

ORDINARY LIVES, EXTRAORDINARY NEEDS:

Assuring Family Life For Children with Complex Health Care Needs



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A Report Prepared for the Every Child Deserves a Home Coalition

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EXECUTIVE SUMMARY

This report grew out of the efforts of the *Every Child Deserves a Home and Family Coalition*, a coalition that was formed in Pennsylvania in 2004 to “ensure that all children with complex health care needs and other disabilities have the opportunity to grow up in a loving, lasting family.” The coalition was mobilized by concern about the estimated 2000 children with disabilities and complex health care needs in out-of-home residential placements in Pennsylvania and the related challenges Pennsylvania faces in assuring family life for all children by more effectively supporting their families in family-centered ways. The coalition is composed of parents, young people with disabilities and complex health care needs, advocates, educators, health care professionals, administrators, direct service providers, policy makers, community service agency staff, funders, and other allies.

As part of its work, coalition members identified the need to investigate and analyze issues related to support for families who have children with complex health care needs. The Highmark Foundation was approached about the possibility of supporting a project to look at the multiple factors that affect families caring for children with complex health care needs in order to better understand what constitutes essential support to assure family life. The Highmark Foundation generously agreed to fund the project. The report that follows is a summary of its findings.

The investigation included several key components: (1) a literature review; (2) the personal perspectives of families and young adults with complex health care needs, direct stakeholders (individuals who interact directly in providing support to children and families), and indirect stakeholders (individuals with experience or influence in administering and managing services that affect children and families); (3) policy perspectives from analyses of health, education, and permanency policies, (4) practice perspectives from investigations of promising practices and cultural competence in delivering services that support children and families; and (5) a summary of key findings, challenges, and recommendations. The intent of the project was to use the findings and identified challenges to mobilize and focus the efforts of parents and young people, advocates, policy makers, decision makers, administrators, funders, health care practitioners, and service providers to implement changes to better assure family life for children with complex health care needs.

The perspectives of the wide range of families and stakeholders who provided input to this study shared remarkably similar views of services for children with complex health care needs and their families. Furthermore, their views are consistent with the perspectives in the literature, policy analyses, and promising and culturally competent practices reviewed for the study. Collectively, they provide a picture of the essential services and supports that families’ need and what makes it easier or harder for them to care for their children with complex health care needs at home.

What constitutes essential support for families with children with complex health care needs?

First, there was broad consensus that children need to grow up in well-supported families for optimal well-being and development. In general, families and stakeholders, and reviews of literature and promising practices suggest the following supports are essential supports for families:

1. Information about the child and about services and resources
2. Practical help, in particular, nurses, transportation, respite, adaptive equipment, and financial assistance
3. Emotional support from service providers and health practitioners as well as from personal networks of family and friends
4. Ready access to adequate and reliable services and supports that are individualized to fit the unique needs and circumstances of the child and the family as a whole
5. Being understood by those who design, deliver, and evaluate services

What makes it easier for families to care for their children with complex health care needs?

There was broad consensus that *how* services and supports are provided is as important as *what* services and supports are provided. The following elements were identified as characteristics of systems, including health, education, mental retardation/developmental disabilities, and child welfare that facilitate families in caring for their children with complex health care needs:

1. Interactions with system representatives that are built on relationships that are personal, face-to-face, in-home, and hands-on to assure that families' daily lives and experiences are truly understood.
2. Systems that have family-valuing and child-valuing cultures, see families holistically, are willing to explore creative and flexible ways to use existing resources, and trust families as capable of prudent resource use.
3. Systems that recognize their own complexity and provide a dedicated coordinator to families whose allegiance is to assisting them in whatever way necessary, and who is knowledgeable or willing to learn about ways to meet families' needs, and committed to find them.
4. Systems that connect families to supports based on their functional needs that are available as needed, when needed, in adequate amounts, for as long as needed.
5. Systems that are family-centered and collaborative and see families as partners in designing, planning, developing, and evaluating services and supports, both at the individual level and at the system level.

What makes it harder for families to care for children with complex health care needs?

Unfortunately, what clearly emerged from the participants in this study was the distance between these identified facilitating characteristics and families' experience with the current systems of services and supports across health, education, mental retardation/developmental disabilities, and child welfare.

The summary below represents common themes identified across multiple sources of input. These themes suggest the many ways in which families are hampered in caring for their children with complex health care needs. Challenges to providing essential support are identified followed by recommendations to move toward more effectively enabling children with complex health care needs to grow up in well-supported families.

1.

Finding: Families lack adequate amounts and types of supports and are fearful about the long-term stability of supports.

Challenge: To increase capacity and access to timely, adequate, individualized supports to families and explore creative ways to use existing resources more flexibly.

Recommendations:

- Holistically support children and their families with family-determined supports.
- Develop an adequate pool of trained nurses.
- Further develop and promote multiple options for in-home support.
- Ensure that sufficient funding is available to provide adequate supports to families.

2.

Finding: Families' voices are not heard and their experiences are not widely understood.

Challenge: To increase understanding and awareness of the general public and decision makers about the daily lives and experiences of families who are raising children with complex health care needs.

Recommendations:

- Promote awareness and understanding of families' lives and issues.
- Include families in all levels of planning and decision-making.

3.

Finding: Families characterize many of their interactions with the service system as negative, impersonal, and problematic.

Challenge: To develop partnerships with families in planning and development of services and supports.

Recommendations:

- Foster positive, collaborative relationships between families and the service system.
- Provide services in a nondiscriminatory manner.
- Provide services in a culturally competent manner.

4.

Finding: Services for families with children with complex health care needs are characterized as a "fragmented maze."

Challenge: To increase cross system collaboration and integration and learn from promising practices that offer family-centered coordination and have moved from categorical to functional needs based services.

Recommendations:

- Provide service coordination that is based on in-depth knowledge of the family, allegiance to the family, and that helps them navigate the service system maze.
- Provide an integrated set of services that is easily accessible for families.
- Promote collaboration across specialties and organizations.

5.

Finding: Information and resources are very difficult for families to obtain.

Challenge: To improve timely and adequate access to accurate and comprehensive information for families.

Recommendations:

- Provide useful, timely information about resources to families.
- Ensure information is comprehensive and easily accessible.

6.

Finding: Families, children, and young adults are often socially isolated, housebound, or interact only with health care or disability services providers.

Challenge: To promote inclusion and participation of all family members in their communities.

Recommendations:

- Provide supports that promote inclusion in community life for families, children, and young adults.
- Provide individualized, coordinated planning for transition to adult life.
- Offer the opportunity for all children to be included in their local school.
- Assure that adequate Individualized Education Plans (IEPs) are developed and implemented.

7.

Finding: Insurance and Medicaid require hours of work from families and are a source of “constant battles” for families to obtain covered services.

Challenge: To provide personalized assistance to families in obtaining covered services, managing denials and appeals, advocating for needed services, and finding ways to obtain uncovered services.

Recommendations:

- Educate funders about the types and quantities of services needed by families’ and their experiences with system barriers in meeting their needs.
- Provide personalized, hands-on help to families to assist in obtaining and coordinating needed services and supports.

8.

Finding: There is no comprehensive, cross system policy articulating a commitment to family life for all children and support for families to provide it.

Challenge: To articulate and implement a cross system policy that establishes and commits to the idea that children should grow up in families and that families need support to care for children.

Recommendations:

- Apply permanency policy in principle and practice to children with complex health care needs by providing support to birth families and alternate families for children who cannot live with their birth families so that all children can grow up in families instead of congregate facilities.
- Recruit and support alternate families for children who cannot live with their birth families.
- Shift from a medical model that focuses on the health care needs of the child, to a family support model that focuses on the child’s developmental need for family life and provides holistic support to families.

CONCLUSION

Findings from the various sources informing this study reveal significant challenges to assuring family life for all children. Overall, the participants concurred that children with complex health care needs have a right to grow up in a growth-promoting family with the relational security of well-supported parents, embedded in supportive communities and service system environments. Given the important developmental need of children for family life, families of children with complex health care needs require better support to provide it. Families have tremendous resilience and strength; at the same time, they are frequently exhausted, isolated, and financially strained. There was consensus that the current systems, including health, education, mental retardation, and child welfare, fall short of providing the desired and needed service system environment.

The participants identified many resources and innovative efforts in Pennsylvania and nationally to build on. In working toward a more responsive system, families and young adults represent one, currently underutilized resource. Guided by the ethos, “Nothing about us without us,” if families and young adults with disabilities are more integrally involved in planning and evaluation of services, there is increased likelihood that efforts will better address their issues. Families are motivated and energized by the strength and resilience of their children; by the support of family and friends; and by support from particular exceptional service providers. Those in the service system who know such families and providers, in turn, can be motivated and energized. This positive energy and those who know what works can be mobilized to help solve the problems that hamper families, and to promote approaches that facilitate families raising children with complex health care needs.

The participants had numerous suggestions and recommendations about how to build a more responsive system, emphasizing work in the areas of policy development; awareness of needs and understanding of families’ experiences; dissemination of knowledge and information; and, most importantly, ready access to individualized support. The participants agreed that strategies for cross system involvement of families and stakeholders offered some of the best opportunities for learning and problem-solving to make the changes necessary to create “real life” services and supports that would more effectively promote family life for children with complex health care needs.

I. INTRODUCTION

This report grew out of the efforts of the *Every Child Deserves a Home and Family Coalition*, a coalition that was formed in Pennsylvania in 2004 by people concerned about the prevalence of congregate care for children with disabilities and about the level of support for families caring for children with complex health care needs. The Coalition set as its mission to “ensure that all children with complex health care needs and other disabilities have the opportunity to grow up in a loving, lasting family.” This coalition is composed of parents, young people with disabilities and complex health care needs, advocates, educators, health care professionals, direct service providers, policy makers, community service agencies, funders, policy makers, and other allies. As part of its work, coalition members identified the need to investigate and analyze issues related to support for families who have children with complex health care needs.

The Coalition members’ voices join a growing national consensus that children with complex health care needs benefit from living with families (American Academy of Pediatrics Committee on Children with Disabilities, 1993; Office of Disease Prevention and Health Promotion, 2005). Two key components of assuring family life are permanency planning and family centered supports. *Permanency planning* refers to planning based on the premise and value that children belong in families. It requires (1) adequate support for birth families; and (2) recruitment and support of other families to care for children who cannot live with their birth families. *Family-centered supports* refer to supports that are individualized and flexible, based on the needs of the individual child and family, and that are developed in the context of collaboration and partnership with families.

Similar to many other states, Pennsylvania faces challenges in assuring family life for all children, and supporting their families in family-centered ways. Estimates suggest at least 2000 children with disabilities live in out-of-home placements in Pennsylvania. The Maternal and Child Health Bureau reports that almost 10% of Pennsylvania’s children with special health care needs are without insurance sometime during the year and of those with insurance, almost 32% do not have insurance that is adequate. Nationally, and across Pennsylvania, 33% of families with children with special health care needs report not receiving services in family-centered ways (U.S. Department of Health and Human Services, 2004).

There is a lack of congruence between the *belief* that children should grow up in families and the *reality* that some children do not live with families and some families do not have the supports they need. The Highmark Foundation was approached about the possibility of supporting a project to look at the multiple factors that affect families caring for children with complex health care needs to better understand what constitutes essential support to assure family life. The Highmark Foundation generously agreed to fund the project and the report that follows is a summary of its findings.

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II. LITERATURE REVIEW

Nancy Rosenau

The overarching question that guides this literature review is: “What constitutes essential support for families caring for children with complex health care needs?” Raising children is never easy. All families face struggles in raising their children. Families who are raising children with complex health care needs struggle, too. Indeed, their struggles are documented in many research studies. How they struggle, what eases their struggles, and why some families struggle more than others with children with similar characteristics is documented in a complex set of findings from a wide-ranging set of research endeavors. The purpose of this literature review is to sort out some of those complex factors in order to inform the pursuit of better ways of helping families. The review presented here is a summary of a much more extensive and in-depth review. Contact details to obtain the full review and references are provided in the Appendix.

The review first examines the needs of children with complex health care conditions and then turns to the needs of families who are caring for them. Finally, the review addresses ways in which service systems and funding mechanisms facilitate or hamper family life for children with complex health care needs.

WHAT DO CHILDREN WITH COMPLEX HEALTH CARE CONDITIONS NEED?

The working definition used in the project to identify children with complex health care needs is: Children who require advanced medical care and sophisticated technology because of chronic illness and/or disability. Literature regarding such children is found both in the disability field and health care field. Much of the literature does not make a distinction between chronic conditions and disability (Perrin, 2002). The overlap and blurred boundaries in the literature are reflective of the fact that there is not a universal, commonly used definition for children who fall under the operating definition of this study. A related but somewhat broader definition in common use is one developed by the Maternal and Child Health Bureau that identifies children with special health care needs (CSHCN):

Children with special health care needs are those who have or are at risk of a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (Allen, 2004).

Another relevant definition is the term “chronic health condition” used for insurance purposes. A chronic health care condition must meet three criteria (National Center on Financing CSHCN, Issue 1):

1. Physical, mental, emotional, behavioral, or developmental disorder
2. Expected to last at least twelve months or longer
3. Requires ongoing treatment and/or monitoring

Another relevant term is “developmental disabilities” which is defined under the Developmental Disabilities Assistance and Bill of Rights Act (Silverstein, 2000) as a severe, chronic disability that meets the following criteria:

1. Attributable to a mental or physical impairment
2. Manifested before age 22
3. Likely to continue indefinitely
4. Results in substantial impairment in three or more areas of major life activity
5. Reflects the need for extended services, supports, or other assistance that are individually planned and coordinated

All of these definitions and the literature that references them include or have relevance for the children who are the interest of this project.

Incidence and Prevalence

Overall, the incidence of children born with abnormalities hasn't changed in 20 years, but increased survival and life expectancy has resulted in dramatic increases in prevalence (Allen, 2004). In the 1960s, an estimated 2% of children had chronic health conditions, but by the 1990s the percentage had risen to 7% (Perrin, 2002).

Child Development

There is considerable evidence to suggest that physical as well as overall functioning of children with complex health care needs may improve as a direct result of being cared for in a family home and that families play a pivotal role in a child's adjustment to illness (Allen, 2004; American Academy of Pediatrics, 1993; Kirk, 1998; Knafl, Breitmayer, Galla, & Zoeller, 1996). The Committee on Children with Disabilities of the American Academy of Pediatrics (1993) identified the important role of parents.

Improved outcomes are most likely to occur when services are based on the premise that parents or primary caregivers are the most important factors influencing a child's development (American Academy of Pediatrics, 1993, p. 163).

An explosion of child development research in the past decade was reviewed in a two and a half year project of National Research Council and the Institute of Medicine. Seventeen nationally recognized child development experts evaluated and integrated the current science of early childhood development (Shonkoff & Phillips, 2000). Their report identified the centrality of parenting in a child's early life as a critical feature

in development. Recent advances in brain research show neurological evidence of the growth-fostering importance of close relationships for development in children and differences between institution-reared and family-reared children (Zeanah et al., 2003). According to the report, the scientific evidence about the significance of early experiences and parental relationships for child development is “incontrovertible” (Shonkoff & Phillips, 2000, p. 6).

Attachment

The parent-child relationship has been the subject of a large body of empirical research under the theoretical framework of “attachment.” Forty years of attachment research has documented that the quality of caregiving in childhood and the establishment of an emotionally secure parental relationship significantly influences later social and emotional development. The necessary relationship is characterized by responsiveness, protection, affection, availability, reliability, continuity, and emotional investment (Shonkoff & Phillips, 2000).

The circumstances that surround parents exert a powerful influence on their capacity to meet the attachment needs of their children. Children’s well-being depends on the health and well-being of their parents (Shonkoff & Phillips, 2000). Extensive or protracted care needs of children can present demands on parental time and energy. Parents’ stress and fatigue can reduce their responsiveness. For many children with complex health care conditions, the extensiveness of a child’s needs and resulting care demands increase the likelihood of multiple caregivers (e.g., nurses, personal attendants, or home help aides). Additional caregivers who supplement parental care can be helpful in (1) assisting with a child’s atypical needs, and (2) providing a rest for parents to re-energize, allowing expression of sensitivity that might otherwise be unavailable from overburdened parents (Carlson, Sampson, & Sroufe, 2003).

While helpful to the parent, multiple caregivers have an effect on the child. According to child development research, the effect is dependent on both the quality of the primary relationship and the quality of the secondary caregiver relationship (Carlson et al., 2003; Shonkoff & Phillips, 2000; van Ijzendoor & Sagi, 1999). When care necessitates multiple caregivers, child development is optimized when (1) the family home provides a secure parental relationship and (2) supplemental caregivers form a positive relationship with the child characterized by continuity, sensitivity, responsiveness, and emotional investment (Howes, 1999; Shonkoff & Phillips, 2000). Parental selection of alternate caregivers is influential in a child’s life, but parental selection is constrained by external factors such as availability of extended family caregivers, income, decisions of employers, government policies, and the way services are organized (Shonkoff & Phillips, 2000).

Out-of-Home Placement

Families without adequate long-term support may seek out-of-home placement. Long-term care for children with complex care needs has historically occurred in hospital settings or nursing homes (Hochstadt & Yost, 1991). While recent care arrangements have shifted to home care, children with complex health care needs continue to be at risk of institutional care. The Office of Disease Prevention and Health Promotion reports 24,300 children and young adults under age 21 living in congregate care settings (Office of Disease Prevention and Health Promotion, 2005). There are at least 100 pediatric facilities in the U.S. and Canada including

dedicated pediatric facilities and pediatric units in facilities serving other populations, and the number of pediatric facilities is growing (American Medical Directors Association, 2004). Complete data about residential placement of children with complex health care needs is difficult to tease out because this population is served through various systems including developmental disabilities, child welfare, and public health, each overseeing their own versions of public and private congregate care.

A long-standing body of literature on institution-reared children has compared outcomes for children raised in congregate care with outcomes for family-reared children. Although the literature is complex and fraught with methodological challenges, it identifies limitations of congregate care where no primary parental figure is part of a child's daily life (Shonkoff & Phillips, 2000). In a study specific to complex health care needs, 219 children with chronic conditions were randomly assigned to either a home care program or a traditional hospital-based program. Home care was found to be more effective in improving the child's psychological adjustment as well as the family's satisfaction (Shelton, Jeppson, & Johnson, 1989). Better outcomes are consistently found for children raised in a continuous family home by responsive parents, compared to children raised by rotating staff in congregate settings which offer limited opportunities for primary relationships and spontaneity (Harden, 2002; Sagi-Schwartz & Aviezer, 2005; Smyke, Dumitrescu, & Zeanah, 2002; Zeanah, Smykes, & Settles, 2006).

In light of research around attachment and residential care for children generally, the merits of such care arrangements are increasingly being challenged for children with complex health care needs (Johnson, Kastner, & the Committee/Section on Children with Disabilities, 2005). Systematic study has now well documented the centrality of parental responsiveness attuned to the child in meeting developmental needs (Shonkoff & Phillips, 2000) and the negative consequences of congregate care (Harden, 2002; Sagi-Schwartz & Aviezer, 2005; Zeanah et al., 2006). The irreplaceable distinction between congregate care and family life is the parent-child relationship.

