly 900,000 in 1994, with a peak enrollment of 1,017,992 children in 1996 [7, 17, 19]. In 1995, there were estimates of child SSI expenditures being approximately 10 billion dollars [7]. Reports of these expenditures fueled Congress to enact the Personal Responsibility and Work Opportunity (Welfare) Act of 1996 in attempts to control cost and eliminate federal waste through the reduction in SSI enrollment [7, 19]. It was this legislation that tightened the definition of children with disabilities and required that children receive SSI for only the conditions be specified on the Social Security Administration's list of impairments [19]. Through this Act many medically fragile children lost their SSI benefits [20].

In addition to the SSI Act, another example of policy concerning CSHCN and their families is Public Law 94-566. Originating in 1935, this legislation required that state-administered Title V programs, under the Maternal and Child Health Bureau Black Grant program, assume the responsibilities for service evaluation, coordination, and delivery for children qualifying for SSI benefits [21]. In 1989, all State Title V program

missions were redefined to provide community-based, comprehensive, family-centered, and culturally-sensitive services [7].

There are several problems with the managed-cared state Title V programs. For families the major concern with state Title V programs involves the delegation of the child's primary care to a general practitioner who may have very little experience with the management of CSHCN. There is also a lack of specialty providers, who are frequently used by CSHCN. Many states have reduced their specialty pediatric service capabilities so that community-based specialty clinics, multidisciplinary teams, and family support programs are not included in managed care contracts [7]. One of the huge limitations of the program is the fact that parents and providers are not included in the deliberation process and Title V agencies are not included in the negotiations [22].

3.4 Shifts of Responsibility

Whereas in the past these children would be sent to state-run care homes or remain in hospitals, now there is a push for these children to be discharged into the care of their families [13]. In the early 1990s there was a shift from a hospital-based model of care to an independent community based case management model [16]. Yet, the support is not there to make this shift of responsibilities a successful transition for the children. The literature shows there is a need for a support system, yet there is a gap in the coordination of care in these services in most communities across the country [13, 23].

Over the past two decades, the family units of CSHCN have become smaller and the rate of marriage break-ups has increased. In the same period of time, with new

technological advances in medicine, we have seen a rise in survival rates of children with disabilities [15, 24] These two factors mean that a small family unit has to shoulder the responsibilities caring for these medically fragile children. With more of these children going home, caregiving responsibilities of parents has increased dramatically.

3.5 Physical, Emotional, and Social Implications on the Family

Having a medically fragile child living in the home requires a strong, physical, mental, emotional support system for both the child and family. Children are best understood as members of the social settings in which they dwell, most notably the family [23].

Oftentimes, it is the parent or an older sibling who is the primary caregiver for the child.

A number of studies have looked at the emotional strain brought on by having a medically fragile child in the home. Parental care for a child with special health care needs is an enormous responsibility; one that far exceeds that of typical parental care.

Parents are performing multiple roles, including managing their child's condition, organizing services, and advocating for their child, as well as the more usual elements of parenting [2, 25].

The entire family is directly affected by the changes brought on by having necessary machines, nurses, equipment, and the like in the home. For instance, home-based care involves a loss of privacy for families. One study shows that more hours of care provided by home health aides increased mother's strain with professional caregivers; more hours of care from nurses increased the father's strain [26]. Home environments can easily become medicalized due to the presence of the medical equipment needed to take care of the child [2, 27]. Each household reacts differently to the stressors brought on by caring for the medically fragile/technology- dependent

children. Research results [12, 26] tell us that parents of disabled children are particularly vulnerable to stress; for example, high levels of distress are found in 70 percent of mothers and 40 percent of fathers of severely disabled children. Quality of the marriage may suffer and divorce is significantly more prevalent in families with children with special health care needs than in the general population [2]. Some couples feel that the inability to spend time together as a couple places a strain on their relationship [2].

The literature [7, 26] shows that there is an association between socioeconomic status and the physical, emotional, and social health of the family. Higher socioeconomic status has been associated with fewer psychological life stressors and better emotional well-being in the caregivers of the children. A large number of families with CSHCN needs do not have higher socioeconomic status. We see that 40 percent of families with children with special needs experience finance-related problems [27, 28]. Some parents have to give up work and have to cope with reduced income at a time when household costs have increased, for example, more laundry, heating, and electricity for such items as ventilators and feeding equipment [2]. Although third-party payers typically do provide caregivers with a set percentage of care reimbursement, often the remaining sum is an overwhelming financial burden for families [7].