Summary of Children's Needs

In summary, a great deal is now known about what is required for optimal development than was known even a decade ago. Family life for children is not simply a normative pattern. Based on now well-established research evidence about child development from brain science and attachment studies, we know that family life, in particular its primary feature of a parent-child relationship, is a developmental imperative. Child psychologist, Stanley Greenspan (1997) described this relationship as an irreducible need of childhood:

Every child needs a safe, secure environment that includes at least one stable, predictable, comforting, and protective relationship with an adult, not necessarily a biological parent, who has made a long-term commitment to the child's daily welfare and who has the means, time, and personal qualities to carry it out (Greenspan, 1997, p. 264).

In answer to the question of what children need who have complex health care conditions, it is clear that they need a secure emotional relationship with a responsive parent and the daily experience of home life where such a relationship develops. Most often, but not always, this relationship will be with the parent(s) to whom the

child was born. That children need parents and the relationships found in daily life with a family is clear. We turn next to what families need in order to provide the nurturing relationship and home life that children need.

WHAT DO FAMILIES NEED?

All families face tasks and stressors in raising their children. For children with complex health care needs, parents have the same as well as some exaggerated and additional tasks and stressors (Knafl et al., 1996; Knafl & Santacroce, 2004) for which they require a wide range of types of assistance and support.

Responses to Disability and Chronic Health Conditions

How well families adapt to raising children with significant disabilities has been the subject of a long line of research. Early research assumed that a child's disability was damaging to otherwise capable families (Ferguson, 2002) and characterized a family with a child with a disability as a family with a disability (Glidden, 1993). The child with a disability was seen as the source of marital disharmony and family stress. Parental responses were interpreted through a grief model to include guilt, anger, denial, and the chronic sorrow of loss. Much of the parental reaction literature did not address variables such as level of support, medical professional attitudes, or availability of social networks (Blacher, 1984). Research methodologies behind uniformly negative findings have been challenged with the conclusion that flawed methodologies led to an erroneous absence of positive outcomes (Shelton, Jeppson, & Johnson, 1989). A more complex and contextual view has emerged that takes into account circumstances, resources, and supports and documents a wider range of responses from floundering to thriving. "Families live, love, and survive within social contexts and these contexts influence their physical, emotional, and social well-being" (Krahn, 1993, p. 245).

A large body of literature has now identified numerous positive responses to family life with a member with significant disabilities or complex health care needs (e.g., Case-Smith, 2004; Ferguson, 2002; Hastings & Taunt, 2002; Knafl & Santacroce, 2004; Scorgie & Sobsey, 2000; Trute & Hauch, 1988). Interviews with families have identified that a sense of control characterized by positive prospects for the future and genuine partnerships with professionals and service providers contributes to positive adaptation (Knox, Parmeter, Atkinson, & Yazbeck, 2000). A study of parents' perceptions found that parents felt most invigorated in their parenthood when professional interactions helped them gain confidence as a parent and when professionals saw their child as valuable (Lindblad, Rasmussen, & Sandman, 2005).

Families' positive responses, however, do not mean they do not face stressful or negative consequences (Gallimore, Weisner, Kaufman, & Bernheim, 1989). A literature review by Kirk (1998) provides a glimpse into families' daily routines and experiences in caring for children who are technology dependent. Four themes emerged: (1) social impact (e.g., housebound by care demands, isolation, exhaustion, loss of privacy); (2) emotional impact (e.g., fear, anxiety, financial stress); (3) financial impact (e.g., inadequate funding, reduced or lost employment, uncovered medical costs); and (4) service usage impact (e.g., constant need to fight for services, inadequate services, lack of information about services, time-consuming coordination). A study of the daily lives of eight families with children with chronic medical conditions and disabilities found three

themes: (1) the challenge of always “being there,” (2) changes in career plans, and (3) tolerating compromises (Case-Smith, 2004). In another study, families reported that most stress and dissatisfaction came from outside sources. Families indicated that the care of their child was worthwhile and that they did not consider it a burden, but they consistently identified the burden as the continual struggle to get the support they need (Knoll, 1989). While families’ experiences include many negative elements, most of the struggles families report are not with negativity toward the child’s disability or illness, but rather reflect things that are amenable to change with better support.

A common and crucial feature of support for many families is the necessity of interacting with multiple helpers and representatives from large service systems (Imber-Black, 1988). The complexity of a child’s needs often requires families to admit helpers into the home to supplement their care by providing hands-on assistance or expertise or both. In-home assistance is a mixed blessing. Families with children with significant needs must often shift their sense of family boundaries to accommodate the entry of individuals from health care and disability services systems. Families report the invasion of privacy as a strain in an already stressful situation, and yet they find they cannot manage their child’s care at home without it. Successful resolution of the inherent tension depends on the characteristics of the helper in terms of competence, attitude, availability, and reliability; and the quality of relationship established between parent and helper (Patterson, Jernell, Leonard, & Titus, 1994).

The extent to which families are able to build a “normal” life is often dependent on the extent of support they have. The wide range of parental responses to children with complex needs requires acknowledgement of the fact that some families manage despite few resources; some families who want to raise their children at home seek out-of-home placement when circumstances become insurmountable or supports are inadequate; and some families choose not to raise their children even with available resources.

Out-of-Home Placement Decisions

A substantial body of literature has tracked out-of-home placement decision-making for children with developmental disabilities. Although not exclusively about complex health needs, children with medical issues are included and sometimes targeted in this literature. In a recent small, but particularly revealing study, Bruns (2000) interviewed five families of children with complex medical needs under the age of 5 who had placed their children in skilled nursing facilities. Parents reported that their initial excitement about the child coming home after extensive hospitalizations had evolved to weariness and subsequent placement. Parents attributed their weariness to a variety of factors: the 24-hour nature of care, their not-always successful struggle to soothe and comfort their children, a sense of isolation due to emotional distance of extended family and friends, lack of services especially preschool and respite, discomfort with strangers in the home providing necessary nursing services, high turnover in nurses, uncovered medical costs, and bureaucratic mix-ups. Parents remarked on the cumulative and relentless nature of these factors. Put simply, one family summarized the feeling: “This is not going to end” (Bruns, 2000, p. 53).

Parents reported that their decision to place was also related to financial burdens. Families reported that insurance and government funds did not cover all illness-related expenses, especially “hidden” expenses like

long distance calls or travel to specialists. Parents stressed that they wanted their child to remain at home, but that costs associated with the child's care were beyond their means. Parents said they would bring their child home "in a heartbeat" if funds were available (p. 57). One parent expressed frustration in contrasting the level of public financial resources devoted to facility care with what was available for family care.

I don't feel like we need the government to pay us money to keep him home, but why will they pay somebody else money to take care of him when we wanted to and couldn't afford to? (Bruns, 2000, p. 57)

Another study interviewed 62 families who had placed their children (Blacher & Baker, 1994). When asked about their reasons for placing, over half of indicated a gradual accumulation of system-related stressors typified by the following quote from a parent:

I was tired, not so much of caring for Jessie, but of fighting with the Regional Center, the nursing registry, Medical [the Medicaid system] and so on to get the services Jessie needed (Blacher & Baker, 1994, p. 12).

Socioeconomic Influences

Families with children with disabilities and complex health care needs struggle disproportionately compared to other families. There is considerable evidence that families of children with disabilities and complex medical conditions struggle more if they are also members of a racial or ethnic minority group or have lower socioeconomic status. The link between poverty, minority status, and a disability or chronic health care condition is well established in the literature (Johnson, Guinan, Brown, & Shearer, 2005). While the incidence of congenital birth abnormalities does not vary by racial group, chronic health conditions and disabilities are more prevalent in children of racial minorities (Allen, 2004). According to the 2000 U.S. Census (Wang, 2005) report on Disability and American Families, (1) families with children with disabilities are more likely to live in poverty, (2) racial minority families are more likely to include a member with a disability, and (3) racial minority families are more likely to live in poverty.

Nationally representative samples provide evidence of lower labor force participation and consequent lost income among mothers who care for children with disabilities (Lukemeyer, Meyers, & Smeeding, 2000). The U.S. Census report found that families raising children with disabilities have a lower median income than families raising children without disabilities. Median annual income of parents of children with disabilities is nearly \$12,000 per year lower compared to parents of other children and almost \$17,000 lower for children with physical disabilities (Wang, 2005).

Socioeconomic disparities have been found, not only in the amount of care, but also in the quality and appropriateness of care for low-income and poor families (Linkins, McIntosh, Bell, & Chong, 2002). Minority and poor or near-poor families are more likely to delay or forgo health care due to financial problems (Huang, Kagan, Yu, & Strickland, 2005). A National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, 2004) found that families with higher incomes were more likely to report family-centered care and that uninsured families were most likely to report care that was not family-centered.

A variety of national surveys have captured an aggregate picture of the economic implications for families raising children with special health care needs and disabilities. The National Survey of Health Care Experiences

of Children with Special Health Care Needs found that 34% of families provided 20 hours per week of exceptional care and that 56% of families faced financial burdens (cited in Hecht, 2001). The National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, 2004) found 17% of families cut back on paid employment and 13% stopped working altogether to care for their child.

Health-related costs not covered by insurance have a major impact on families who face increased care responsibilities and expenditures with decreased earnings (Allen, 2004). The financial effect on families is cumulative over their life span. Child care costs and reduced income are magnified many more times across many more years as dependency stretches over a longer period (Hodapp & Zigler, 1993). A longitudinal study found that early reductions in employment patterns persisted into mid-life (Parish, Seltzer, Greenberg, & Floyd, 2004). Foregone employment has implications for aging parents who consequently do not have employer-provided retirement contributions and health care benefits.

Cultural Influences

Factors that influence family decisions about raising children and using services are highly influenced by cultural values such as beliefs about family and kinship obligations, the appropriateness of seeking support outside the family network, privacy and public airing of problems, and the relative importance of family group cohesion versus personal achievement.

A common limitation in the research on families with children with chronic health care needs and disabilities has been that findings are based on only white, middle class subjects (Mary, 1990). Despite these limitations, however, there is evidence that cultural differences play a role in families with children with chronic health care needs and disabilities. Research studies have found cultural group differences in a variety of areas. Mary (1990) found that the grief was not a universal response to a child with a disability in a more culturally diverse sample. Studies have found higher use of extended family care for children with disabilities and increased likelihood of remaining at home in ethnic minority families. Other studies have found higher perceived burden of care in white families compared to ethnic minorities. Cultural differences have also been found in the likelihood of minorities accessing public agency services (Krahn, 1993). Hispanics (Bailey et al., 1999; Heller, Markwardt, Rowitz, & Farber, 1994; Magana, 1999) and African Americans (Quirk et al., 1986; Rogers-Dulan & Blacher, 1995) have lower utilization rates of formal services (although with considerable variation). Explanations offered for variations include: language or communication problems; lack of knowledge about systems; acceptability of external help seeking; discrimination by service systems; and distrust of dominant group authority.

Summary of Families' Needs

The literature around families with children with disabilities and complex health care reflects an evolution of views of families' needs. Understanding has shifted from viewing families as harmed by the presence of a child with complex needs and weighed down by chronic sorrow and powerlessness, to recognizing that the majority of families experience positive adaptation and even beneficial outcomes such as personal growth, family pride,

and greater appreciation for life. Even with positive adaptation, however, families face numerous struggles as a result of external factors that are amenable to change with better support.

Families' daily life experiences are shaped by multiple interrelated contexts including their culturally-shaped beliefs and values; the circumstances and configuration of their households; and the availability of external social, emotional, and financial support. Without adequate support, families can be housebound by their child's extraordinary care needs; exhausted by the daily demands of having to always be there; stressed by financial burdens of increased expenses and forgone employment; frustrated by inadequate, complex, and fragmented service systems; and anxious about their future and the cumulative effect of the extended duration of childhood dependency.

In answer to the question of what families need to care for their children with complex health conditions, they need to be supported. They need trusted people to assist them, equipment and home modifications, information and advice, and financial assistance. But to thrive, they also need to have a sense of control, hope for a positive future, and genuine partnerships with those in a position to help. Families with children with complex health care needs or disabilities are a heterogeneous group and their needs are likewise heterogeneous. Families vary in their personal capacities; in the nature and intensity of their struggles; in their resources and use of supports; and in the ideas and perceptions that shape their decisions. Families differ in their use of formal services, but there is also growing evidence about discriminatory differences in access to services that are not explained by family preferences. We turn now to how service systems respond to families with children with complex health care needs.

HOW DO SERVICES, SUPPORTS, RESOURCES, SYSTEM DESIGNS, AND FUNDING MECHANISMS FACILITATE OR HAMPER FAMILY LIFE FOR CHILDREN WITH COMPLEX HEALTH CARE NEEDS?

Families with members with chronic health conditions have greater than average need for support and often require complex orchestration of supports and services. Studies of parents' experiences raising children with complex medical technology show strong recurrent themes reflecting the inadequacy of support they receive (e.g., Diehl, Moffett, & Wade, 1991; Kirk, 1998). Parents report fragmentation of services; problems with getting information; lack of adequacy, timeliness and/or flexibility of support; ineligibility for financial assistance despite staggering medical bills; and lack of social acceptance.

Support has been found to play a significant role in decreasing the demands and stress associated with caring for children with disabilities (Parish, Pomeranz-Essley, & Braddock, 2003). Family support has become a national movement which views the family as the recipient of services rather than one of its members. Family support is defined in legislation in the Omnibus Budget Reconciliation Act of 1993:

Community-based services that promote the well-being of children and families designed to increase the strength and stability of families, to increase parents' confidence and competence in their parenting abilities, and to afford children stable and supportive family environments and otherwise enhance child development (Kagan, 1996).

Since the 1970s, numerous definitions and sets of principles have been offered as underpinning family support for children with disabilities. These incorporate such features as individualized and flexible supports; family control of resources; family oversight of design and implementation; and promotion of inclusion (Agosta & Melda, 1996; Center on Human Policy, 1987).

Families raising children with complex health care needs often come in contact with multiple services systems including health care, developmental disabilities, education, child welfare, and income support systems. How systems have been organized has a tremendous impact on families with children with complex health needs. Families may fall between the cracks of various systems or find gaps in support that other families take for granted. For example, although all children are guaranteed an education, if the education system cannot routinely provide a full day of schooling because of health concerns, families face increased childcare responsibilities and costs that other families face only occasionally or only in early childhood.

The systems that affect families raising children with complex health care needs are undergoing an evolution in the way services are organized. Policy changes in all systems have contributed to an increased emphasis on care at home but have not (yet) contributed to adequate support for families providing home care. Below key trends and issues for each of four major systems serving children with complex health care needs are summarized.

The Developmental Disabilities Service System

- The trend away from institutions has shifted resources to community-based services.
- Family support, however, makes up only 4% of total service dollars.
- Medicaid waivers, which leverage resources formerly allocated to institutions to support families, serve a limited number of children and could be expanded.
- Cash subsidies have demonstrated a way to provide flexible and individualized support for families (Agosta & Melda, 1996; Parish et al., 2003; Seltzer & Heller, 1997)

The Health Care System

- A shift has been underway to move from hospital to home-based services for children with increasingly complex medical needs.
- Healthy People 2010, the national public health agenda, identifies congregate care as inconsistent with the developmental needs of children and positive health policy and practice.
- The concept of a “medical home” is gaining interest whereby comprehensive, family-centered health care is coordinated through an identified primary care physician.
- Health care financing reforms intended to address fragmentation and inadequacy of funding have been piecemeal and suffer from a lack of data and good research about their effects on children with complex health care needs and their families.
- Care coordination is a promising practice directed at the family as a whole crossing a broad range of programs and community services.
- Family-directed services are another promising way of enabling families to have flexibility and control.

(Hochstadt & Yost, 1991; Johnson & Kastner, 2005; Perrin, 2002; Shelton et al. 1989)

Income Support Systems

- The presence of a disability increases the risk of poverty.
- Poverty is linked to higher prevalence and severity of disability.
- Families of children with complex health care needs have decreased labor force participation and reduced insurance coverage and retirement benefits.
- Even with insurance, families of children with complex health care needs have higher out-of-pocket costs for non-covered needs that they must manage with lower income than other families.
- SSI, which is intended to provide cash assistance to low-income families with children with disabilities, is often unable to lift families with health and disability related expenses out of poverty.

(Huang et al., 2005; Lukemeyer et al., 2000; Parish et al., 2004; Wang, 2005)

Child Welfare and Protection Services

- Children with disabilities and chronic health care needs are overrepresented in child welfare systems.
- A link between disability, race, and socioeconomic status is well-established as is a link between disability and abuse and neglect.
- Permanency planning is a philosophy, a policy framework, and a planning process to assure family life for children that has been mandated by federal legislation in child welfare systems since 1980.
- Children with disabilities and chronic health care needs have poorer permanency outcomes than other children who come into care.
- Specialized family foster care is an evidence-based cost-effective way to provide family-based alternatives to residential care for children with complex health care needs who cannot live with their birth families.
- Adoption subsidies provide increased support for potential adoptive families for children with special health care needs.

(Bruhn, 2003; Hochstadt & Yost, 1991; Rosenau, 2000; Taylor, Lakin, & Hill, 1989)

Summary of System Responses to Child and Family Needs

A national family support movement is underway which is challenging conventional bureaucracies and traditional categorical service boundaries, but this national trend has not yet been fully embraced by the service systems that affect children with complex health care needs and their families.

In answer to the question of how service systems facilitate or hamper family life for children with complex health care needs, they facilitate when they prioritize family life for children and when they treat families as partners in figuring out what support will best fit their situation to enable them to thrive as a family. They hamper when families who seek assistance face fragmentation, complexity, and confusion, and when cost constraining decisions are disconnected from child and family well-being.

Solutions to meet the urgent unmet and under-met support needs of children with complex health care conditions and their families have been illusive. Children with disabilities and complex health care needs are at a higher risk than other children for placement in congregate care. A policy framework for addressing this risk is permanency planning which takes as its premise the value of rearing children in families (Rosenau, 2000; Taylor, Lakin, & Hill, 1989). Federal legislation mandating permanency in child welfare systems requires

efforts to support stable, enduring family homes for children, however, permanency planning has not typically been embraced as policy in disability services with the exception of a few states such as Michigan and Texas (Rosenau, 2000). Two interrelated features required for implementing permanency are (1) adequate support for birth families; and (2) recruitment and support of other families to care for children who cannot live with their birth families.

A driving philosophy that underpins successful approaches to supporting families is the belief that family life is essential for children and that sufficient support should be provided to a family, whether the family of origin or another family, so that they can thrive and offer their children the nurturing and enduring relationships and experience of belonging that are the essential features of family life and its developmental benefits.

OVERALL SUMMARY

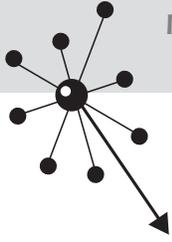
The literature reviewed here offers a broad view of what is not working. It offers less clarity about what is working but suggests potential avenues to explore. This much seems clear from the literature reviewed:

- Children with complex health care conditions and disabilities need families.
- Families need support.
- Families are not currently supported well.
- Collectively we need to reconsider how better to support families so that both families and children with complex health care needs can thrive.

The issues that families with children with complex health care needs face are complicated. Problems raised in trying to support them have so far been intractable. The literature about children with special health care needs and their families is vast, yet solutions are not readily visible. What is visible is the urgency of need of real families and real children.

Policy-making requires some degree of public understanding. According to a recent National Council on Disability report on long-term services and supports, neither policy-makers nor the general public understands the needs of individuals living with lifelong disabilities (National Council on Disability, 2005). Many American citizens have trouble imagining the lives and circumstances of families raising children with complex health needs (White, 1996). Few members of the general public understand the deficiencies in service systems until they need them. Most members of the general public expect that there will be services available to support them should their family have a member with a severe disability or chronic health care need (National Council on Disability, 2005).

To alter these understanding gaps, the stories of families must gain more public clarity and visibility (Kagan, 1996). In reviewing the history of research on parental reactions to having a child with a disability, Ferguson (2002) identified the need for extended narrative accounts of families that capture the full range of details of their daily lives and family routines, especially narratives that reflect cultural diversity and intergenerational variation. Perhaps the stories that emerge from the project for which this literature review was prepared, will contribute to wider understanding, richer imagining, and better solutions.



III. FAMILY PERSPECTIVES

Pam Walker, Nancy Rosenau, Bonnie Shoultz, Holly Manaseri, and Perri Harris

ASSURING FAMILY LIFE: A STUDY OF THE EXPERIENCES OF FAMILIES RAISING CHILDREN WITH COMPLEX HEALTH CARE NEEDS

A key component of this study to assess the factors that affect families raising children with complex health care needs was to hear the perspectives of families about their lives and the services and supports they receive and need.

Design of the study

The research on family perspectives involved interviews with 34 families (mothers) and 4 young adults with disabilities. Participants were recruited through agencies that provide services to families of people with disabilities and others who have contact with families or young adults with complex health needs. A flyer describing the study was distributed to agencies that serve children with complex health care needs and their families; these agencies then distributed this flyer to families. Based on information in the flyer, families who were interested in participating in the study contacted Every Child, Inc. Written consent was obtained for participation in the study, and all families were assured that their responses were confidential (e.g., no family would be identified by name in the study) and that they could choose to not answer specific questions or could withdraw from the study at any time.

An interview guide was developed containing general areas of questioning. We completed 35 telephone interviews (34 families and 1 young adult). After the phone interview, participants were asked if they were willing to participate in an in-person home visit and interview as well. We conducted home visits and in-person interviews with a total of 15 families and 3 young adults (this includes the 1 young adult who participated in the phone interview, as well as 3 young adults who we did not interview by phone). These visits provided information that expanded upon that gained from phone interviews. In addition, through these visits, we obtained brief observation of families, children, and caregivers as they went about their daily life. Information about the demographics of these participants is presented in the following section.

Demographics

Overall, as noted above, this section of the report is based on interviews with 38 families and individuals. Of the 38 interviews, 34 were with families, and within families, almost exclusively the mothers (in a few cases, fathers participated as well as mothers). The remaining 4 interviews were with young adults (ages 19-23). The

large majority (30) of families were birth families; 2 were adoptive families, 1 was a foster family, and 1 was a birth family whose child is in foster care. Twenty-three of the families were white; 7 were African American; and 4 were bi-racial; all 4 of the young adults were white. Twelve of the families lived in urban areas; 14 lived in rural areas; and 8 in suburban locations; two of the young adults lived in suburban locations, one in a medium size city, and one in a rural area. There were a total of 37 children with special health care needs in these families (a few families had more than one child with special health care needs). The children and young adults ranged in age from less than 1 year old to 23 years old. They have a wide range of disabilities associated with things such as prematurity, mental retardation, cerebral palsy, spinal muscular atrophy, achondroplasia, a brain tumor, muscular dystrophy, automobile accident, and more. Many of them have multiple disabilities that also include deafness, blindness, mobility impairments, limited communication, and so forth. Approximately 15 of the children and all 4 of the young adults use ventilators and/or are fed through g-tubes.

PROFILES

RYAN

Barb is a single, divorced mom with two children. One has a rare condition which causes severe disabilities. Her son, Ryan, is four years old. He doesn't walk or talk. He uses a ventilator to breathe and is fed by a feeding tube into his stomach and has constant seizures. He doesn't appear to be aware of others around him, but his mother feels he knows her and sense her presence. His condition is precarious and subject to rapid changes, so he needs a specially trained health care provider within eyesight at all times. His mother is able to care for him with the assistance of nurses which she has 18 hours per day. Although she would prefer working, she has not been able to find a job that would accommodate the unpredictability of his health care. She says, "I wouldn't be a reliable, dependable worker." When the nurses don't show up, she is required to be at his side for 16 hours straight. "I have wonderful nurses, but things happen: sickness, weather, family responsibilities." Sometimes, even with the nurse present, she needs to be available too. As she describes it, "On a bad day, I can't take a shower, take the dog out, or go downstairs for a load of laundry."

**"We had
primary
health
insurance
but the
bills are still
outrageous."**

BEN

Ben is an outgoing, creative 15 year old who lives with his parents in a semi-rural community. He enjoys acting and graphic arts, would like to learn to drive, and is planning on going to college. When he was an infant, he was diagnosed with spinal muscular atrophy (SMA). He has used a power wheelchair since he was about 4 years old, has had a g-tube since he was about 8, and uses a bipap ventilator at night. Ben has a full-time aide in school, and a nighttime nurse Monday-Friday, from 11 pm – 7 am. Respite is provided by the Ventilator Assisted Children's Program. When he began school, his parents hoped he could attend school with other children who live nearby. However, that school was inaccessible. His mother fought for a few years to get him into that school, but was unsuccessful. Over the years, there have been various other battles with the school system, as they have periodically encountered negative attitudes among teachers and administrators. Currently, Ben is enjoying his high school years. However, outside of school, he is isolated from peers who gather in homes and other community places that are not accessible. A manual wheelchair would increase Ben's mobility (e.g., including the ability to ride with friends), but the insurance company denied this request as it was not considered a "medical necessity." Though they could use some of the kinds of services provided through mental retardation services (e.g., residential, vocational, service coordination), he does not qualify for these services based on his high cognitive ability. Ben's parents are concerned about planning for college as well as his transition to adult services. They feel it would be very helpful to be engaged in such planning at this point in time, rather than waiting until Ben is 17 or 18, when vocational planning typically begins.

CHRISTIE

Judy and Ron live with their 7 year old daughter, Christie, and her 6 year old brother, in a small upstairs flat in a large urban area. Christie got sick at 2 months of age with a rare disease that resulted in her disabilities. She has multiple impairments, including cerebral palsy, seizures, and a severe developmental delay. She uses a ventilator at night and gets nourishment through a gastrostomy tube. Initially, doctors said she wouldn't live past 5 years of age. Her mom describes her as a "fighter." When Christie first became ill, Judy wishes there had been more information and medical coordination available. She wishes her physicians had described the positive aspects of the future as well as the negative aspects of her daughter's future. Ron works outside the home; Judy has also tried to work but found it too difficult to work and attend to Christie's special needs as well. Christie praises her daughter's school and says the staff have been supportive to the whole family. At various times, the family has qualified for in-home nursing services. At one point they had 40 hours of nursing per week. Judy reported that they did not always need that much, but that if they did not use the 40 hours, they would lose it. They have also been eligible for the Vent Program, which allows 60 hours of respite every 3 months to use in any arrangement they choose. The family appreciates this flexibility. Accessibility and mobility are major issues for the family. As Christie grows, it is becoming increasingly difficult for her mother to carry her. Christie's specially adapted wheelchair will not fit in the family car. They have a donated van, but no lift. Medicaid will pay for a driver and a van with a lift to pick them up to take them to appointments, but won't pay for a lift for their family van. Judy doesn't understand logic of denying a one-time expense for a lift when compared to the ongoing cost of paying for a van and driver. They also need home modifications. They carry Christie up the stairs and around the home because there is little room to maneuver a wheelchair and other special equipment in the small apartment. They are on waiting lists for Medicaid waivers that would provide adaptive equipment and home and vehicle modifications. They were on the ongoing list for 3 years, and were then moved to the emergency list which they have been on for an additional 3 years. Overall, Judy most wishes people who work in the system could have a better understanding of families' daily lives, and that parents could understand the logic behind decisions that are made by those in the system.

"Other than a voice on the phone, they have me on a computer screen; they don't have a clue."

KEY THEMES AND ISSUES

There were many themes based on the perspectives of families and young adults with disabilities. While the perspectives of the young adults who were interviewed are integrated into all sections of the paper, a separate section is also devoted to special issues that they raised.

Efforts to Assure Family Life: Parenting Work, Health-Care Related Work, and System-Imposed Work

Like all other families, the families in this study want, most of all, to create a secure, nurturing family life for their children with special health care needs, as well as for their family as a whole. As is common among most families with children, the parents in our study were very busy trying to juggle paid employment with the work and responsibilities that typically go along with raising children, maintaining a household, and creating a quality family life. What was most striking about the interviews with families was how much parenting energy was devoted to work above and beyond the responsibilities of most parents. In part, this extra energy was due to the child's health care condition. But, in part, it was also due to the way in which systems of care are organized, sometimes offering essential supports but often times failing to do so. Having children with special health care needs, often multiple health care needs, means a significant amount of health care related work, in addition to the typical household and child rearing work. For many families, it also requires significant

paperwork and coordinating activities to be able to use support services. For some, the work is compounded by other circumstances; for example, single parent households, lack of financial or other resources, having more than one child with special health care needs, or households with a parent with a health condition.

Many aspects of the system greatly exacerbate the degree of health care related work; some aspects of the system facilitate this health care related work. The aspects of the system that exacerbate the health care related work have a tremendous impact not only on the child's health care, but on the overall ability to have a quality family life. The next section focuses on some of the aspects of the system that detract from or constrain families' efforts to create quality family life for their children. A later section discusses some of the system characteristics that help facilitate their efforts.

System Constraints to Family Life

The following sections provide detailed themes about the system, and factors associated with each theme that facilitate or detract from quality family lives.

Messages from the System

Messages that families are given by the system set a powerful tone for the context within which services are delivered. Families tended to orient themselves to seeing the positives—the energy, joy, and strength of their children. Occasionally they found an individual or program within the service system that affirmed this outlook. However, for the most part, families felt that the primary messages that they receive from the system reflect negative attitudes and a devaluing of their children. For example, one mother, who describes her child as “an active, happy kid,” was told by a doctor that she would “be a vegetable.” Another mother recalled that when her daughter first came home from the hospital, they were not assisted through discharge planning to have their home properly equipped to care for her. She felt that this reflected their outlook on her child: “I think they thought she would not live long, and they were just sending her home to die. Well, that was 12 years ago. She's 12 years old now.” A third mother observed very different attitudes by hospital staff toward her child who does not have intellectual disabilities as compared to her child with an intellectual impairment. While the doctors were very engaged when treating a medical condition for her first child, they were dismissive when treating her second child:

The doctors wouldn't communicate with us. We weren't given options. . . You go from having people treat you with such concern [referring to her first daughter]. We have a [second] child who is neurologically impaired, and they're like, why would you want a child like this?

Other families observed that adequate supports had been available when their child first came home, but that over time these have diminished or they are threatened by cuts. As one mother commented, supports are always being “whittled away.” As a result of these cuts to services and threats of more cuts, families questioned the system's long-term commitment to their children. Messages from the system regarding the expendability of supports indicated to families that their children were viewed as expendable as well.

“I've got service coordinators, they just really don't understand these special needs. It scares them. They don't know what to do.”

Health Care Professionals

Families sometimes mentioned a specific physician who was very helpful to them and with whom they had a positive relationship. For example, they talked about physicians “who listen and are responsive,” those who “go above and beyond their job,” and those who “think beyond their own box” and are willing to listen to the input and perspectives of other specialists who are involved with the child. One mother said that her child’s pediatrician has attended IEP meetings. Another mother described how her child’s doctor demonstrated his concern for her well-being: “He asked me how I was doing.”

Other families mentioned particular hospitals that they felt were better than others. For instance, they noted hospitals where they felt that doctors worked as a team; hospitals where they received good discharge planning and support with the transition home to the community; and hospitals that helped connect them to community resources.

The above examples, however, are the exceptions. There are many more frustrating and negative experiences with health care professionals than positive ones. These are described below.

**“They don’t
have a clue
what our life
is like.”**

Doctors who do not communicate. Despite families’ attempts to establish positive relationships, there are many times when families feel that physicians do not listen to their perspectives, when they seem dismissive, and when they do not respond to numerous attempts at communication. This sometimes seems to be exacerbated by physician’s judgments about certain children or families. For example, as mentioned previously, one family felt the doctors ignored their attempts at communication regarding their daughter with severe cognitive impairments. A teenage mother reported that the doctor gave her so little information about her child’s condition that she instead turned to the Internet to learn about it. Another mother described the lack of communication: “The nurses were wonderful, but to get one of the doctors, to actually get them to sit down and tell you what’s going on with my child. . . you need to get everybody together for a sit-down meeting.” Families felt that doctors not only did not communicate with them, but did not communicate with other physicians and specialists, as well.

Doctors who cannot come up with a diagnosis. Many of the children in families who were involved in this study face multiple and complex health issues. Diagnosis is not always easy, and sometimes takes a long time. Families are understanding of this, to a degree. At the same time, families are frustrated when they do not get a diagnosis, when doctors refer to their children as “puzzling,” and when they do not collaborate with other specialists to try to understand the child’s condition. One mother attributed her child’s eventual diagnosis to finding a hospital where doctors representing various specialties listened to and communicated with one another.

Lack of access to specialists. There is a lack of specialists (e.g., pediatric neurologists), particularly in some areas of the state, so families sometimes have to drive a few hours to see them, and may have to wait several months for an appointment. The problem of locating a specialist is compounded by the need to find a specialist who is covered by their insurance.

Insurance, Medicaid, and Other Funding Issues

With only a few exceptions, everyone we interviewed said that dealing with insurance was a “constant battle.” The exceptions tended to be people who qualified for Medicaid waiver services through the mental retardation service system. For example, one mother stated: “Because of the waiver, I can get as much as I need.” These families did not have to engage in as many battles with insurance. However, for the most part, families spent a tremendous amount of time and energy dealing with insurance and Medicaid issues. These include the following:

Ongoing paperwork and phone calls. Families typically have mountains of paperwork that they must complete and phone calls that they need to make in order to get coverage for the services and supplies that they need. Often, families reported spending at least 1-2 hours per day doing this, amid the many, many other demands in their daily lives. One mother described the impact of the phone calls, alone, on her life: “It’s not just one or two calls. It’s constant phone tag. It’s exhausting.” For example, in order to get some things covered by the Medicaid waiver, they must first get denials of coverage from their other insurance companies. One mother described how difficult and time-consuming this could be:

It can take many phone calls and letters, it can be hard to get the insurance company to write a denial for something they don’t cover. I just tell them, please just put that in writing, that you don’t cover it.

In addition, when something which is a necessity is not covered by Medicaid or is denied by insurance, parents must spend hours pursuing appeals. One mother commented, “It’s like pulling teeth to get something to be paid for. Something that’s going to cost \$50 or \$100, it takes about \$5,000 of my time to get it covered.” Even when appeals are successful, families may feel a sense of frustration that the expense could have been approved without a fight. One parent said the amount of paperwork prevented her from getting potential resources: “I have a stack of paper—grants I may be eligible for but I don’t even have time to read it.”

Limited choice of doctors and vendors. Insurance places distinct limitations on choice of doctors and vendors (e.g., for equipment repair) for the individuals and families whom we interviewed. For example, one family’s insurance would not pay for surgery in Philadelphia, but they could not find anyone in their nearer but smaller home town to do it. One individual reported that she has had unsatisfactory experiences with a particular wheelchair repair company; however, she is forced to continue working with them, as that is the only company in her area that is approved by her insurance.

Cutbacks. As indicated in the introductory section on “Messages from the System,” many families experience continual cutbacks in services. In addition, they live with the constant fear of further cutbacks. As one mother put it: “There’s not a lot to begin with, and they’re taking what we have.”

Narrow definition of medical necessity. Many families mentioned services or equipment or other things that they felt were essential for daily life, but that were not considered by the system to be “medically necessary” a requirement for insurance or Medicaid coverage. The narrow definition of medical necessity has a critical impact on their lives. For example, families routinely have to fight for essential hours of nursing, even

“It’s not just one or two calls. It’s constant phone tag. It’s exhausting.”

when these have been determined by their doctors to be medically necessary. Many families told stories of equipment that they regarded as essential that was not approved. One family reported that their son had outgrown a stander, yet they were having to fight with insurance to replace it. Also, this mother recalled that when her child was younger “insurance told me a crawler was a luxury item.” An example from another family is that insurance refused to pay for a lift to transfer their son from his wheelchair to a stair lift. In yet another family, use of a manual wheelchair facilitates their son’s inclusion in various community activities. However, insurance will not cover this. Finally, a number of families reported that they had a van, but that insurance would not cover a lift for the van. Therapies are deemed unnecessary if a certain degree of progress is not evident to those who are making funding decisions, so they may be cut back or denied. At the same time, families argue that the therapy was helping to maintain important skills and abilities, and that cutbacks result in declines and loss of ability. Finally, the family of a 20-year-old described the small uncovered, but necessary adaptations that are taken for granted in daily life, but are impossible without support, such as turning off the TV, opening a door, or reclining a chair.

Lack of information. Families reported that they were uninformed about available services. The mother of a child with a ventilator, tracheostomy, and a g-tube said: “I wasn’t even told about nursing care for six months.” Another mother described sleeping on a bench at the hospital, while nobody told her that the nearby information desk included a place to sign up for a sleeping room. A third mother described the lack of information as follows: “Some people are just not willing to give you information. I met parents who are still paying for diapers [for older children] that insurance is supposed to pay for.”

Length of time to get new equipment or repairs. Individuals and families who were interviewed mentioned that it is challenging to have to wait a long time for equipment replacements or repairs. For example, one family commented, “Maybe if they could just come and see the bruises [from an outgrown harness for his wheelchair] it would happen more quickly.” Another person talked about needing to plan ahead at least a year or more to get a new wheelchair.