Nine percent of CSHCN live in families with a need for respite care, 7 percent need genetic counseling, and 13 percent need family counseling to help deal with the stresses involved in having a child with special health care needs [14]. Informal and formal social support is essential in helping families cope with both the disability and the continuous care these children need to remain at home with their families. Recent studies

[3] show that when families find social networks and activities for the entire family to participate in, all the family members can relax. However, when families cannot find suitable activities, they are more likely to limit activities or leave part of the family at home[3].

3.6 Costs and Benefits for the Children, Families, and Community

Children with special health care needs and the complexity and costs of their care gained widespread attention in the United States during the 1980s. In a November 1981 news conference, President Reagan cited the case of Katie Beckett, a three-year old Iowa girl who, due to lack of any means to fund home care, had to live in a hospital since three months of age, when she was diagnosed with viral encephalitis. After the conference, a special waiver was issued to her, and she was able to go home. By the following summer the Secretary of US Department of Health and Human Services had established a waiver program covered by Medicaid [5].

The financial impact of the care of CSHCN can be substantial: more than one in five CSHCN are in families who spend more than \$5000 per year on their care. Moreover, one in five CSHCN live in families for whom their condition has caused financial problems. These problems can be exacerbated if parents must stop working or cut work hours to care for their children; 30 percent of CSHCN have parents whose employment has been affected by their condition [14]. A recent study shows that fully 40 percent of families with CSHCN, or 3,746,000 families nation-wide, experience financial burden related to their child's condition. However, from the perspective of insurance companies and hospitals, cost-comparison studies [6] of home-based versus acute care

management of medically fragile children have further shown fewer hospitalized days and significantly decreased financial costs associated with the delivery of home care.

3.7 The Parent-Professional Relationship

Economic and sociocultural barriers often affect the coordination of care between the families and health care professionals [29]. It is vitally important that health care providers are in a synergistic relationship with the parents. Care for CSHCN should be family-centered. It should respect the family as the constant in the child's life and family members as the child's primary caretakers.

Some parents feel that the emotional aspects of caregiving are neglected by professionals, who emphasize only the acquisition of technical competencies when teaching parents [2, 30]. Factors contributing to a positive parent-professional relationship include the professional's competence, genuine caring for the child, and respectful collaboration with the family [31]. Ultimately, what parents need are services to work in partnership with families and with each other at both strategic and operational levels, to develop coordinated services that can meet the need of the children [8, 29, 32].

Family cohesion and organization as well as support from the community reduce the amount of strain the family has with the health care providers. To assure that care is family-centered, providers must spend enough time with the family; assure that they have the information they need; listen to the family's concerns; be sensitive to the family's values and customs; and make the parents feel like partners in their children's care. Family members are able to be active participants in the care coordination team when they are knowledgeable about their child's condition and their skills and strengths are

supported [29]. This type of involvement gives the parents a small sense of control in the healthcare of their child.

Published reports [17] and the families themselves [29] have indicated a greater need for the involvement of primary care pediatricians in the care coordination process. The absence of involvement results in incomplete coordination and episodic, expensive, fragmented care. A recent study [2] showed that parents are reassured by having an accessible and reliable person who knows their child, whom they can approach when they need help, advice, or information---someone who is 'there for them.

3.8 Coordination of Care

Care coordination for children with special health care needs has been defined as “a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care” [14, 18]. Care coordination often is complicated because there is no single entry point to systems of care, and complex criteria determine that availability of funding and services among public and private payers [18]. In addition, there are multiple systems of care, each with its own mission and eligibility criteria.

In the health care system, care coordination may involve the following: planning treatment strategies; monitoring outcome and resource use; coordinating visits with subspecialists; organizing care to avoid duplication of diagnostic tests and services; sharing information among health care professionals, other program personnel, and family; facilitating access to services; planning a hospital discharge; and notification, advanced planning, training of caregivers, education of local emergency medical services

when a child with special health care needs lives in the community, and finally ongoing reassessment and refinement of the care plan [18].

Poor coordination of care could leave parents feeling overloaded with visits from professionals, with little time to establish a sense of a “normal” family and confused about the responsibilities of different professionals [2]. This is an overwhelming task for any one person. Families and children themselves are important participants in the care coordination team, along with the primary pediatricians and community nurses. This collaboration is vital, since they are the ones who know their needs the best.