Lack of coverage. In addition to things that are or may be covered by insurance or Medicaid, families incur many, many other extraordinary expenses in the process of caring for their children with special health care needs. For example, with equipment running and extra people (e.g., nurses) in the house, there was sometimes significant expense added to families’ utility bills. One family mentioned that their electricity bill, alone, was over \$4,000 for the past year, but there was no source of assistance for this due to their income level. Another low income family described the impact of some of the extra costs associated with caring for a child with complex health care needs: “Little things add up, electricity for the machines and the nurses who are awake at night, heat—I can’t dial down because he can’t regulate his temperature, water for the nurses in the house and the extra laundry.” Many supplies are essential for a child’s health care but are not covered because they can be purchased over the counter, such as enemas or saline solution. When these are needed on a daily basis, the costs can be substantial. Home modifications are not covered, yet these are often essential, particularly as children get older and cannot easily be carried up or down the stairs. Even when insurance covers services, families can be left with extraordinary expenses: “We had primary health insurance but the bills are still

outrageous.” Another family stated: “Having insurance does help. Insurance paid 80% but it took years to pay off our 20%.” As one mother put it, due to lack of financial support, she felt like the system is “making people poor, and keeping them down.”

Impersonal way decisions are made. A common theme expressed by families related to the way decisions about funding are made with little or no personal contact with the child and family as a whole. As a result, families felt that these decisions could not accurately take into account the real needs of children and their families. As one mother stated, “They decide hours on a child they’ve never met, in a house they’ve never visited.” Another commented that in regard to her son with special needs, the insurance companies “just look at him on paper.” Still another commented, “Other than a voice on the phone, they have me on a computer screen; they don’t have a clue.” It was particularly frustrating that the opinions of the family physician and therapists who know the child and family situation are overridden by others who have never met them or their child.

Illogics of approvals and denials. To families, it is illogical that certain things considered by them to be essential (e.g., certain number of hours of nursing, certain equipment, certain therapies, access to community) are considered luxuries by the insurance and Medicaid system. In addition, some of the expenses that the system would cover, as compared to what it would not cover, seemed illogical. For example, one family could obtain ongoing funding to pay providers who have adapted vans for medical transportation, but could not obtain funding to purchase a lift for their own van. One mother described another example of something that seemed illogical to her:

A lot of nursing companies won't pick her up [if the child is over 50 lbs.], they're required to have a lift. But, I was told by my insurance that a lift was not a medical necessity. How is a lift not medically necessary?

She was also denied funding for an umbrella stroller base because they had already gotten a wheelchair. However, the wheelchair will not fit in the car and a lift for the van is not covered. Also, some of the mechanisms and processes associated with payment or nonpayment did not make sense to families. For example, even though a family is eligible for a particular service, if they pay for it upfront, they will then not be able to be reimbursed. Overall, families feel it is illogical for the system to promote home care, but then not fully and adequately support it.

Nurses and Nursing Agencies

Most families interviewed received nursing or had used nursing services at some point in time. Having good, reliable nursing in place had a tremendous impact on the daily lives of the families who participated in this study. On an individual basis, many families pointed to one or a few nurses who offered exceptional support to the family, described as “life-saving” both in terms of health care to the child and emotional support to the family. Families characterized these nurses as “like part of the family,” and as a “God-send.” The key factor in these assessments was the nurse’s relationship to the child and family as a whole. Such relationships are characterized by a mutual commitment and caring between the nurse and the child and family. Other positive aspects included a nurse’s ability to balance professionalism with the flexibility of fitting into a family. In addition, nurses sometimes serve as important resources for the family, telling them about services about

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which no one else has informed them. For example, one mother reported that one of her nurses told her that Medicaid would cover diapers after her daughter is 3 years old; this nurse also told her she could be reimbursed for mileage (e.g., to appointments). She commented, “I never would have known these things unless the nurse told me.” When there is a positive relationship between a nurse and family, this creates at least some degree of stability for the family. In some cases, families had nurses who had been with them for a number of years. Finally, a few individuals and families mentioned positive experiences with nursing agencies. Central to this was a positive relationship, in which the young adult or family felt that the agency would do its best to fill the hours, and in which the agency would be upfront about its difficulties filling hours.

At the same time, every family mentioned having had at least some, and sometimes many, negative experiences with nurses and nursing agencies. These include the following:

Call-offs and unfilled shifts. Many families often do not get all the nursing hours they are approved for due to nurse call-offs and unfilled shifts. When nurses call off, families can try to find replacements. This seems to be more difficult in rural areas, where there is not as large a supply of nurses, and it is especially difficult for weekend hours. While call-offs are sometimes unavoidable due to illness and other emergencies, they result in increased sleeplessness and exhaustion for family members. As one mother described:

This last week, for example, the nurse left sick at 4:00 a.m. I didn't have another one scheduled for the next shift, then the weather prevented the next scheduled one from getting here. It meant going from Sunday 4:00 am to Monday at 4:00 pm without sleep.

Also, if a nurse calls off and the family cannot fill the hours, then they lose those hours. One mother described her frustration in trying to get her approved hours filled: “I was so upset with the agency. They refused overtime, yet they couldn't provide enough nurses to staff my hours. I was left with hours and hours [unfilled]. I was getting no sleep.”

Dependability, reliability, and personality of nurses. In order for home nursing to be successful, families must have nurses who are dependable and reliable. In addition, they must have nurses who fit into a family home—who can balance professionalism with a relaxed fitting in with the family—and who are a good match for the family. All of the families had some experience with nurses who were not reliable. For example, a number of families recounted instances of finding nurses asleep on the job. Others questioned the nurse's skills. One mother described a nurse who was reliable about showing up, but not reliable in terms of her clinical skills: “She's great on day-to-day, but her assessment skills are not that great.” Some families mentioned nurses who just did not fit in well with their family context. One mother recalled: “There were times when we had to settle for someone who didn't fit with our family. . . . To some extent you have a choice of who works here, but you're limited by who wants to work here.” Another mother made a different choice: “I would prefer to go without a nurse than have someone come in off the street.” Another family described nurses who were very competent clinicians, but did not take time to interact playfully with the children they were caring for. Other nurses did not relate at all to the other children in the household.

“It's not like you can just pick up and go. You have to take the vent, oxygen, and the suction machine. It takes two people, one to bag while one hooks up the machines.”

Training and skills of nurses. Some families indicated that it was difficult to find nurses who are comfortable and skilled at caring for children who have trachs and use ventilators. For example, one family has 11 nurses who work for them; out of these, only one will change the trach, while the others are not comfortable with it. Another family reported that none of their nurses were familiar with their type of ventilator. Contrary to popular wisdom, many of the families report training the nurses, rather than vice versa. One mother described her experience when her child was first discharged from the hospital:

They said a nurse will be waiting at home. She had never seen a vent before. I was counting on them; they were counting on me [to have been trained]... The nurses have no training on a vent til they work here.

Inflexibility of the system. There were some aspects of the nursing system that seemed illogical and inflexible to families. These include: (1) sometimes the nursing schedule lacks the flexibility to fit the family schedule (e.g., one child is always late to school due to the nursing schedule); (2) no flexibility in nursing hours for families who may not always need the same amount of assistance; (3) if a parent has a short-term illness, they cannot get extra hours of nursing; (4) if parents have a long-term illness or disabling condition, they have to battle the system to try to get extra hours because hours are tied to the child's condition. A mother described wanting to use hours only as she needed them, rather than on a set schedule. She felt she could sometimes use fewer hours than approved. Although this would be preferable for her and less costly for the system, she could not get approval for a flexible arrangement. She said: "If you're approved for 40 hours, you have to use it or they will cut it. If you only use 20 [one week], then need 30 [the next], they won't cover it." One family has had three nurses in their home at the same time for three different children, as the nurses were only allowed to care for the particular child assigned to them. Some families would like to be able to hire their own nurses and pay them directly (rather than through a nursing agency), and could in this way more easily fit their preferred schedules or fill some of their unfilled nursing hours, especially on weekends. Finally, though many families need some nursing care, others would like more opportunity to use people who are not necessarily nurses, such as personal care assistants, homemaker aides, friends, and neighbors. Along with this, they would like some of these in-home assistants to be able to drive their child to and support their child in community activities, and on occasion to watch other children in the household in addition to the child with special health care needs; but these means to meet family needs were prohibited by agency policies.

Disability services

In addition to nursing, most families in this study received some other types of disabilities services. However, there is no one set of services or service system that supports these families. The particular services that families received depended on factors such as the label or diagnosis of the child, the age of the child, and the information that families received about services. The families and young adults who were part of this study received services from a wide variety of sources. Many had received early intervention services and found them to be very helpful. Some families received services (such as therapies, respite, behavioral health services, case management, etc.) from the mental retardation/mental health (MRMH) system. Agencies such as United Cerebral Palsy (UCP), Easter Seals, and the Muscular Dystrophy Association (MDA) were sometimes helpful with therapies and early intervention, helping cover equipment that was not covered by insurance, or in helping

families identify resources. In fact, one mother described the \$1,000 a year that she gets through Easter Seals as a “Godsend—I’ve used it for a ramp, a special beanbag chair, some adapted toys, and communication device, and other things that are not covered any other way.” Some of the service providers, in particular, some of the therapists, were mentioned as a good source for informing families about other resources. One mother commented:

The therapists gave us a lot of information, like where we could get equipment on loan. Also, our daughter has outgrown her stander, and we’re fighting with insurance for a new one. But, in the meantime, our therapist found one we could use from a family she knew who had one [that they no longer needed].

At the same time, there were many challenges with regard to disability services. These included the following:

Lack of information about available services. Some families were not informed through their physicians, hospitals, and other service providers that they were eligible for disability-related services.

Variability of services, depending on label. Families received different types and amounts of services, based on the label of their child. For example, one mother contrasted services for her two children with disabilities. Both need the same level of physical assistance, but one has a cognitive impairment and the other does not. Describing the services she gets for her child with mental retardation, she concluded, “A child is better off with a diagnosis of MR.”

Waiting lists for MRMH services. Some families reported long waiting lists for the waivers, for some families as long as 6 years. One mother described being on waiting lists that were categorized according to urgency of need: “We were on the ongoing list for three years. They upped her status to emergency. She’s been on the emergency list now for three years.”

Cutbacks on MRMH services. As with health care services, some families who had older children and had been receiving services over a number of years reported a “continual cutting back of essential services such as hours of assistance and respite.”

Lack of cross-disability coordination. Many families reported that their services are very fragmented, based on the various diagnoses of their children. As one mother stated: “It isn’t a system; we have to piece things together.” For example, one family with a child who has a developmental disability label and also a physical disability reported difficulties gaining access to resources for people with physical disabilities due to her developmental disability label. Another mother described the limitations of workers who were knowledgeable only about a small range of disabilities:

I’ve got service coordinators, they just really don’t understand these special needs. They understand mental retardation and behavior, but not medical and g-tubes. It scares them. They don’t know what to do.

Lack of access to therapists, adaptive equipment, etc. Families sometimes experience long waits for therapists. One mother said that when they moved and had to change physical therapists, months went by before a new one was assigned. She commented, “Things take too long. There shouldn’t be a waiting list for therapists.”

There should be therapists waiting for children.” A number of families mentioned delays in getting speech therapy. Also, more than one family mentioned having to wait at least a few months for a communication device, but then still not having the software program to run it.

Respite

Families reported the need for respite in order to do things that other families take for granted. As one parent said, “You need to also have a life.” One mother of a 20-year-old son who uses a ventilator described not being able to go with co-workers for a break after work: “My colleagues, they’ll say, let’s go out for supper and to a show. That’s just not an option for me. You’ve got to make plans so far in advance.” The families we interviewed received respite services from various sources, including special programs such as the Children’s Ventilator Assisted Home Program (CVAHP), as well as from the MRMH system. A number of families obtained respite hours through CVAHP, and appreciated the flexibility of being able to hire nurses on their own for whatever day and time they desired. These extra hours of support helped compensate for missed hours of regular nursing, helped a few mothers remain in the workforce, and provided some parents with a little bit of a break. Through this program, families can hire either nurses or home aides. The home aides can be friends and neighbors who families know and trust, who can become credentialed as home aides (e.g., CPR certification, and criminal and abuse background checks). In this way, for example, at least one family hired a high school student to assist their high school age son with community activities. MRMH respite programs also allow families to hire friends or neighbors. A few families mentioned utilizing other sources of respite, such as a respite house at a beach provided with funding from a charitable foundation.

At the same time, there are also difficulties with respite, as described below.

Difficulties finding nurses for respite. Some of the families are eligible for respite hours from CVAHP, but cannot use these hours because they cannot find nurses to fill them. Families who do use the respite hours from CVAHP most often reported that they hired their regular nurses for extra hours.

Lack of information about respite or about flexibility within respite services. While a few families hired friends and other community members to provide respite, some families did not seem to be aware that they could do this.

Lack of respite. Families who do not have in-home nursing may be more dependent on respite services. Some families who are eligible were not informed about the possibility of obtaining respite through MRMH services; other families receive limited respite services but are in need of additional respite. For example, one mother commented, “Three times in twelve years I’ve had one night away.” One family talked about not having had respite in two years, as the nurse cannot watch their other child.

Educational Services

Within the families we interviewed, some children were in inclusive settings, some in segregated settings, and some had home-based instruction. There were parents who favored each of the three types of settings. Some

chose a segregated setting, based on the belief that this sort of specialization would be best for their child. Some chose home schooling due to the fragile health of their child or risk of infection. Finally, other families preferred inclusive settings. One family had been initially hesitant about inclusion, but the district encouraged them to try. Recalling advice she got to consider inclusion, the mother commented: “I couldn’t visualize it, but I listened. He got on that bus and never looked back.” This family and others with children in inclusive settings spoke about some of the “wonderful opportunities” afforded to their children as a result of inclusion. This included opportunities for social relationships with a range of children with and without disabilities, as well as participation in extracurricular activities such as school bands and clubs.

Parents reported many school districts were at least initially resistant to serving children with extensive health care needs. At the same time, there were some districts that were willing to learn. As one mother recounted: “When he was in preschool, they said, we’ve never had a kid with a trach. You teach us what to do.”

Overall, there were also many challenges for families related to schooling associated with resistant districts and other issues:

**“Let us care
for our
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don’t make
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all that.”**

Battle for inclusion. Almost all of the families whose children were in inclusive settings said that they had to battle to get the inclusive placement.

Districts that are resistant and unprepared. In addition to battles for inclusion, a number of families mentioned that it was a struggle to get their district to serve their children at all. More than one family talked about having to hire an attorney to get their child into public school. Some of this resistance seemed to be based on lack of experience or knowledge about supporting a child with extensive health care needs. Over time, some of these districts seemed to adapt and learn. Others continued to be resistant. This resistance was manifested in numerous ways, from lack of accessibility (one student was forced to be bussed to a neighboring district rather than attend his local school due to the facility’s structural inaccessibility); to lack of expertise and creativity of teachers working with students with special needs; to lack of adaptive equipment and supplies (e.g., computers, switches) to facilitate participation of students with special needs.

Failure to fully implement IEP. Some families mentioned having to fight to get the school to implement at least certain aspects of the Individualized Education Program (IEP). For example, one mother commented: “I’ve spent 5 years fighting for them to put things into her IEP and then implement them. One example is computer software. The school bought it, but never loaded it onto a computer.” Another mother said she had not even been informed about what an IEP is or the IEP process.

Lack of therapies. A number of families said they felt that the amount of therapy offered by the schools to their children was inadequate and that they are always having to fight for more, or to maintain what they have.

Service Coordination/Case Management

Families receive case management or service coordination services from a variety of different sources. For

example, there are case managers associated with hospitals, insurance companies, and with various service agencies and service systems. Many families have more than one case manager. They feel that the quality of case management is highly dependent on chance, varying widely from one agency to another and among case managers within one agency. They most appreciate case managers who are knowledgeable about resources, who can anticipate some of their needs, and who can provide information about a range of options for resources and services. In addition, they appreciate case managers who might do some of the legwork for them, and help advocate with them. Perhaps above all, they appreciate case managers who make an attempt to get to know the child and family and assist in obtaining resources that support both the unique needs of their child and their family as a whole. As one parent described their case manager: “He was exceptional. He played with the kids. He tried to understand what we needed.” Families referred to a few case managers and organizations/ programs that are helpful to them. However, for the most part, they felt they had to identify resources on their own or through other families; do all the legwork on their own; and advocate on their own behalf. Some of the issues raised about case management include the following:

Multiple case managers and no overall coordinator. Families often had multiple case managers, based in different organizations or systems, but no overall coordinator who helped them identify resources and navigate among and between organizations and systems.

Lack of general information and resources from case managers. Many families spoke of a need for more information for families about what resources are available. As one mother stated: “One of the most difficult things is the lack of information as a parent. No one agency sits you down and tells you everything. You have to discover things for yourself.” For example, families wanted information about what is covered. Numerous families reported that they had learned about information themselves or through other parents rather than through their case managers. Another commented, “The road to getting anywhere has been through other parents.” In the absence of information from the system, they spoke of turning to the Internet to learn about their child’s disability. A number of the families felt that they have missed out on valuable assistance (e.g., transportation, diapers, nursing, respite, MHMR services) because they were not informed about services for which they were eligible. For example, one mother remarked: “We missed several years of WIC because we didn’t know he was eligible.” Another commented: “A lot of things I may have gotten, I didn’t even know about.”

Scope of assistance from case managers. The scope of assistance provided by case managers seemed to be very narrow. Families reported that most case managers, overall, were not a good source of information, resources, or assistance. Many families expressed the need for someone to help them do some of the leg work, help with some of the paperwork, help coordinate some appointments, and help them advocate for needed services. One mother commented, “Let us care for our children—don’t make us deal with all that.” Another said, “There’s a case manager, but they really don’t do the hands on stuff. It’s up to me to find the equipment, see if insurance covers it, get the physician to write a letter, send it to the insurance company.” Another recalled, “People don’t say, here’s this. I wasn’t even told about nursing care for six months. I was never told about the vent program. Nobody calls to ask, ‘Is there anything you need?’” And, another commented, “Things you’re not thinking about, somebody should. That’s the stuff that will make it or break it.”

“They just sit in a little cubicle and say yes or no. They just see a piece—what things cost.”

Case managers who have never met a child or family or visited their home. Families reported that their case manager had very little knowledge about what life was like for their child and family as a whole. One mother commented, “They don’t have a clue what our life is like.” Another stated: “They’ve never met [my son] or been to the house.”

Orientation toward resource constraint. In the experience of some families, case managers are more oriented toward resource constraint (e.g., discouraging families from seeking resources) than assisting families to locate and obtain needed resources. One parent described the case manager this way: “They just sit in a little cubicle and say yes or no. They just see a piece—what things cost.”

Compartmentalized knowledge of case managers. Some families have found that case managers do not necessarily have a lot of information about cross disability resources. For example, one family found that their MRMH case manager did not have a lot of knowledge about resources that would help address their daughter’s physical disability; another family found that their MRMH case manager did not have a lot of knowledge about resources that would help with their daughter’s deafness.

Transition

Families felt that transition was a critical issue, including transition from school to work, as well as, more broadly, transition from children’s services to adult services. Families suggested that there is need for more attention to transition. In particular, they raised the following issues.

Lack of planning for school-to-work transition. Families who had older children mentioned the need for more in-depth, individualized planning for this transition. One family felt that the planning should begin earlier:

VR starts getting involved when the student is 17 or 18. Nowadays kids are starting to think about their futures at a much earlier age. It would be very helpful to have VR planning and involvement earlier, not just before graduation.