4. Design of the Child's Way program in Pittsburgh, PA

4.1 Targeted Community At A Glance

Established in 1758, Pittsburgh is one of the largest cities in southwestern Pennsylvania. Its population in 2003 was estimated to be about 325,337 persons. The median household income is \$28,588 and as of 1999, 20.4 percent of persons living in Pittsburgh, PA lived below poverty. The total number of children ages five to twenty years is 70,862. Of these 70,862 children, 5,763 of them or 8.1 percent have a disability [33].

4.2 Targeted Agency At A Glance

The Children's Home of Pittsburgh, established in 1893 is an independent, non-profit licensed organization that promotes the health and well-being of infants and children through services that establish and strengthen the family. One of its three programs, Child's Way, is a pediatric extended care center serving medically fragile infants and children. Child's Way was opened in 1998 and provides expert skilled nursing and child development services to medically fragile children from birth to age 8 in a day care setting. Child's Way currently offers limited services to the families of their CSHCN population; however, they want to expand their services to better meet the needs of the families of CSHCN in the greater Pittsburgh, PA area.

4.3 Background Information on Pittsburgh, PA area Children with Special Health Care Needs

In January and February 2005, a survey was mailed to 1020 Pittsburgh-area families by the Bayer Center for Nonprofit Management at Robert Morris University. Of these, 875 were sent to families with medically fragile children; 150 to families who have experienced death of a child. The bulk of the mailing was done by the Make-A-Wish Foundation of Western PA. A total of 194 surveys were returned from families with medically fragile children. The results rendered are helpful in understanding the current situation for CSHCN and their families in the Pittsburgh, PA area [34] .

The survey results show that most families (84 percent) are caring for other children in addition to their medically fragile child. This means that for care coordination for health and social services is vitally needed in their daily lives. Figure 2 displays the services received by families with medically fragile children in the greater Pittsburgh, PA area.

Services Rendered	By Families with a Medically Fragile Child
Case management/social worker	57 %
Pain management	4 %
Home Health Care	25 %
Support groups	9 %
Hospice	1 %
Respite*	44 %
None	33%
* Majority provided by extended family	

Adapted from Pittsburgh Palliative Care Family Results 2005; N=194 [34]

Figure 4: Services Received by Families in the Pittsburgh, PA area

N=194

Study results [34] show that non-whites were slightly more likely to report that their families received no services (42 percent and 29 percent respectively). Lower income families had knowledge about services available similar to as higher income counterparts. They also reported receiving no services at a rate similar to their higher income counterparts. Also, married parents were slightly more likely to know about services than single, divorced, and widowed parents [34].

The care of a medically fragile child is daunting enough without having to deal with issues of the social and health care systems. Of the participants in the study (n=217) 57 percent have or had a case manager through insurance, mental health agency, Children, Youth, and Families (CYF), or another entity. However, the survey results indicate that the case managers are not meeting the comprehensive set of needs of the child. Figure 3 shows what the families deemed as limitations of the agency case managers [34].

Limitation	Number	Percent
Only able to assist with issues related to their agency	43	34 %
Is not familiar with other community services	11	9 %
Only gives my information about things I specifically ask about	54	43 %
Other limitations	28	22 %

Adapted by Pittsburgh Palliative Care Family Results 2005; N=124 [34]

Figure 5: Limitations of the Agency Case Managers

N=124

Of all the families with medically fragile children, 64 percent say more comprehensive case management services are needed for their child. The demographics show that Caucasians are slightly more likely to have a case worker or social worker. Families with incomes under \$50,000 are slightly more likely to have a case manager. Families with incomes over \$50,000 are more likely to request assistance from a caseworker for navigating the medical system and for help navigating the insurance system. However, families receiving Medicaid are much more likely to request a case manager's assistance for finding other services and much less likely to request assistance navigating insurance [34].

5. Discussion

A social ecological model as applied to families predicated a broader view focusing on the social and environmental factors that affect families of disabled children, social attitudes towards impairments, and inadequacies in support [13]. In order for there to be a sustainable outcome for the CSHCN and their families a coalition of major stakeholders in the Pittsburgh community must be formed. The coalition will consist of the families of CSHCN, staff at Child's Way, administration at the Children's Hospital, and local researchers from the University of Pittsburgh Graduate School of Public Health Department of Behavioral and Community Health Sciences. The community in question will be the children with special health care needs ages 0-8 years and their families in the greater Pittsburgh, PA area. Using an adapted version of a survey done by the Pittsburgh Pediatric Palliative Care Coalition (PPPCC), the staff of Child's Way, Children's Hospital of Pittsburgh, and the University researchers will tailor the program as indicated by the results of the survey (see Appendix).

The survey results will help the program designers assess the desires of the families with CSHCN in regard of coordination of care. Changes must be made on each level: individual, family, community, and policy level in order to see sustainable change in care coordination. In designing strategies for change, one must understand the dynamic nature of this problem and thus the dynamic nature of any proposed intervention. Any possible barriers to change could have an adverse effect on all the other levels of the system. Barriers, such as lack of insurance, hinder the dynamics of the intervention. Foreseeing these possible barriers in the planning stages of the intervention

will allow planners to minimize the impact of these obstacles on the entire system.

Table 4 illustrates proposed strategies for intervention at four different levels- individual, interpersonal, community, and policy. The strategies are recommended in order to increase the proportions of children with special health care needs in the Pittsburgh area who have access to a medical home and its services in their community. If each of the proposed strategies is successful at its respective level, then ideally it will lead to a greater policy change and will increase the number of children with access to coordinated community-based social and health services.

Table 1: Proposed Strategies for Intervention

LEVEL	PROPOSED STRATEGIES
Individual (disabled child)	* Self empowerment through hospital and community-based programs
Interpersonal (disabled child’s family)	* Educational sessions with primary care pediatricians/nurses and families to deal with the child’s disability and its affects on the entire family
Community (other disabled children and their families)	*Parental educational and social support groups held at Child’s Way, a local health and social services non-profit for disabled children and their families
Policy	*Collective parental involvement in legislative process (i.e. lobbying, petitions, writing to congressmen *Passage of childhood disability-related legislation leading to providing access to a medical home for more children with special health care needs in the greater Pittsburgh area

Local staff and volunteers of Child’s Way, a local non-profit that provides health and social services for disabled children and their families, will conduct the interventions. The families in the intervention will be recruited from current families enrolled in program at Child’s Way and other local agencies, such as the Children’s Institute, as well as through referrals from local hospitals and doctor’s offices in the greater Pittsburgh

area. The staff of Child’s Way has fostered relationships with local hospitals and doctors working with medically fragile children. The facilitation of this multi-level intervention would be done by a team of two or three staff people in collaboration with the Department of Behavioral and Community Health Sciences at the University of Pittsburgh Graduate School of Public Health. The entire intervention is projected to take place over a five- year time period. It is important that evaluation takes place on each level during the initial run of the program. Each year, the program director will conduct a mixed method evaluation, consisting of surveys, focus groups, and quantitative data collection.

5.1 Individual Level

On the individual level, the main intervention is to have community and hospital-based programs promoting self-empowerment for children with special needs. This special population is unique in that many cannot take an active role directly affecting issues in the policy level. However, their involvement in successful programs gives them a voice in advocating for others like them to have the same access to a medical home. Legislators and other funders will look to these children as “poster children” for allocating more money to help other children with disabilities, and to provide more broadly family support, rather than focusing solely on treatment of the child and remediation of the effects of impairment [35].

5.2 Interpersonal Level

It is important to take a look at the social, economic, and cultural context in which the families find themselves. These contexts often create an infinite variety of circumstances in which stress is created and manifested in the family unit [27]. Available research [7] indicates that the greatest needs during the critical period of diagnosis are information, especially about education and social services and emotional support from professionals, informal and social networks, and support groups.

On the interpersonal level, the proposed strategy is to start an initiative to have education and coping sessions with the entire family of the affected child with the primary care pediatrician and nurses. Letters explaining the initiative will be sent to the doctor's offices, followed by a phone call to verify participation. It is the hope of the planner to involve the Allegheny County Department of Health in this initiative to give validity to the project. The time around diagnosis is a key milestone for the parents of children with special needs. Social support is vital in helping families get the emotional support needed for the days ahead.

This is the point in the intervention at which key workers come into play on the interpersonal level. The families experience numerous contacts with a variety of providers and one of the biggest problems lies in the lack of coordination of the work of the different agencies and the resulting confusion for and demands upon parents. It is the responsibility of local community-based hospitals and agencies to provide for the family a key worker. Regular contact with the family by the worker should be maintained. The worker should also be responsible for collaborating with professionals from a large range of services [13]. This role can be filled by a professional nurse, social worker, or health

professional that is aware of the child's condition and the family's situation. Nurses may assist children to obtain a medical home through the provision of family-centered, culturally competent case management in a variety of settings.