One mother described trying to get VR started when her son was 14, but they told her she was two years early. Another family said that while there are job coaches who are trying to provide some work experience, it would be helpful if this process was more connected to their child’s interests and future plans. Also, as part of transition planning, some families would like more information on financial and other resources that would assist their son or daughter to go to college. Families and young adults reported that it was sometimes a battle to get the Office of Vocational Rehabilitation (OVR) to pay for things. In addition, they felt that there is a lack of coordination between OVR, school, and adult services.

Concern about transition to adult services. Families and young adults were concerned about being able to maintain their level of nursing and other services when they transition to the adult service system. Some have worries about placement in a nursing home or other facility if they cannot maintain their current level of support. They would like assistance with planning for the transition to adult services which would allow their child to remain in the community. In addition, there is concern that transition from children’s medical services

to adult medical services may have an impact on their ability to maintain relationships with physicians who have known them for years.

Transportation

Families reported various challenges with transportation. These include:

Lack of coverage for vehicle modifications. Several families indicated that they had a van, but that insurance was not willing to cover a lift. For example, as described previously, one family could obtain ongoing funding to pay providers who have adapted vans for medical transportation, but could not obtain support to purchase a lift for their own van. Another family described the excessive expense of their van and lift, beyond what typical families need. “We got a van 3 years ago. It cost \$17,000. The lift cost another \$25,000, not covered by anybody.”

Lack of information about funding to help pay for transportation. Some families indicated that they had not been informed by case managers or others in the system about funding that is available to assist with transportation. They ended up finding out about this by chance, through friends or a specific therapist or nurse.

Limitations of covered medical transportation. Some families were covered for medical transportation services. However, there were some distinct limitations, in that it must be scheduled ahead of time, and it was not available on weekends and was not available for participation in community life.

Special Issues Raised by Young Adults

Four young adults who have complex health care needs were interviewed for this report. Of the four, one lives in her own apartment full-time, another lives in a college dorm during the week and with her family on weekends, the third lives with his family, and the fourth previously lived in a nursing home and now lives in a group home with seven other individuals. Many of their experiences are similar to those identified by families throughout this report. At the same time, it is important to highlight some key issues as they were expressed by young adults.

Segregation and isolation during school years. While two of the four young adults were educated in regular school settings, all four of them in some ways missed out on opportunities for learning and socialization alongside their peers. This occurred either because they were living in segregated settings (e.g., nursing home), were home schooled, or were surrounded by nurses at school. The two who attended regular school reported a lot of involvement with peers at school, but no access after school to participate in extracurricular activities or spend leisure time with friends.

Current social isolation. Since graduation from high school, three of the four report that they currently experience significant social isolation. Though one of the young men has nurses 19 hours a day, and an adapted vehicle available to him, he cannot go anywhere because the nurses are not allowed to drive him. He remarks: “I don’t have a social life. Not going anywhere, not doing anything doesn’t help.” The young man living in the

group home longs for life with a family, and has expressed this desire repeatedly over several years. The young woman living in her own apartment reports, “I don’t have any friends.” The fourth young adult was the only one who did not emphasize social isolation as a significant factor in her life. She has a strong family network and is highly involved with disability rights advocacy with other young people. The flexibility of her support system, including use of personal care assistants (PCAs) versus nurses as much as possible, facilitates her community participation.

Challenges in obtaining supports. The young adults reported various challenges to obtaining needed supports. In particular, the one young adult who lives in her own apartment spends a great deal of time and energy arranging needed supports and services (e.g., finding backup nurses when there are call-offs, arranging wheelchair repair and replacement). She has assistance from her father who works full-time, however, and is thus limited in his flexibility to provide assistance. Three of the young adults attend or have attended college. There is significant work associated with this, including arranging schedules, transportation, support, and so forth. Finally, as mentioned above, transportation is a barrier to community participation for at least three of the four young adults. The young woman referred to above who hires her own PCAs had previously had difficulty finding nurses who were a good match for her needs and interests. She has been much more satisfied with use of the PCAs as this gives her the ability to hire friends, which provided much more flexibility in terms of transportation and community participation (e.g., her friends can drive her van to community events and they share an interest in the activities they attend together).

“Pursuing resources is very tiring and emotional. It is a struggle even for those who know the system...It can take 30 calls for one service for their child.”

Concern about the future. The young adults expressed varying concerns about the future. One issue they raise is the lack of attention to or conversation about their future from those in the service system. As one young man put it, looking back, “Nobody ever asked before what I wanted for my future.” Second, the young adults were concerned about their ability to acquire or maintain a level of services that will allow them independence and control in their lives. For example, the young woman in her own apartment is concerned about continuity of services at age 21 in order to maintain her needed 24-hour nursing coverage and other supports that are essential for her independence.

Finally, the young adults expressed their concerns about segregation and isolation of people with disabilities. One young adult remarked: “It’s totally wrong to be secluded.” Another commented, “I didn’t belong in a nursing home; living in a nursing home is not a place for any person.” They desire the same opportunities as others in society—to have some degree of choice and control over where they live and work, and to be able to pursue further education, interests, and relationships.

SUMMARY OF KEY STRATEGIES AND FACTORS THAT FACILITATE FAMILY LIFE

In light of all the challenges and frustrations that families face, one might wonder what sustains them. Above all, they reported that it is their children who sustain them and motivate them to keep going. At the same time, parents have certain strategies that help them deal with the challenges of the system. Additionally, some positive interactions with the system provide them with needed support and with evidence of what is possible.

Parent Strategies and Circumstances that Facilitate Family Life

With all of the challenges they face, families said it is essential to feel some sense of control over their lives. There are numerous strategies that parents used to maintain a sense of control and deal with the challenges of the system.

Social networks. Many families who had extended family and/or social support networks referred to these people as “saviors,” though even with a supportive social network, they found the work was often exhausting and overwhelming. However, numerous families, for various reasons, did not have significant help from family or friends. A few families were connected with support groups, but for many families, there was no possibility of taking a break to attend a support group meeting.

Knowledge. As one parent commented, “Knowledge is key.” This includes knowledge about what resources there are, and how to obtain these resources. Parents felt that they gained knowledge themselves or through other parents. They felt they did not have a lot of knowledge at first, but after they gained more knowledge, they felt an increased sense of control. Families found that their sense of control was heightened when they recognized that they have become experts in their child’s needs, even surpassing the expertise of specialists with whom they interact.

Persistent advocacy. The advocacy that parents do on behalf of their children and family as a whole involves becoming known to and establishing personal connections with key people within the service system, documenting everything (e.g., phone calls, conversations), and, perhaps above all, being persistent. A number of parents mentioned the importance of being persistent. One commented, “You have to be aggressive to get things.” Others advised: “I make it my business to find out everything.” or “Call, call, call.”

Maintaining a sense of purpose and hope. In order to maintain a sense of purpose and hope, families invariably referred to the strength and resilience of their children with disabilities as their source of motivation to continue fighting for adequate supports. One parent, referring to her child, said, “I persevere because she does.”

Overall, families feel that they have developed the networks, knowledge, and strategies which bring a sense of control primarily on their own, not due to assistance from the system. At the same time, families identified some key system circumstances and factors that seemed to help.

System Factors that Facilitate Family Life

Amid the many, many daily struggles in their lives, families felt that there were conditions that contribute to the system playing a role that truly facilitated family life. They identified the characteristics of a system that facilitates family life including:

- **Adequate supports.** With a certain level of adequacy of supports, families are not as physically and emotionally exhausted from doing the work themselves or battling with the system.

- **Utilizing a family-centered approach.** Family life is facilitated when supports are based on the unique needs of the child and his or her family.
- **System-wide acceptance of a guiding principle that children belong in families.** An articulated belief and focus on permanency helps to ensure that all children will have the opportunity to grow up in families, and that families and children will receive the support they need.
- **Flexibility.** Family and children have unique needs, and these needs change over time. System flexibility increases the likelihood that supports will effectively meet these needs.
- **Listening, responding, and caring about families' needs and perspectives.** While families understand that health care providers and other service providers do not have all the answers or solutions, they deeply appreciate providers who listen to them, are responsive, and seem to care about their child and family as a whole.
- **Willingness to learn.** Some children with complex health care needs present new challenges to service providers. In order to respond in a positive way, families feel it is key that service providers have the willingness to learn new strategies and approaches.
- **Getting to know the child and family.** The most effective system representatives (from case managers to policy makers) are those who have taken the time to get to know families or have some personal experience with children and families with complex health care needs, and make decisions based on this knowledge.
- **Collaboration and teamwork.** Families feel that services for their child are most effective when service providers collaborate with them, as well as with one another.

CONCLUSION: KEY CHALLENGES IN SUPPORTING FAMILY LIFE AND THEIR IMPACT

In conclusion, participating families were prepared to take on the responsibility of caring for their children. When they needed assistance they sought it for those aspects of caregiving that were above and beyond typical parenting and were directly related to the significant nontypical needs of their children. They reported many ways in which they are hampered in their attempts to maintain a quality family life. The key challenges reported to supporting family life for children with special health care needs include:

1. Lack of resources;
2. Lack of information about resources;
3. Lack of understanding by people in the service system about the realities of families' daily lives and needs; and
4. A system that endorses the concept of home care but does not holistically support children and their families to achieve quality family lives over the long term.

The impact of all of these challenges has an impact on families. A summary of these follows below.

Stress, exhaustion and sleeplessness. The ordinary work of family life, including attention to special health care related work needs, is compounded by (1) lack of support and resources (e.g., too few nursing hours, unfilled nursing hours, lack of respite); (2) the energy spent seeking what is available; and (3) the continuous amount of frustrating and demoralizing work battling the system for services. Because of this, many families are physically and emotionally stressed, and experience routine lack of sleep, sometimes for years on end. One

mother explained that she had not slept eight hours undisturbed “since [my son] was born.” In one family, the mother sleeps in one room to be near the child who is awake much of the night; the father sleeps in another bedroom at the other end of the home to get sleep in order to work outside the home. In relation to her degree of stress and exhaustion, this mother commented: “A typical day is pretty much hell. I don’t know how I get through each day.”

Lack of time/attention to siblings and family as a whole. The exhaustion and stress, combined with lack of support, takes time and energy away from siblings and the family as a whole. One mother mentioned that her friends take her nondisabled son to Boy Scouts. She is not able to leave her son with complex health care needs or to bring him along to Boy Scout activities. She has a small car, and when she has her child with a disability in the car along with all the necessary equipment and the nurse who must accompany them, there is not room for her other son. Thus, they have very limited opportunities to go out together as a family into the community. Families feel that the service system does not take into account the needs of the family as a whole, particularly siblings. Nursing support is rarely 24 hours. During hours when no nurses are available, one mother must sit inside with one child, watching her other child play outside. While it is dangerous to leave her child alone inside, she also feels that, if her child outside experiences any danger, “I have to decide which child to save.”

Housebound/isolation. Due to shortages of nursing, lack of accessible means of transportation, and limited resources, mothers often feel like they and their children (both disabled and nondisabled siblings) are housebound for significant periods of time. It is difficult if not impossible for them to spontaneously go on an outing in the community. First, it can be a physically exhausting effort to handle all the necessary equipment. In addition, some children cannot go out unless there are two adults. One mother described: “It’s not like you can just pick up and go. You have to take the vent, oxygen, and the suction machine. It takes two people, one to bag while one hooks up the machines.” Parents are particularly concerned about the impact of the isolation on their children, and the general lack of social opportunities for them. One mother commented about her 19 year old daughter: “She has no friends. Her happiest times were at the vent camp, but she’s too old for that now.” Young adults themselves also raise the issue of being housebound and socially isolated. After a vibrant, inclusive high school life, one young man now almost never leaves his home.

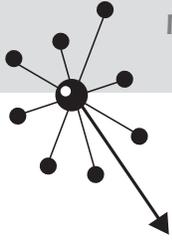
Financial hardship. In general, families make the case that good, quality home care is a good investment—it saves money, and often makes a big difference in the number of hospitalizations as well as the general quality of life of children. However, because the system is not making an adequate investment, many families are forced to undergo extreme financial hardship. Their expenses are so extraordinary that even if insurance covers 80%, the 20% is an excessive amount. Financial hardship is exacerbated when inadequate support prevents parents from entering the workforce or forces them to leave the workforce due to frequent absenteeism. One young divorced mother expressed her frustration at trying to get ahead: “The system is meant to keep you at a bad level.”

Constant battles and state of frustration with a bureaucratic and impersonal system. Families are exhausted not only from the physical work, but sometimes even more so from the continuous battles they must fight on

behalf of their children. As many expressed: “Everything is a battle.” This exhaustion is compounded when they feel that those who are making funding and service design decisions do not know their child or family or families like them, and thus do not have an understanding of their needs.

In the face of all the challenges, what motivates families most is their desire to create a normal family life for their children and family as a whole. They need and desire support from the system that enhances rather than detracts from their ability to do so. Such support is based on the establishment of positive, respectful, and caring relationships. Additionally, such support entails collaboration across multiple systems and entities which maintains a focus on the child and family. What facilitates family life is joy in their child, allies who value their child, personal engagement and relationships, and a shared belief in the importance of family life and supporting families. As one parent summarized, “When everyone work together and keeps focused on my child (and family), not bureaucracy, everything works great.”

“Home nursing is often provided for 16 hours per day. This covers 8 hours of work and 8 hours of sleep. What happens to that time that someone has to drive to and from work? So the family takes time off from sleep. This leaves no hours for getting groceries, auto repairs, walking to the mailbox, and the things we need to do everyday.”



IV. DIRECT STAKEHOLDER PERSPECTIVES

Dianna Ploof

In order to obtain a broad perspective on what is essential to assuring family life for children with complex health care needs, we interviewed direct stakeholders. For the purposes of this study, direct stakeholders are defined as individuals who interact directly with families of children with complex health care needs in some kind of assistive capacity to lend support, provide expertise, or to help solve problems. Some serve as a bridge between the family and one or more of the formal systems designed to provide support or assistance. Some provide direct services in the family's home. Others provide medical care to the child. Direct stakeholders have a unique vantage point from which to view the factors that influence the success of families as they raise their children with complex health care needs at home. As such, they may add particular insight to our understanding.

Methodology

Families who participated in this study (see Section III on family perspectives) were asked for names of direct stakeholders who they felt had a good understanding of what it takes to maintain family life for children with complex medical needs. The nominated direct stakeholders were then contacted, informed about the study, and asked if they were willing to participate in a 45-60 minute telephone interview. Once they provided written consent, they were contacted by an investigator to schedule the semi-structured interview. The interviews sought stakeholder perspectives regarding general family and service system issues rather than focusing on details of the particular families who had nominated the direct stakeholders. Stakeholders were asked about what they believe it takes for families to care for children with complex health care needs at home. Written notes were taken during the interviews; the interviews were not audio-recorded.

In total, 10 direct stakeholders were nominated by families, and all 10 consented to participate in this study. Of these, one was unable to participate due to unexpected medical reasons, and another was not successfully contacted. A total of eight interviews were conducted. Participants represented the following roles: case coordination; in-home nursing; pediatrician; and administrator or supervisor in social services, education, and in a foundation serving families with children with complex health care needs. Years of direct stakeholder experience with children with complex health care needs ranged from 3.5 to 31 years. One interviewee, in addition to her professional role, was also a parent of a child with complex health care needs.

Notes taken by the investigator during the interview were entered into Atlas.ti, a qualitative research software system, for coding and analysis. Comments were reviewed and coded and recurrent themes were identified

and grouped. These themes are discussed within the framework of essential supports for families. The areas of essential support that emerged included: knowledge and information, case management, in-home nursing, insurance and other financial support, respite care, and emotional support. These are described in more detail below. Furthermore, while there was universal agreement that children should grow up in families (biological, adoptive, or foster), there was also agreement that no family with a child with chronic health care needs, no matter how resourceful, stable, or competent, can raise their child without additional support. Direct stakeholders offered their sense of family characteristics that facilitate success in caring for children at home. These are presented in the second part of this report in that they may add insight into strategies to better support all families.

WHAT DOES IT TAKE? ESSENTIAL SUPPORTS

Direct stakeholders were highly consistent in their discussion about what is necessary for families to be successful.

“A lot of things I may have gotten, I didn’t even know about.”

Knowledge and Information

Direct stakeholders reported that parents need knowledge about their child’s physical/medical care and information about resources to help their child and family.

Physical/medical care for their child. One aspect of knowledge and information that families need pertains to the physical care for their child’s medical condition at home. This information and training is most helpful early on, particularly when preparing to bring their child home from the hospital: “[Families need] preparation before the child is discharged from the hospital. Parents need skills to be experts in their child’s care and to know their child’s medical condition and complications.” Stakeholders felt that information should anticipate families’ needs: “They should have an early assessment to prepare them for what will happen when they take the child home. Say, ‘These things are available when you’re ready. This is what you do.’”

The direct stakeholders generally felt that, in the past, families were carefully trained in the hands-on care of their child prior to bringing their child home. However, they report that now discharge occurs more quickly and, as a result, families have less time for hands on training while in the hospital and are less prepared when it is time for their child to go home: “Sixteen years ago, hospitals used to spend months preparing families for their child’s discharge, and children were more stable when they left the hospital. Now, families are not trained as well.”

However, even in today’s environment of minimizing hospitalizations, families quickly become facile in this area, acquiring particular expertise in the care of their child. While hospitalizations are shorter, some major children’s hospitals have incorporated family support in a fashion that did not exist before: “CHOP (Children’s Hospital of Philadelphia) and most major children’s hospitals have family services that were not available 15 years ago.” One interviewee indicated that services such as sibling workshops and parent conferences are now addressed as a part of ongoing hospital activity when in the past these were initiated by family groups from outside the hospital.

Information about resources. The second issue identified by stakeholders, how families find out about and gain access to resources, is more complex. Resources are available to help address some of the many needs associated with promoting child and family health, however, it is not easy for families to learn about and successfully gain access to these resources. Every stakeholder made reference to the critical need families have to find out about and learn how to effectively use resources. For example, one stakeholder commented:

If they have no idea of where to start or what questions to ask first, they miss out on services and funding opportunities. They know they need something and don't know how to get it. They need knowledge or a helper—a navigator and advocate.

Resources and services were often referred to as a “maze” that needed to be “navigated.” There is no consistent, predictable way parents of children with complex health care needs become linked with a person who can assist them in locating and coordinating existing services and supports. A direct stakeholder commented:

The bottom line is that families have to wear all of the hats: care provider, case manager, and so forth. They may tap into an advocate from hospital discharge or a specialty clinic, but there is no guarantee this will happen. They have to deal with the maze themselves.”

There is a serendipitous quality to finding out about resources. For example, resources may be discovered because of the happenstance of meeting another family while in the same waiting room. Important information is discovered through informal networking and random events. Parents may or may not be aware of what is available. One participant observed: “There is no systematic way right now that families can easily find out about and utilize resources. . . There should be a centralized way of directing families.”