Key worker programs for families of children with disabilities, to promote information provision, emotional support, and liaisons among different agencies, have long been advocated but not extensively implemented [8]. A study done by Sloper and Turner in 1992 found that families who did not have a key worker had significantly more unmet needs and that this was particularly the case for families with the most problems and the fewest resources. Beresford's recent national study of over 1000 families showed little change in parents' views about whether services met their need when compared with similar surveys carried out many years ago [6]. Beresford's (1995) study indicated that while only a minority of families received key workers service, those who did reported better relationships with professionals, but they did not necessarily report fewer problems with services [13].

Research shows that many parents are reluctant to use services for themselves. They will go to great lengths to obtain appropriate help for their children, but they may view support for themselves as an admission of failure as a parent. This emphasizes the importance of interpersonal factors in parent support and the need to maintain the parent's sense of control and build upon their strengths [13]. Families dealing with the news of a child's long-term condition often have issues coping and dealing with the responsibility of care. The hope is to foster a healthy working relationship between the primary care provider and the family in order to work together towards the best outcome for the child.

5.3 Community Level

The concept of the medical home for children was developed initially by the American Academy of Pediatrics in 1992. In its 1992 position statement, the Academy affirmed that all children have a right to “accessible, continuous, comprehensive, family-centered, coordinated, and compassionate” medical care, which is essential for optimal growth and development [7, 36]. The medical home in the context of pediatric health care links children to a single primary care provider in the community who assumes a central role in the coordination of the child’s care [21, 37].

Evidence demonstrates that families of CSHCN have difficulty finding appropriate community support networks and services [38]. A study done by McIntosh and Kerr suggest that parent of children with special health care needs are uniquely qualified to help each other. The challenge is to ensure that health professionals are aware of the potential benefits of parent-to-parent support and provide parents with information about appropriate local organizations and agencies [39]. Sometimes health professionals’ inherent power can dissolve parents’ position when it comes to decision-making and information. An important personal resource is a parent’s sense of control, feeling that he or she is in control of events and can obtain appropriate help for the family and child [13].

On the community level, the staff of Child’s Way will be essential for working with the parents of these children, since they already have a meaningful relationship with the families. The facility is also a great venue for support groups for both the parents and siblings of the children with special healthcare needs. Creating the sense of community among the families will help in enabling community capacity. The greater the

community capacity, the more we will see sustained behavioral change in the community. Through “creating a voice” for these children, outside communities will be made aware of these medically fragile children and more children in the special population will have access to a medical home.

5.4 Policy Level

Although recent reforms in SSI and State Title V CSHCN programs were designed to decrease federal expenditures while promoting access to primary and preventative care, medically fragile children may be hindered by this legislation [7]. Oftentimes stringent eligibility requirements and inadequate managed care limits families access to health and social resources, an already fragmented system becomes even harder to navigate through.

On the policy level, we must see this legislation passed in order that the policy is changed and money is allocated to this community. Advocacy is the key to policy change in the communities that they affect. There needs to be a call for more research in this area, to assist in the formulation of social and public policy [38].

The empowerment of the parents in this community can lead to greater action on the legislative level. No one can advocate better for these children than their own families. Through letters, petitions, and even lobbying, the children will have a voice on legislation affecting their lives and the lives of other children like them in the Pittsburgh area. Research shows that health professionals need to support parents, respond to the identified needs, and then help parents mobilize resources and build upon strengths [40].

The ideal outcome is to have more government money allocated for local collaborative programs between hospitals, universities, and community-based programs for the children and their families. Much has been written about the change in approach of professionals from expert models to those based on partnership, with recognition of the complementary knowledge and expertise of the parents and professionals, and the accommodation of different perspectives [41, 42]. This collaborative effort would reach a greater number of children with special health care needs and their families, many who cannot afford the holistic care that the child deserves.

The barriers to change are the greatest and hardest to overcome at the community and policy level. It is oftentimes hard to reach people in positions of power who can make a difference. In the collective effort, families and advocates can make the appropriate legislators and funders pay attention to this issue. Policy is the key to making this intervention sustainable in the community.

6. Conclusions

Findings suggest that the development of appropriate community-based services have not kept pace with the medical and technology advances that now allow children with complex conditions that require intensive care to be discharged from the hospital [2]. Oftentimes, disabled persons are marginalized and people mistakenly look at them with uneasiness or pity. Though care coordination can be complex, time-consuming, and even frustrating, it is the key to efficient management of the many complex issues surrounding the care of children with special health care needs within the context of a medical home [18].

It takes the combined efforts of legislation, universities, hospitals, and primary care providers to work towards a better outcome for this community of disabled children and their families. Facilitating access to community-based services through the use of the medical home care concept would lead to more productive lives of CSHCN. Child's Way here in the Pittsburgh area is a community-based agency that is willing to help solve this problem around care coordination for families with CSHCN. However, it will take more resources than this agency may have.

My paper has explored the issues around care coordination for this population, but in no way entirely conclusive. It is my hope that this paper will add to the general knowledge around this issue and spark interest among the research community. Ultimately, we need more research is needed to develop new approaches to coordinating care and to investigate the outcomes and benefits of care coordination within the context

of the medical home. My proposed strategies for intervention at the four levels of individual, interpersonal, community, and policy may lead to improved access to coordinated community-based social and health services. Only when we begin to do this, will children with special health care needs and their families begin to lead the lives that they deserve.

Appendix

Survey for Families Whose Child is Medically Fragile

We thank you in advance for taking the time to fill out this survey. We know this is a difficult subject. A group of service providers and families have created a coalition in Pittsburgh that is working to improve the care of medically fragile children and their families. In order to achieve this mission, we have created this needs assessment survey to document the needs and experiences of medically fragile children and their caregivers. By completing this survey, you will be a part of improving the system!

DEMOGRAPHICS

This section will allow Child's Way to assess if there are differences in services that are based on family characteristics. (e.g. race, finances, family structures, etc.)

1. Would you consider yourself: *(Check all that apply)*

- African American
- Caucasian
- Asian
- Latino
- Multi-Racial
- Other

2. What is your marital status?

- Married
- Single
- Divorced
- Widowed
- Long-Term Committed Relationships

3. Household income

- Less than \$25,000
- \$25,001 – \$50,000
- \$50,001 – \$75,000
- \$75,001 – \$100,000
- More than \$100,000

4. What kind(s) of health insurance did you have in the last year to help pay for your child's health care costs? *(Check all that apply)*

- Medicare
 - Medicaid/ DPA
 - Other government health insurance plan (e.g., military, or state plan)
 - Private health insurance plan
 - Other program that pays for medical care
 - None. What one reason best explains why?
-

5. What is your relationship to the child who is medically fragile?

- Mother
- Father
- Grandparent
- Guardian
- Other

6. How old is this child?

- Under a year
- 1+ to 3 years
- 3+ to 5 years
- 5+ to 8 years
- 8+ to 11 years
- 11+ to 14 years
- 14 + to 18 years
- 18+ to 21 years

7. What is this child's diagnosis? (*Check all that apply*)

- Cancer/Oncology
- Heart/Cardiology
- Lungs/Pulmonology (cystic fibrosis, etc.)
- Gastroenterology (ex. liver failure, stomach/bowel diseases, metabolic diseases, etc.)
- Blood/Hematology (sickle cell, Fanconi's, etc.)
- Neurology (M.S., cerebral palsy, seizures, etc.)
- Rheumatology (systemic lupus, dermatomyositis, etc.)
- Transplants (bone marrow, stem cell, organ, etc.)
- Immunology (immune deficiencies, HIV, etc.)
- Urology/Nephrology (renal diseases, etc.)
- Other – Please specify: _____

8. Was this child born with this condition?

- Yes
- No

9. How many siblings does this child have?

- None
- One
- Two
- Three
- More than three

10. Which of the following services are being received by this child and his or her family in relation to this child's diagnosis?

- Case management/social worker services
- Pain management
- Home health care
- Support group
- Hospice care
- Respite care (short-term, temporary care)
- Spiritual support
- None
- Other – Please specify: _____

SERVICES: We have focused on five service areas for medically fragile children and their families: respite care, long-term care, case management, hospice and end-of-life care. The following sections ask about your experiences with these services.