Case Management

Interviewees commented that many families have multiple case managers or service coordinators assigned to them. However, as noted above, they felt there is no guarantee that this person will be adept at informing them about and helping them get connected to necessary resources. According to direct stakeholders, effective case managers, care managers, or others who know about resources can offer significant assistance in helping families locate and secure what they need: “Having an advocate--social workers, case managers, Elks nurses, are a tremendous resource that can help.” Effective case managers help families “navigate the maze” by providing assistance to locate resources and by assisting families through appeal processes when services and supports are denied. Stakeholders felt that the maze-like quality of the service system makes seeking services very time consuming: “Pursuing resources is very tiring and emotional. It is a struggle even for those who know the system. . . It can take 30 calls for one service for their child.”

As an example of a positive effort with regard to care coordination, one stakeholder described a physician's office that has a state grant to pay for care coordinators in the office because the complexity of resource needs is beyond the purview of a typical pediatric practice. This care coordination is geared toward assuring a “medical home” for the child and family:

Care coordinators can touch base with families before appointments to address logistical needs such as refills, so that the office visit can be streamlined. We also do home visits for those families who cannot come in with

their children, such as children using ventilators. Care coordinators meet monthly with physicians about each family. There is a disconnect between community resources and physicians' offices. Prior to the medical home, we didn't know about resources like the Medicaid loophole.

Finally, interviewees reported that families need case management that provides emotional support as well as practical support: "They need someone to talk to, vent to, to rely on doing little things that make a big difference."

In-Home Nursing

Stakeholders felt that the single most important practical resource for families raising children with complex health care needs is in-home nursing. Many children use sophisticated technology and require ongoing physical care and observation. Many families do not have the physical ability to do this along with the daily demands of managing a household, caring for other children, maintaining employment, and advocating for needed services for their child. Parenting is challenging in the best of circumstances, and even more difficult in single parent families, in families with parents who have medical problems of their own, and in families with social or economic challenges. As one direct stakeholder put it: "Families need nursing in the home. This is vital to families to prevent them from becoming exhausted, weary; physically, mentally, and spiritually...to maintain what is needed." Direct stakeholders identified a number of challenges related to nursing that are described below.

"They decide hours on a child they've never met, in a house they've never visited."

Inufficient hours of nursing. Direct stakeholders reported that insurance companies or nursing agencies provide insufficient numbers of nursing hours each week. This significantly taxes families whose only other option is to provide this care themselves as well as take care of the many other responsibilities of running a household and raising children. One participant remarked:

Home nursing is often provided for 16 hours per day. This covers 8 hours of work and 8 hours of sleep. What happens to that time that someone has to drive to and from work? So the family takes time off from sleep. This leaves no hours for getting groceries, auto repairs, walking to the mailbox, and the things we need to do everyday.

Nursing shortage. A national shortage of nurses presents particular difficulties to families who rely upon them for the kind of care needed at home. As one direct stakeholder remarked: "The nursing shortage is a perfect example of a system capacity issue. Families can have services [i.e., are eligible for services], but there are no nurses." Another direct stakeholder commented that parents have said they dread holidays because nurses do not show for their shifts and the parents have to work around the clock. The nursing shortage also worries families who want to support the nurses that they already have. A nurse described how a family would forego approved hours because they did not want to exhaust the only available nurse: "Sometimes the mother won't ask me to work because I've worked 66 hours each week for the last three weeks."

Families must be creative to maintain their nursing care in the midst of this nursing shortage. In order to allow their daytime nurse a vacation, one family scheduled a needed surgery for their child during that nurse's vacation week. Another time when there was no nursing, following a hospitalization, the child stayed in the

school nurse's office for observation during the day while the mother went to work. Such arrangements are not an option in all situations for all families.

Nursing pay and benefits. Pay rates and lack of overtime pay were identified by participants as presenting barriers. Some nursing agencies do not pay overtime. One nurse reported no pay increases for more than 18 months. Nurses also leave in-home nursing roles and find other jobs: "The work is not easy. There is lots of physical stuff."

Frequent hospitalizations of children present a problem as there is no compensation for nurses while their usual hours are not needed. Nurses may need to find alternative work to meet their own income needs and if their work is interrupted due to a child's long hospitalization: "If a child is hospitalized and doesn't use in-home nursing for a while, that nurse will look for another child to care for." They may not then be available when the first child returns home.

Insurance and Finances

Insurance coverage is key to addressing many of the costs associated with in-home nursing. Insurance companies can be an important resource for funding nursing care, medication, medical equipment, and other health-related needs. However, participants felt the processes to obtain and maintain resources are cumbersome, requiring proper and timely documentation and knowledge of appeal processes. Direct stakeholders raised some key issues about the difficulties families face with insurance companies.

"Insurance paid 80% but it took years to pay off our 20%."

Denials and uncertainty about approvals. Direct stakeholders reported that families experience an element of uncertainty with requests for coverage, even anticipating reductions for expenses that have been covered in the past. For example, one stakeholder mentioned a family who is waiting to hear about approval for a steering device for a wheelchair that requires periodic replacement: "We have been waiting three weeks. . . . In the past, we always got two approved. We'll see what they do this time. He's in an improper wheelchair while he is waiting."

In addition, families often are faced with denials of funding for what is to them, essential support. These denials can contradict their treating physician's prescriptions. One interviewee commented that, "Insurance companies are trying to cut costs and expenses and are making decisions that are not consistent with doctors' prescriptions." Participants felt that dealing with insurance companies to obtain approval and manage appeals of denials can be difficult for families and for those trying to assist families in getting what they need: "The insurance company can decide to cut back hours in spite of doctors' prescriptions. Families have 10 days to file an appeal, and have to go back to the doctor to get more paperwork." A physician remarked: "For awhile I was getting denials every week for reasonable requests, and I have limited time to appeal the denials."

Decision-makers' lack of knowledge of families' situations. Stakeholders recognized that the costs associated with caring for a child with complex health care needs are significant. They also shared the concern that insurance companies are driven to cut costs regardless of the effect on children and families. Some insurance

company requirements and decisions are perceived as reflecting a sense of being out of touch with the practical experiences of families: “Insurance companies have no personal touch, no understanding of the psychosocial anxiety and transportation issues that families have.” For example, for some families, it makes sense to schedule a short hospital stay for their son or daughter and conduct a series of diagnostic tests all at once. However, according to one direct stakeholder:

The insurance company may not allow this. They don't want to hospitalize the child. They say each diagnostic test needs to be scheduled separately as outpatient tests. It is hard to get the coordination done. A short hospital stay would shorten the time to diagnosis, and allow for families who have to travel and would have to plan multiple trips. . . . With outpatient, they will have to wait months to get all this done.

As one direct stakeholder summarized: “Sometimes to get what is minor but big in terms of child’s quality of life is very hard.”

Decisions that do not seem to make good fiscal sense. Direct stakeholders expressed concern that some of the insurance denials actually lead to greater costs at a later date. One participant suggested:

“Everything is a battle.”

If insurance companies could assist with smaller costs, they may prevent significant expenses for hospitalizations and family stress. For example, air conditioning—a requirement for children with asthma, cystic fibrosis, kidney disease. Insurance won't cover the cost of a window air conditioner, but will pick up the tab for the emergency room, and hospital stay [that are the result of not having an air conditioner], costing thousands.

Sometimes the system discourages family initiative. For example, one interviewee recounted a story of a family who had obtained a donated van. Insurance would not pay for the lift so the family found a grant to cover the costs. After the adaptations, they found that the child’s Social Security benefits were affected because the van was considered an asset.

Out of pocket expenses. Even with the help that insurance provides, there are significant out of pocket costs incurred by families with children with complex health care needs. For example, one direct stakeholder mentioned the expense for electricity to keep lights on for nurses around the clock and to keep medical equipment running: “Electric bills are doubled and tripled. Insurance won’t cover added costs of electricity. Somebody should be covering that.” In addition, there are hidden expenses associated with required hospital stays for children. A participant suggested, “Buying meals in the cafeteria, long distance phone calls, and co-pays can be \$600-700 per month.” Another added, “. . .when a child is hospitalized there are additional expenses. There is a threat of job loss when parents stay at the hospital with their child. There are home changes/renovations to accommodate the child.”

Respite Care

Participants identified that respite care is available through the Ventilator Assisted Children’s Home Programs to that subset of children who use ventilators, but felt that respite is needed by all families caring for children who have complex health care needs: “The state sees this respite as a luxury. We have lots of single parents and parents with spouses who are ill who use this resource for basic needs.”

The home ventilator program allows some families to hire their own caregivers as needed. Often these are nurses who are already working with the families but it can also be friends or someone from the family's personal network. Participants felt that this kind of flexibility is welcomed by families.

Emotional Support

There was agreement among all of the direct stakeholders that emotional support is essential for families. Emotional support can come from formal and informal sources: professionals, family, friends, and community.

Families need an extremely supportive support system—family, churches, nurses—for everyday tasks: shopping, laundry, watching other children. And they need emotional support: knowing they are not out there in the world alone, that others understand the energy it takes, the needs and the challenges and demands [they face]—and how it feels.

Participants reported that emotional support involves listening to families, being available to them for assistance, and standing with them to advocate for needed services: “Family support means being available to families...praying with them, holding their hands through things; someone is always available to talk.” While some families have strong social support networks composed of relatives and friends who provide emotional support, others have limited social networks and have to rely on those in the service system as their sole source of emotional support.

FAMILY CHARACTERISTICS THAT FACILITATE CARE AT HOME

In response to the question, “What does it take for families to successfully raise their child with complex health care needs at home?” direct stakeholders discussed the system and resource issues described above. At the same time, some also emphasized specific characteristics of parents and families that facilitate care at home for children with complex health care needs. This information suggests that families with different characteristics may need different kinds or levels of supports for children with similar characteristics. These insights may prove useful in designing strategies so that support intensity and form can be tailored to the unique circumstances that every family faces.

Family stability. According to the interviewees, the families that have the most success raising their children at home are those that are described as stable. Families with complications of mental illness, drug abuse, lack of social support, extreme poverty, or other significant challenges are perceived by direct stakeholders as having more difficulty.

The challenges of attending to complex care, complex systems, changing “rules,” and the persistence required in advocating, are taxing even for families with the strongest internal resources. Some families are overwhelmed. There was general agreement among direct stakeholders that, in extreme cases of family instability, foster or adoptive families may provide greater stability. However, overall, there was a strong sentiment among those who were interviewed that children should be raised in families rather than institutional settings.

Dedication. Caring for children with complex health care needs is a long-term commitment. Participants felt successful families must be prepared for the ongoing work and responsibilities.

Aggressiveness/persistence. There was agreement among direct stakeholders that families need to be aggressive and persistent to get the supports they need. One direct stakeholder remarked: “Families have to be aggressive—networking, making hundreds of phone calls.” Another interviewee commented, “Parents have to be very, very persistent in getting what they want. They can’t take no for an answer—they get ‘no’ many times. They have to push on.”

Social supports. As one direct stakeholder put it, families “need an extremely supportive support system” to help with some of the work such as shopping, laundry, watching other children in the family, as well as to be a source of understanding and emotional support.

“One of the most difficult things is the lack of information as a parent. No one agency sits you down and tells you everything. You have to discover things for yourself.”

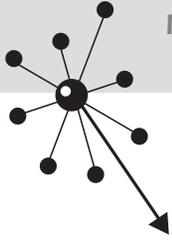
“It isn’t a system; we have to piece things together.”

SUMMARY

In summary, direct stakeholders believe that children belong with their families. They displayed an empathic appreciation, based on their personal experience with families and children, for the challenges faced by those who make this commitment to their children. They describe the lives of families who care for children with complex health care needs at home as demanding, unpredictable, and complex. Families who are most successful are stable, persistent, and well supported. While there are a wide range of services and supports available to families and children, even in the best of circumstances, learning about them, and successfully accessing them presents an ongoing challenge. Furthermore, sometimes the system does not have the capacity to delivery even the services it determines are medically necessary and families are left to struggle on their own. The interviewees communicated that each family's experience of finding and securing resources was like a "brand new journey" rather than one that has been traversed successfully by other families before them.

Direct stakeholders saw both positive and concerning aspects in the future for children with complex health care needs and their families. The most positive aspect of the future was seen to be advances in medical technology that will improve the lives of children: "I do see that there will be interesting technologies that will benefit children." The most distressing concern about the future related to rising health care costs and increasing limits on insurance coverage. One participant commented: "I see over the short term more tightening of insurance funding, cuts in services at the national and state levels." Another stated: "We have all these great things—research wise, care wise, but it all boils down to the delivery of services and the ability to pay for services."

The most significant needs for children and families described by this group of individuals with a wide range of direct experience with families and children include: 1) information and case coordination; 2) reliable and sufficient in home nursing services; 3) reliable and predicable insurance coverage or funding for health-related needs; and 4) the opportunity for respite care and emotional support. Finally, at the systems level, direct stakeholders felt that the key issues that need to be addressed include: 1) gaps in service delivery; 2) a more effective means of coordination of services and supports; 3) the nursing shortage; and 4) rising health care costs coupled with increasing limitations of insurance and funding for services.



V. PERSPECTIVES OF INDIRECT STAKEHOLDERS REGARDING ASSURING FAMILY LIFE FOR CHILDREN WITH COMPLEX HEALTH CARE NEEDS

Liz Healey

In order to gain a broad-based understanding of issues related to families with children who have complex health care needs, we decided to interview selected individuals representing the major public systems that serve children and families, who hold or have held positions of influence related to services and/or policymaking. Contacts were made to individuals and invitations to be interviewed were extended. In some cases, contacts led to others to whom invitations were extended. This section of the report is based on interviews with eight senior policy analysts or administrators, all with direct experience with families of children who have complex health care needs. Two have current or past experience in leadership with the Department of Public Welfare (DPW); one each with the DPW Office of Mental Retardation and the Office of Medical Assistance Programs; two with Child, Youth, and Families; one with education; and one as a legislative staffer. Interviews were between 45 minutes and an hour in length, and were conducted either in person or by telephone.

CHALLENGES TO FAMILY LIFE

Indirect stakeholders were in agreement about a number of major challenges facing families with children who have complex health care needs:

- Families lack flexible, family-determined supports.
- Many children and adults with complex health care needs, as well as their family members, in particular mothers, are homebound due to lack of accessible transportation and other community supports.
- Families lack information about resources.
- Decision makers within the system often lack in-depth understanding of families' needs, and are sometimes judgmental and discriminatory toward families.
- Funding for family support is inadequate.
- It is very difficult to navigate and coordinate within and between various systems of services.
- There is lack of policy articulating a commitment to family and community life for all children.

STEPS TOWARD ASSURING FAMILY LIFE FOR ALL CHILDREN

Based upon the challenges, those who were interviewed identified various needs and possible solutions. A compilation of these is provided below.

Family-determined, flexible supports. Parents expressed that when supports are not adequately tailored to the specific needs of children and adults with complex health care needs and their families, family life is compromised and families are forced to battle for what they need, resulting in significant stress and exhaustion. All indirect stakeholders emphasized the need for flexible supports based on the needs of children and families, as defined by the family. They identified various barriers to this. For instance, one stakeholder mentioned inflexible regulatory restrictions. Others felt that those who control resources question the decisions or judgments of families. One stakeholder suggested that, based on resource limitations, supports should focus on the child, but not necessarily the family as a whole. However, other stakeholders argued that these needs are inseparable, and that families as a whole need to be supported. It was suggested that there is need for a flexible pool of money for things that are not covered through Medicaid or insurance.

Transportation and respite. In particular, a number of indirect stakeholders noted the need for additional assistance with transportation and respite. While families may get some assistance with these, it is generally very inadequate. The availability of additional respite and transportation support would help reduce isolation and the degree to which children and their families are homebound.

Accurate information. Indirect stakeholders agreed that families need access to accurate and up-to-date information. As part of the solution, a few of the interviewees suggested that there is need for additional training for those who are in positions of providing information to families.

Decision makers and service providers understanding of families' lives. Some of the indirect stakeholders noted that people who make decisions about services and resources often do so without in-depth knowledge and understanding of the daily lives and issues of families of children who have complex health care needs. Negative judgments are made about families, questioning their ability to determine what services are needed and, ultimately, questioning their ability to provide quality care for their children.

Attention to racism and discrimination. The view was expressed that families from minority racial and ethnic groups, single parent families, and those with low socioeconomic status experience racism and discriminatory treatment from health care and other service providers.

Adequate funding. Participants agreed that the funding allocated to support children with complex health care needs and their families is insufficient. There was agreement among the indirect stakeholders about the need for cost containment. At the same time, they emphasized that families are very conservative with regard to resources. Some suggested that institutions and other congregate care facilities should be closed, and that resources should be redirected to providing family and community supports. It was recognized that there are certain things that families need that are not covered by current funding streams, and that there should be a pool of flexible funding to assist families with these expenses. Finally, there is need to advocate with legislators for increased funding.

Effective support coordination. Participants felt that there is not an integrated set of services. The system is

very complex and fragmented, and it is very challenging for families to coordinate health care and disability services, overall, as well as to coordinate services within a particular arena, such as school or transition from school to adult services. The fragmentation of the system is an impediment to timely solutions to problems that arise. There was agreement among indirect stakeholders that families need effective support coordination. As one person put it, “Families need competent help navigating the system.” Another suggested that there should be no “wrong door” for families to obtain assistance. A few of the stakeholders commented on weaknesses of current support coordination efforts. One noted that support coordination typically represents county interests and is directly linked to cost control and suggested the need for independent support coordination. Another identified the need for updated education and training for support coordinators.

Policy of inclusion. Some of the indirect stakeholders identified the need for a policy that articulates the right of all children to family life and inclusive community life.

Advocacy. Participants felt there is need for advocacy at the individual and systems level. It was suggested some families would benefit from the availability of an ombudsperson to help them advocate for needed services. Additionally, there must be systems level and policy change that promotes the right of all children to family life and that provides the funding to back this. Participants felt this would entail promoting increased awareness among policymakers about family issues. According to some of the indirect stakeholders, policymakers are often out of touch with the experiences and needs of children with complex health care needs and their families and felt it is essential for advocates to educate them through portrayal of real people and real stories.

Health care and disability services provider collaboration with families and with one another. Participants agreed that children need doctors and other service providers who understand both disability and health issues. In addition, participants felt it is essential to have providers who work in partnership with the family and with one another across specializations and fields.

Adequate, coordinated supports for school. Participants expressed a number of issues related to education. First, school districts need to ensure there are nursing and health related services available for children who need such services at school. As one indirect stakeholder remarked, “Saying no to a parent is unacceptable; saying no aid on bus or no aid in school, so child can’t come, is unacceptable.” Second, there is need for coordination between school, home, and medical services. Third, there is need for accessible transportation so children can participate in extracurricular activities. Fourth is the need for a culture of welcoming all students, which must be cultivated from the top down.

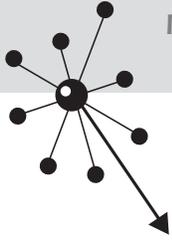
Coordinated transition services. The need for more attention to be devoted to transition from school to adult services was expressed. In part, participants felt this would entail greater collaboration between education, the Office of Mental Retardation (OMR), and the Office of Vocational Rehabilitation (OVR).

Need to learn from promising practices. Indirect stakeholders identified the need to build on existing promising practices. These included practices currently being implemented in disability services within

Pennsylvania (e.g., coordination of health care services within the Pittsburgh school district through Project Healthy Child); practices currently being implemented in disability services in other states (e.g., transition services in the state of Michigan), or practices being implemented in other fields within Pennsylvania and beyond, that could be used in disability services (e.g., the Gateway MCO related to behavioral issues).

CONCLUSION

In summary, indirect stakeholders emphasized the need for family determined supports; for greater understanding of families by decision makers, administrators, and policy makers; for coordination and collaboration with families and among service providers; for assistance to families in obtaining information and navigating the maze of services; and for policy and accompanying funding that promotes family and community life for all children. The issues and needs that indirect stakeholders identified corroborate those identified by families themselves, by direct stakeholders, and in the literature.



VI. RESEARCH TEAM PERSPECTIVES

Nancy Rosenau

The Research Team consisted of an invited membership chosen to represent broad system experience, expertise, and commitment to children with complex health care needs and their families. A number of members brought experience from multiple roles. Members were **not** asked to represent agencies with which they are affiliated or employed, but rather to apply their personal and professional experience and views in discussions at the Research Team meetings. This section summarizes discussions of four meetings of the team.

Research Team Membership

Members experience represented in the following roles:

- Parents of children and young adults with complex health care needs
- Young adults with complex health care needs
- State and federal agency administrators
 - health
 - child welfare and protection
 - mental retardation
 - education
 - public welfare
 - medical assistance & health care financing
- Service providers and administrators
- Health care practitioners
- Philanthropic foundation administrators
- Legal advocates

Research Team Charge

The Research Team was designed to be one of the multiple sources of information for the study. Specifically, the team's charge was:

- To be a source of information based on personal and professional experience
- To contribute personal perspectives based on experience
- To react to findings of other elements of the study
- To offer recommendations to improve the lives of families of children with complex health care needs
- To agree to remain involved in activities to implement changes which fall within member's scope of influence and agreement following the close of the study

Research Team Meetings

The team met on four occasions from July 2005 through June 2006. Each of the meetings was devoted to a specific focus.

First meeting:

- Identified issues
- Developed framework for research team discussions

Second meeting:

- Discussed literature review
- Developed description of current status of services to children and families and described vision of desired service system

Third meeting:

- Discussed findings from interviews with parents and stakeholders
- Developed preliminary goals and possible action strategies

Fourth meeting:

- Discussed policy analyses and promising practices
- Identified goals and possible action strategies and opportunities

Details of these discussions are described in the following sections.

ISSUES AND FRAMEWORK FOR SUPPORTING FAMILY LIFE

The Research Team members developed a description of the elements that make for “a good life” and what helps families to lead a good life.

What makes life good?

- A sense of safety, well-being, belonging, personal control, heritage, pride, and continuity
- Interactions with others characterized by acceptance, encouragement, and friendship
- External conditions including an adequate home, resources, access to the community, and social and economic opportunities
- Participation in activities (both planned and spontaneous) that include laughter and play, traditions, celebrations, vacations, caring and being cared for, learning, and performing valued family roles

What helps families lead a good life?

- People, supports, and resources
 - housing
 - transportation
 - financial
 - respite
 - nursing
 - equipment

- Time to be together
- Attitudes
 - child is valued
 - positive messages from others
 - welcoming communities and neighbors
 - families feel empowered
 - families feel understood
- Knowledge and information
 - about resources
 - about choices
 - about how to use system
- The way systems and resources are organized
 - decision-makers understand families' day-to-day lives
 - systems communicate and coordinate with each other
 - family-directed use of existing funds
 - needs-based rather than categorical/diagnostic-based service access
 - early, ongoing, and seamless services including transition to adulthood
 - adequate insurance coverage
 - systems engage families and are evaluated by families

DESCRIPTION OF STATUS OF CURRENT SERVICES TO CHILDREN AND FAMILIES

Characteristics of current systems, in particular health, education, mental retardation, and child welfare included the following:

- Professional-driven
- Variability by geography and funder
- Management across large number of decision making entities is complex
- Constant changes
- Lack of accountability
- Turf battles
- Lethargy
- New approaches and innovation have difficulty making it into practices
- Decisions guided by gate-keeping and rule compliance rather than family needs
- Systems under criticism react defensively
- Allegiances to providers and funders more than to families
- Market forces, financial survival, and big business thinking pervades decision making
- Medical model guides service delivery
- Interest and willingness to collaborate and promote positive change exists but is often diluted by multiple challenges

DESCRIPTION OF VISION OF DESIRED SERVICE SYSTEM

A description of an overall vision of the desired service system included the following:

- View of future
Children will grow and thrive in families that are well-supported by systems and policy development
- Guiding principle
Children thrive and grow in families and communities where growth-promoting relationships are paramount
- Beliefs
Children have a right to live with a growth-promoting family
We know from child development literature that a child's well-being is affected by their parenting relationship(s)
Families are affected by the quality of support they have
- Responsibility
To work through whatever barriers prevent children from living in growth-promoting families
To create a system that is unified around an unflagging commitment to growth-promoting family life for all children
- Purpose
To assure and support family life that is
safe, secure, protective, comforting, nurturing, reliable, stable
with parents who are responsive, loving, dependable, emotionally invested, consistently available, and committed long-term
- Allegiance
To children first
To families who are committed to growth-promoting family life
To those who support growth-promoting families

GOALS, ACTION STRATEGIES, AND OPPORTUNITIES

Consensus emerged about the need for an overarching philosophy articulated in policy that children have a right grow up in families. While the term “permanency” was applied to such a philosophy and supporting policy, the group was concerned about negative connotations that might attach to the term emerging from child welfare system practices where permanency might be interpreted narrowly as relinquishment and adoption. The group concurred that children should grow up in families but emphasized important qualitative features of family life. The intent of the group was to articulate a policy that sought “relational security” for a child achieved by living within a family home with parenting characterized by safety, security, responsiveness, nurturance, and continuity; and a family embedded in a supportive community and service system environment.

Recommendations for changes were reflected in articulation of a number of goals and possible action strategies. The group also identified a number of opportunities afforded by already existing resources or by activities that were already underway which could be engaged and further developed.

Goals:

1. Public policy will consistently reflect support for family life.
2. The public will better understand family support issues.
3. Knowledge, information, and awareness about family needs will be improved among all stakeholders and access to information about resources will be ensured.
4. Families will have access to timely culturally competent services and supports based on individual child and family needs.

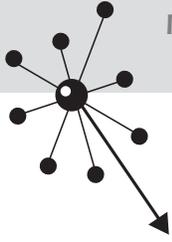
Possible action strategies:

- Disseminate final report of this study
- Present findings and recommendations to
 - Secretaries and Deputy Secretaries
 - Interagency Coordinating Council
 - Children's Cabinet
- Collect and disseminate family stories
- Develop marketing strategies to “package” family stories
- Provide information and training for stakeholders
 - Policy makers
 - Legislators
 - Insurers
 - Providers
 - Clinicians
- Establish knowledgeable advocates
- Study reasons for services denials and patterns of appeal decisions
- Pursue mechanisms for family-directed payment of nursing and personal care attendants
- Pursue foundations and grant makers for funding
 - Forums like the Every Child Deserves a Family Coalition
- Develop national standards regarding permanency planning in all service systems
- Establish special needs units within health insurers
- Encourage families to use available protections built into current laws by contacting existing advocacy organizations
- Identify changes for policy makers that are do-able within existing resources
- Explore how other states are developing non-categorical funding
- Develop relationships between families and decision makers

Opportunities:

- Build on existing Every Child Deserves a Family Coalition
- Participate in the Department of Health planning process for Title V
- Pennsylvania Developmental Disabilities Council (PADDC) has provided grant funded for Every Child, Inc. to host a summit inviting other states to explore strategies
- Engage Youth Leadership Network to increase voice of youth in policy making and planning forums
- Utilize the Center on Human Policy as a resource for innovative practices nationally

Overall, the group felt that more effective services and supports were needed by families in caring for their children with complex health care needs. Participants felt that greater understanding of families' lives must be promoted and that cross system forums for families and stakeholders to come together presented some of the best opportunities for learning and strategizing for change to promote family life for children with complex health care needs.



VII. HEALTH POLICY REVIEW

David Gates

This review analyzes health policy in relation to four major issues: access to information, insurance, system capacity, and quality. These have been identified as barriers to obtaining adequate services by the families who were interviewed for this study (see Section III) as well as by staff at the PA Health Law Project in the course of their ongoing work with families of children with complex health care needs. The paper first discusses what families require in order to care for their children with complex health care needs at home. It then discusses the barriers families experience in getting what they need along with the relevant policy issues.

HEALTH-RELATED SERVICES FAMILIES NEED

Families with children who have medically complex needs will commonly need several health care related services in order to maintain the child at home. The most commonly needed health care related services are set out below. We have divided these services into “Medical” which require a prescription by a licensed health care professional, most commonly a physician, and are provided by or under the direction of a licensed health care professional; and “Non-medical supports” which may not require a “prescription” and are not provided by or under the direction of a licensed health care professional. However, for children with medically complex needs, non-medical health care related support services are often as important if not more important in enabling a family to maintain the child at home as traditional medical services.

Types of needed services

Medical

- Inpatient hospital
- Outpatient physician services (including specialists)
- Labs & diagnostic services
- Home health
- Outpatient therapies
- Durable medical equipment
- Medical supplies
- Medical case management

Non-medical health-related supports

- Personal care
- Respite care

- Transportation
- Assistive technology
- Home modifications
- Climate control
- Nutritional supplements
- Service coordination/case management

BARRIERS TO OBTAINING NEEDED SERVICES AND THE RELATED POLICY ISSUES

The types of barriers reported by most families interviewed fall into four categories: (1) lack of information, (2) insurance coverage, (3) capacity of the service delivery system, and (4) quality. Each of these will be discussed in detail below.

Lack of Information

Families often identify lack information about what services are available and how to access those services as a serious barrier, especially in regards to non-medical supports. For families whose child has medically complex conditions, especially where the child is born with those conditions, the first contact is with physicians and nurses who are providing medical care for the child, usually in a hospital. Physicians and nurses are usually knowledgeable about other medical services the child will need as the physicians usually have to prescribe these services and they are often provided by the hospital or some other medical provider frequently connected to the hospital.

Unfortunately, doctors and nurses may be far less knowledgeable about the types and availability of non-medical supports the child may need due to the fact that non-medical supports do not require the same level of involvement by physicians and nurses in prescribing and managing these services as do the medical services. To overcome this problem, Pennsylvania funds other sources of information for families with children with medically complex conditions. The best well known is the Special Kids Network which provides “information and referral to services that children with special health care needs and their families may need” both over the phone and online through a “Health & Human Services Portal.” However, families have to know about the Special Kids Network in order to obtain information from it. Sadly, it appears that many families still do not. The Special Kids Network had run a series of television ads several years ago which did appear to raise awareness of the existence of this service. However, those ads have stopped. Parents interviewed for this study did not report receiving referrals to the Special Kids Network from their child’s physicians or other medical providers.

There are a number of other organizations that provide information and referral for parents, including the PA Health Law Project, PA Protection and Advocacy, the Disabilities Law Project, Parent to Parent, Every Child and the PEAL Center. Here again, however, parents must know about these organizations in order to contact them.

Our parent interviews indicate that the most common source of information about non-medical supports comes from other parents. Parents will come into contact with other parents whose children have similar needs

at hospitals and doctors' offices, especially in children's hospitals and connected physician offices as they are more likely to see children with medically complex conditions. Unfortunately, the connections between parents in hospital and physician office waiting rooms are often a matter of chance. There remains a great need for hospital discharge planners and social workers who are knowledgeable about the various resources available to assist parents in identifying and assisting parents to obtain non-medical support services. This will require not only the provision of information to hospital social workers and discharge planners, or follow-along clinics and practitioners, but the recognition by hospital management that information about non-medical support services is important to families and the provision of that information is a valid function of hospital staff.

Insurance Coverage

Due to the chronicity and complexity of services needed for children with complex medical conditions, the cumulative costs of ongoing services and supports are frequently beyond the means of all but the wealthiest families. Therefore, lack of or limits on insurance coverage can pose a significant barrier to access to needed medical services and health-related supports. There are several different basis under which insurance coverage can be denied. They are discussed below.

Diagnosis-based exclusions. Many commercial health insurance policies exclude coverage for the diagnosis and treatment of certain conditions, most commonly mental retardation and autism. Such exclusions are not permitted for Medical Assistance or the Children's Health Insurance Program ("CHIP")

Medical services vs. health-related support services. Most health insurance, including Medical Assistance and CHIP, exclude coverage of most non-medical health-related support services. Unlike commercial health insurance, Medical Assistance does cover the costs of transportation to and from medical appointments (including therapies) but even that coverage is provided through a different mechanism (contracts between the state and county-based transportation agencies) than coverage for traditional medical services. The primary funding sources for health-related support services are the mental retardation waivers (Consolidated and Person/Family Directed Support Waivers), Early Intervention and school districts (as part of a child's Individual Educational Plan (IEP)(or §504 plans).

DME vs. assistive technology. There is a growing range of equipment and devices, known collectively as assistive technology, that can help compensate for numerous functional limitations that result from disabilities or complex medical conditions, making it easier, or even possible, for a family to maintain a child at home. However, health plans, including Medical Assistance, do not cover "assistive technology." Instead, they cover "durable medical equipment" ("DME"). The problem is that the definition of durable medical equipment is much narrower than that of assistive technology. Medical Assistance defines DME as:

An item or device... that can withstand repeated use; which are used primarily and customarily to serve a medical purpose; which are customarily not useful to a person in the absence of illness or injury and which are appropriate for home use.

The main problems with the way DME is defined are the requirements that the equipment be used "to serve a

medical purpose” and not be useful “in the absence of illness or injury.” For example, computers and software are frequently denied as not meeting the “medical purpose” and not useful “in the absence of illness or injury” requirements. Other devices that may assist with functional limitations but not “serve a medical purpose” are likewise frequently denied on the basis that they are not “DME.”

Assistive technology is covered under most of the Medicaid Home and Community Based waivers. However, except for the Birth to 3 Early Intervention waiver, a child’s eligibility for a waiver is based on the type of disability the child has. Children 3 years of age and older without mental retardation do not meet the disability criteria for a waiver unless they are ventilator dependent.

Service limits/caps. Many commercial health insurance plans impose caps on the amount the plan will pay out on covered services during the individual’s lifetime. Although these lifetime caps are usually around \$1 million, children who need frequent hospitalizations for chronic health conditions can often reach that cap in a few years. Plans may also place limits on the annual amount (by number of visits or number of hours) of specific services the plan will pay for. These limits are frequently imposed on in-home nursing and various therapies (PT, OT and speech) as well as on durable medical equipment.

There are no lifetime caps on services paid for by Medical Assistance or CHIP. There are annual limits on some individual services under CHIP. While there are also annual limits on individual services under Medical Assistance for adults, those limits cannot be imposed on persons under 21 for medically necessary services due to a federal law known as Early Periodic Screening Diagnosis and Treatment (“EPSDT”).

Utilization review & medical necessity. Even if a medical service is of a type of service covered by the insurance plan, it may still be denied on the grounds that it is not medically necessary for the child. Health plans, including Medical Assistance and CHIP, identify certain services, usually higher cost services including home health services and durable medical equipment, for which the plan will require the provider to get approval from the plan before providing the service. This is known as “prior authorization.” It is through the process of prior authorization that access to medical services can be denied on the basis of lack of medical necessity. Therefore the standards under which medical necessity or the lack thereof will be determined by the health plan are very important. In general, standards and guidelines include the following:

Experimental services. Health plans, including Medical Assistance and CHIP, do not cover procedures, services or equipment they deem to be experimental. The Medical Assistance definition of experimental procedure is: “A procedure that deviates from customary standards of medical practice, is not routinely used in the medical or surgical treatment of a specific illness or condition, or is not of proven medical value.” The terms “customary standards” and “routinely used” make it difficult to get coverage for new and cutting edge treatments. Frequently, health plans will not cover newer treatments and equipment until there has been at least one study published in a peer-reviewed medical journal which demonstrates the efficacy of the treatment or equipment (“proven medical value”). This creates a disparity of care between those families who can afford to pay out of pocket for cutting edge treatments/equipment or are able to get into subsidized studies and those who cannot.

Rehabilitation vs. maintenance. Aside from Medical Assistance, most health plans require that the treatment or therapy result in an improvement in the individual's medical status or function ("rehabilitation"). This presents a problem, especially with therapies, when the child stops making progress ("plateaued"). Continued therapies may be needed to maintain function but commercial health plans do not cover "maintenance care." This results in a loss of coverage of therapies when a child plateaus with the potential for loss of functioning resulting from the loss of therapies. By contrast, Medical Assistance does recognize maintaining function as meeting its medical necessity criteria: "The service or benefit will assist the individual to achieve or maintain maximum functional capacity in performing daily activities..." (HealthChoices RFP). While this gives parents a means of paying for therapies after commercial insurance stops paying, it does shift costs from the private sector to the government. Also, families may need to switch providers when they change from commercial insurance to Medical Assistance.

Custodial care. Another way insurers use medical necessity to deny services—usually home health—is to classify care as "custodial." Custodial care is care that does not involve a skilled nursing service—most commonly assistance with activities of daily living (feeding, dressing, bathing, toileting etc.). With the exception of Medical Assistance, these custodial services can usually only be covered if there is also a need for one or more skilled nursing services (administration of medication, tube feedings, monitoring a vent etc.). However, children who have significant personal care needs but who do not need skilled nursing on an ongoing basis are often denied the personal care services they need to remain at home by commercial health plans under the rationale that the care needed is "custodial."

Fortunately, Medical Assistance covers personal care services for children and adolescents (up to age 21) regardless of whether a skilled nursing service is also needed. However, some of the Medical Assistance HMOs continue to deny personal care services on the grounds that they are "custodial" and therefore not covered. Even when the personal care service is covered, it is usually covered as a home health service through a nursing agency, even though this service could be provided by less costly providers (even friends and family) with greater family control.

Less costly alternatives. Another aspect of medical necessity is the notion that services and especially durable medical equipment will be denied if the health plan believes there is a less costly alternative. This means that prescribers must often document not only that the prescribed piece of equipment is medically necessary but also that the alternatives are either not effective for the particular individual or cannot be used by that individual.

Use of utilization review criteria. Because of the volume of "prior authorization" requests, health plans frequently use commercial "utilization review" criteria. These criteria enable plans to use staff other than physicians to make at least initial decisions on prior authorization requests. While these criteria may represent currently accepted medical practice for common medical conditions, they are less useful for persons with medically complex conditions and especially those with low incidence disorders. The state recognizes this, at least for state licensed HMOs, by prohibiting HMOs from denying medical services solely on the basis of utilization review criteria (28 Pa Code §9.752).