RESPITE CARE

11. Have you heard the term “respite care”?

- Yes
- No
-

Respite care is short-term, temporary care that the family receives apart from the care provided by the child's primary caregiver or insurance-allotted nursing hours. Respite care allows time for the primary caregivers to take a break from the daily routine of caregiving. This time allows the caregiver the opportunity to do such things as attend appointments for themselves or for other children, complete chores, attend social functions, or be used in a crisis situation. Respite care can last for a few hours, overnight or for a few days. It can be provided by family, friends or professionals. It can be also be provided in the family's home or in a facility.

12. Based on the definition given above, who provides respite care for your medically fragile child when you need to be away or need a break? (*Check all that apply*)

- Extended family member
- Child's sibling
- Organization/nonprofit
- Day care facility
- Home health care agency
- Other – Please specify: _____
- We don't use respite care

13. Based on the definition given above, how many hours of respite care did you **receive** in the past year (*Jan '04 – Jan '05*)?

Day/Evening time:

- Non-applicable because respite care was not available
- None
- Less than 1 hour/month
- 1-2 hours/week
- 3-6 hours/week
- 12-24 hours/week
- 48-72 hours/week
- Full-time assisted care

Overnights:

- Non-applicable because respite care was not available
- None
- 1-2 nights/year
- 3-7 nights/year
- 2-4 weeks/year

14. Child primarily lives outside of the home
How much did you **need**?

Day/Evening time:

- None
- Less than 1 hour/month
- 1-2 hours/week
- 3-6 hours/week
- 12-24 hours/week
- 48-72 hours/week
- Full-time assisted care

Overnights:

- None
- 1-2 nights/year
- 3-7 nights/year
- 2-4 weeks/year
- Child primarily lives outside of the home

15. If you have used overnight respite, has it been provided:

- At home
- At relative's/friend's home
- In a facility
- Not applicable

16. How much have you spent for respite care in the past year?

- 0-\$250
- \$251-500
- \$501-750
- \$751-1000
- \$1,001-1,500
- More than \$1,500
- Not applicable

17. How did you pay for it?

- Self-pay
- Insurance
- Grant or fund specifically for respite care
- Free service
- Other – Please specify: _____
- Not applicable

18. If you had easy access to overnight respite at a facility that was dedicated to quality care for medically fragile children and their families, would you use it?

- Yes
- No – Why not? _____ (Skip to # 22)
- Not applicable

19. How many nights a year do you think you would use an overnight respite facility?

- 1-5
- 6-10
- 11-20
- 21-30
- More than 30
- Not applicable

20. What kinds of restrictions have made it difficult for your family to access overnight respite services? (*Check all that apply*)

- Didn't know services were available
- No services are available for my child
- Did not accept technology-dependent children (trach, feeding tubes, ventilator)
- Did not accept children with my child's diagnosis of:

 Child is too old – Age _____
- Child is too young – Age _____
- Lack of money
- Times available weren't convenient
- Too few allowable days per year
- Agency couldn't meet demand – not enough personnel
- Didn't like the set-up of program

- Other – Please specify: _____
- Not applicable

21. Who referred you or told you about your current respite care services or funds?
(Check all that apply)

- Have never been referred
- Hospital
- Doctor
- Another parent
- School
- Not applicable

CASE MANAGEMENT SERVICES

Case managers provide referrals and coordinate services available. These services come in many forms from many different agencies. This section is about your experiences and views of case management.

22. Does your child have a case manager?

- Yes
- No (Skip to # 25)

23. If yes, what agency is your case manager with?

- Insurance company
- MH/MR agency
- Children, Youth and Family Services
- Other – Please specify: _____

24. What are some of the limitations of your case manager?

- Only able to assist with issues related to their agency
- Is not familiar with other community services
- Only gives me information about things I specifically ask about
- Other – Please specify: _____

25. Do you believe more widespread case management services are needed for your child?

- Yes
- No (Skip to # 27)

26. How could a case management service help you and your child more effectively?
(Check all that apply)

- Become involved at time of diagnosis
- Provide continuing service through age 21
- Provide emotional support to me and my child
- Assist with navigating the medical system

- Assist with coordinating all of the services involved with my child's care
- Assist with finding other services (such as respite, support groups, educational resources)
- Other – Please specify: _____

HOSPICE

Hospice programs provide family-centered care to enhance the quality of life of children and their family to the fullest extent possible. Hospice assists the child and family in the decision-making process about services and treatment choices.

27. Has anyone ever provided information about hospice services?

- Yes
- No

28. Are you currently receiving hospice services?

- Yes – How has it been helpful to you?

- No

What are your thoughts regarding hospice?

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