Qualifications of health plan reviewers. Most health plans have nurses initially review “prior authorization” requests. In state licensed HMOs, those requests that the nurses do not approve must go to physicians for review (28 Pa Code §9.752). While not required, that is common practice for many other health plans. However, except for Medical Assistance, there are no requirements on the particular qualifications of the physicians who deny requests. This can present problems for children with medically complex conditions and low incidence disorders if the reviewing physician is not familiar with the child’s conditions or the treatments requested.

Medical Assistance requires that the HealthChoices HMOs use physicians that have “generally comparable experience or expertise” to the prescribing physician in reviewing requests for services for persons under 21. In addition, the reviewing physicians are required to make “a reasonable effort to consult with the prescriber” before making a decision (HealthChoices RFP, Ex. H, B2).

Capacity and Predictability

Assuming the family can obtain coverage of a needed medical or health related support service, the next potential barrier is the lack of capacity of the service delivery system to provide the service in a predictable fashion. Home health—especially in-home nursing—appears to have the greatest service capacity problems affecting families with children with complex medical conditions. Being prescribed and approved for a certain number of hours of in-home nursing does not mean the family will receive those hours. These capacity issues present in the following ways:

Travel issues. Since home health services are done in the child’s home, staff must travel to the child’s home, rather than vice versa. In rural areas, available staff may live quite a distance from the child’s home. It is often difficult to find nurses and other home health staff who are willing to drive great distances to and from the family’s home, both in terms of time and costs, especially with increasing gas prices. Even in suburban and urban areas where travel distances are not as great, if travel costs are not adequately reimbursed, nurses may choose jobs in hospitals, nursing homes or even HMOs if the travel is not as far as traveling to a child’s home.

Safety concerns. Nurses and other home health staff may be reluctant to staff a particular child due to concerns about their own safety for the following reasons:

Child’s weight. Some home health staff may be unwilling to staff an older, heavier child if that staff person would have to lift, turn or position the child for fear of injuring their own back, especially where mechanical lifts are not available or inadequate.

Child’s neighborhood. It can be difficult to find nurses who are willing to staff for children living in some inner city neighborhoods due to fears for their personal safety, especially for night hours.

Infectious diseases. Some home health staff may be concerned about their own health if the child has a disease the staff person fears may be contagious. These fears are more prevalent with staff who themselves have medical conditions that make them more susceptible to infections or have family more susceptible to infections.

Behavioral issues. Home health staff are less willing to work with a child who has challenging behaviors if they fear they may be hit, kicked or bitten by the child.

Short shifts. Insurers authorize a specific number of hours of in-home nursing or other home health services based, among other things, on the amount of time it takes to perform necessary nursing services. Where the authorization for nursing services is for 2 or 3 hours a day, it is often difficult to find a nurse willing to take those hours. Nurses frequently want longer hours so they can earn a day's pay without having to travel to multiple homes. Willingness of nursing staff to work a short shift is not taken into consideration by most insurers in determining the number of nursing hours they will authorize.

Lack of backup. Just like anyone else, nurses and home health staff are sometimes unable to get to work due to their own illness, family illness, car trouble and other reasons. In fact, there appears to be an even higher than average rate of absence among the lower paid nurses aides as they are often unable to afford reliable transportation or child care. However legitimate the reason for the absence, the impact on the family waiting for that nurse or aide can be disastrous. Unfortunately, many home health agencies do not have reliable backup systems to provide another staff person to fill-in with little advance notice. As a result, parents must often call off from their own jobs, with little notice, to stay home and care for their child. Sometimes parents will lose a job as a result of missing too many days of work to cover for an absent nurse or aide or else they do not look for work because they fear they would need to cover too many days when home health staff fail to show up.

Lack of qualified staff. Most of the barriers above are exacerbated by a general lack of qualified staff. For nurses, this may be the result of less stressful or more remunerative job opportunities, such as doing utilization review for a health plan. For nurses aides, home health agencies must compete with other jobs like fast food or retail sales which may pay comparably with fewer challenges.

Quality

While quality is a concern in all areas of health care, it presents a special challenge for families seeking to maintain their medically complex child at home, especially in regards to home health services. However, because nurses and home health aides usually spend far more time with their "patient" than treating physicians and because home health services are inherently intrusive, quality, in the context of home health services, includes factors beyond those considered for other forms of medical care, at least from the perspective of the parent(s). Some of special factors of quality home health services from a parent perspective are:

Skilled observation. While nurses receive basic training in skilled observation, it is often more difficult to ascertain the current health status of a child with medically complex conditions than an adult, especially if the child is non-verbal and unable to communicate his or her symptoms in a traditional manner. Is the child just fussy or in serious pain? When the child stares, is he having a seizure? Being able to interpret subtle changes in behavior or affect can be essential in determining when and what type of medical intervention may be necessary. However, knowing when the child is exhibiting changes in behavior or affect requires knowing the child's "baseline" behavior and affect. It often takes time, and training by the parents, for a nurse to learn the child's baseline behavior and be able to contrast that with behaviors that signify a medical event or change in the child's condition that requires medical intervention. This means that it can take several weeks if not months of "on the job training" before a parent feels comfortable leaving the child with a new nurse. However,

many health plans, including Medical Assistance, do not authorize nursing for periods when the parent is not at work, making it difficult for the parent to have the time to stay home with the nurse and “train” the nurse in how the child manifests or communicates changes in his/her medical condition. In addition, parents face turnover in nursing staff and having to train a new nurse.

Respecting the expertise of parents. Parents are usually the most knowledgeable about the daily care needs of their child. Unfortunately, some nurses do not respect this “expertise,” which not only undermines the important relationship between the nurse and the parent but can undermine the child’s care as well. Home health staff need to listen to parents because the parents have far more experience with the child than the home health staff. In addition, home health staff need to communicate with parents regarding the care they have provided and expect to provide as well as their observations of the child’s condition. Parents need to be accepted as full members of their child’s treatment team.

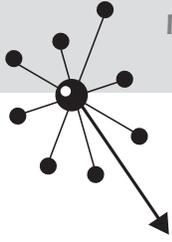
Interaction with the child. Children with medically complex conditions are often authorized eight hours or more a day of nursing during the time the parent(s) is/are at work if the child is not at school. As a result, the child may spend a significant amount of time with the nurse. Most parents feel that personal interaction between the nurse and the child improves the quality of care when the nurse is spending significant amounts of time with the child because it builds trust between the child and nurse, resulting in better compliance by the child with the nursing services and a reduction in separation anxiety and acting out behaviors. It also improves the child’s socialization skills.

Reliability. Because so much hinges on home health service, such as the parent’s ability to get and keep a job, reliability of home health staff is a very important factor. By reliability, parents mean showing up on time and making arrangements for coverage if the scheduled staff person is unable to work on a given day.

Continuity. Because of the need to develop knowledge about the child in order to be a skilled observer of the child’s condition and to build trust with the child and parent, parents are looking for staff that will remain with their child for some time. While some turnover in staff is inevitable, parents are looking for home health agencies that work to keep good staff and ensure that new staff are properly educated about the child’s conditions and trained in the services that need to be provided to that child.

CONCLUSION

Key policy issues have been identified in relation to: access to information, insurance, system capacity, and quality of services. These act as significant barriers for families in obtaining the medical and nonmedical supports that are crucial to them in caring for their children at home. To address these policy issues, it is essential to work in partnership with families, in order to arrive at solutions that truly meet the needs of and support quality community lives for children with complex health care needs and their families.



VIII. EDUCATION POLICY CONSIDERATIONS FOR STUDENTS WITH COMPLEX HEALTH CARE NEEDS IN PENNSYLVANIA

Nancy A. Hubley and Shari A. Mamas

Introduction

The overarching question posed to the Research Team is “What constitutes essential support for families with students with complex health care needs? And specifically, what makes it easier or harder for families to care for students with complex health care needs?”

The primary premise of this paper is that high quality appropriate public education services in the least restrictive environment are an essential community support system needed by students with complex health care needs and that when such educational services are in place and properly implemented, it is easier for families to care for these students. Although this paper focuses on the right to a free appropriate public education for students with complex health care needs under the Individuals with Disabilities Education Act (IDEA) [20 U.S.C. §§ 1401 *et seq.*], it is important to note these students are further protected from discrimination by other laws, including, among others, Section 504 of the Rehabilitation Act (§504) [29 U.S.C. § 794], the Americans with Disabilities Act (ADA) [42 U.S.C. §§ 12101 *et seq.*], No Child Left Behind (NCLB) [20 U.S.C. §§ 6301 *et seq.*], and a full body of federal and state case law.

Some of the Problems

Many parents and family members of children with complex health care needs simply do not know the breadth and depth of the legal entitlement to public education services or how this entitlement can be used to make their lives easier at home and further promote the educational progress of their child. Too often, families are overwhelmed, dealing with myriad health and community agencies on top of the normal demands of family life and barely have time to breathe, much less learn what education laws apply to their child and how to enforce them.

Even parents who are aware of legal entitlements find it difficult to translate these into meaningful support services for their children with complex health care needs. For example, when school personnel tell parents something is not available or not possible, parents often give up or in some cases struggle to provide the service themselves, further complicating their own family’s lives with additional unnecessary stress, expense and inconvenience. This is especially true in areas such as transportation (parents give up on seeking different or specialized transportation to which the child is legally entitled and try to provide it themselves), assistive

technology devices and services (parents fail to ask school districts to provide equipment and devices including things such as computers, catheters, positioning and communication devices, and other needed equipment, and moreover, to provide training on how to use them), and school health care services. Parents are also reluctant to request services they feel are “too expensive” or inconvenient for schools. For example, parents are hesitant to request ramps, elevator use, emergency health crisis plans, and personal care aides or special training fearing the cost of such services. They further hesitate to request modified schedules, specialized training for school personnel, or involvement of peers and other families if they feel it will be time consuming or inconvenient for schools.

Students with complex health care needs often miss school for medical appointments and hospitalizations, and are kept at home for even longer periods of time or go without educational services. Sometimes schools penalize these children academically, lower grades, retentions etc. Parents are reluctant to request the school accommodate their child by providing meaningful services at home, in the hospital or through technology or otherwise accommodate the child’s absence and irregular learning schedule.

Overview

This paper explores the right to such services and how administrators and policy makers can make it easier for parents and students to access these services, but begins with a brief description of the legal context within which public educational policy is made; and provides a discussion of current and emerging policy issues. Given the legal rights and policy considerations, it concludes with some specific recommendations for public policy makers to improve educational outcomes for students with complex health care needs and make it easier for families to care for them.

LEGAL CONTEXT FOR PUBLIC EDUCATION POLICY IN PENNSYLVANIA

Statutory Framework

Public education policy in the United States for students with disabilities has recently moved from the traditional bifurcated approach to public education as either “special” or “regular” rooted in the Individuals with Disabilities Education Act (IDEA) (passed in 1975 as the “Education for All Handicapped Children’s Act”) to a broader approach to public education that views students with disabilities as one of several “sub-groups” that must be educated, along with their peers, consistent with academic standards and a new sense of accountability under the No Child Left Behind Act (NCLB) and many of the new provisions of the IDEA, as it was first reauthorized in 1997 and most recently in 2004 as the Individuals with Disabilities Education Improvement Act.

Constant throughout this shift in educational philosophy has been the anti-discrimination provisions of two very significant federal laws, Section 504 of the Rehabilitation Act (§504) and the Americans with Disabilities Act (ADA). Both prohibit discrimination on the basis of disability, and further mandate “reasonable” accommodation, effective communication, auxiliary aids and services and the removal of architectural barriers for persons, including students with disabilities.

Significant Federal Case Law

Due to the diligent efforts of lawyers, parents and advocates for students with disabilities, federal and state court decisions since the passage of the IDEA in 1975 have consistently interpreted the IDEA and other disability laws to ensure that students with disabilities have equal access to quality public education services in the least restrictive environment, and have been critical forces in the development of public education policy and practices impacting students with disabilities.

The significant Supreme Court decisions from *Rowley* [Bd. of Ed. of the Hendrick Hudson Central Sch. Dist. v. Rowley, 458 U.S. 176; 102 S.Ct. 3034 (1982)] (Supreme Court case defining what constitutes an appropriate educational program for a child with a disability) to *Garret F.* [Cedar Rapids Comm. Sch. Dist. v. Garret F., 526 U.S. 66; 119 S.Ct. 992 (1999)] (Supreme Court explains the entitlement to free and appropriate related services and distinguishes these services from medical services provided by a physician) and more recently to *Murphy* [Arlington Central Sch. Dist. Bd. of Ed. v. Murphy, ___ U.S. ___; 126 S.Ct. 2455 (2006)] (Supreme Court denies parents reimbursement for expert fees incurred in special education cases), and Pennsylvania's own rich history of federal court cases continue to establish rules and parameters for the education rights of students with disabilities.

Significant Pennsylvania Case Law

In Pennsylvania, the PARC Consent decree provided the foundation for the IDEA's right to special education services and put Pennsylvania in the forefront of public educational policies that encouraged the education of students with disabilities in the least restrictive environment, with necessary support services. The right to special education was further enhanced by federal courts in Pennsylvania, by a series of cases which continue to put Pennsylvania at the cutting edge, further enforcing the right of students with disabilities and others, to access educational programs and to receive appropriate services. For example:

- *Oberti* [Oberti v. Bd. of Ed. of the Borough of Clementon Sch. Dist., 995 F.2d 1204 (3d Cir. 1993)] - children with disabilities are entitled to be educated in regular education classrooms with appropriate supplementary aids and services
- *Armstrong* [Armstrong v. Kline, 476 F.Supp. 583 (E.D. Pa. 1979)] - children with any type or severity of disability must receive extended school year programming if necessary for FAPE
- *Cordero* [Cordero v. Pennsylvania Department of Education, 795 F.Supp. 1352 (M.D. Pa. 1992)] - PDE must have a system to provide intensive interagency coordination to students with disabilities whose school districts have determined that they cannot be appropriately educated in a public educational setting and who have waited more than 30 days for the provision of an appropriate educational placement
- *Nancy M.* [Nancy M. v. Scanlon, 666 F.Supp. 723 (E.D. Pa. 1987)] - children in foster care are entitled to all free school privileges accorded to resident children of the district
- *Gaskin* [Gaskin v. Pennsylvania Department of Education, No. 94-CV-4048 (E.D. Pa. 2004)] - PDE must undertake a series of reforms in special education processes and procedures to ensure that districts provide FAPE to students with disabilities in the least restrictive environment
- *Pardini* [Pardini v. Allegheny Intermediate Unit, 420 F.3d 181 (3d Cir. 2005)] - children transitioning from the early intervention system to the school age system are entitled to pendency of services in the event of a dispute

These cases, read in conjunction with federal statutes provide the foundation for public educational policy, but it is the state and local policy makers that truly shape the educational experiences of students with disabilities through implementation, enforcement, monitoring and accountability.

Pennsylvania's Policy Framework

Families in Pennsylvania have seen an increasing commitment—both programmatically and financially—to more integrated approaches to the implementation of federal disability laws. Integrating and serving students with disabilities has become a critical component of the State's educational policy, with the recent settlement of the *Gaskin* case (a class action lawsuit designed to enforce the least restrictive environment mandate of the IDEA), and the steadfast commitment in recent years to students. The current commitment to students is reflected in many new state level initiatives, including the establishment of an inter-departmental Department of Education and Department of Public Welfare's Office of Child Development; expanded funding for child health care; school-based mental health initiatives; and regulatory proposals that strive to ensure that students with disabilities, including those with complex health care needs, have access to quality pre-kindergarten and early child care programs that address and accommodate their special needs. The Department of Public Welfare is proposing to amend its child care facility regulations to promote inclusion of children with special needs in all child care facilities and comply with the ADA philosophy. These and other state level initiatives provide fertile ground and new opportunities for different ways to address public policy issues impacting the education of students with complex health care needs. They also improve the overall quality of family life for children with complex health care needs and their families (e.g., having access to a safe and quality pre-kindergarten program ensures that the child has an opportunity to benefit from early education while the family has time to focus on other tasks or get a much needed break while the child is at the program.)

Policy Opportunities

To take advantage of these opportunities and others, and to ensure that laws and policies are meaningful and effective for students with complex health care needs, the laws have to be understood by parents; and implemented and enforced by public officials. More importantly, these opportunities, like the policies themselves, have to be shaped and used to create stronger more responsive policies and practices that help students with chronic and significant health care needs remain at home and attend school in the least restrictive settings. Continuation of the current climate of commitments to education can provide invaluable opportunities for changes to public policy that will improve outcomes for students with complex health care needs and make it easier for their parents to care for them at home.

Given the opportunities for both participating in and influencing the changing tides of public education for students with disabilities, and particularly those with chronic and significant health care needs, it is critical that families, advocates and others first understand the underlying legal context that dictates rights and responsibilities and prescribes procedures for the education of students with chronic and significant health care needs. Second, it is critical to identify current and emerging issues and opportunities for systems change and finally, provide specific recommendations for action steps that can be take immediately by state and local

officials, policy makers, advocates, families and the students themselves to increase their chances of remaining at home with their families.

EDUCATING STUDENTS WITH COMPLEX HEALTH CARE NEEDS – THE LAW

The Right to Special Education

Eligibility

The Research Team for the project for which this report was prepared has defined “students with complex health care needs” as: “Students *who require advanced medical care and sophisticated technology because of chronic illness and or disability.*” The IDEA defines a child with a disability as a child who has a physical, mental or emotional disability and by reason thereof is in need of special education and related services [20 U.S.C. § 1402(3)]. Although one may argue that there are some students who require advanced medical care whose conditions do not adversely effect their educational performance and thus, do not need special education services, this paper assumes that *all* of the students with complex health care needs are in need of some special education service and are protected by IDEA and are further protected as individuals with disabilities by Section 504 of the Rehabilitation Act to be free from discrimination on the basis of disability by any recipient of federal funds, including all state and local educational agencies.

Special Education and the Least Restrictive Environment

The IDEA defines “special education” as “specially designed instruction, at no cost to the parent, to meet the unique needs of child with a disability...” [20 U.S.C. § 1402(29)]. The law further mandates that the instruction be designed to confer some educational benefit to the child with the disability and that the instruction be provided in the “least restrictive environment.” This means that students with disabilities, including those with complex health care needs, must be educated with their non-disabled peers to the maximum extent appropriate and can only be removed from regular education classrooms when the nature or severity of their disability is such that they cannot be educated in regular classrooms satisfactorily, even with supplemental aids and services. Parents often need to understand that special education is not a placement, but a service and for students with complex medical needs special education is often a wide variety of services, often delivered in more than one educational setting, including home and hospitals. Equally important for parents to understand is that the least restrictive environment is also not a place, but a continuum where a student with complex health care needs may spend time with non-disabled peers for all or some of the school day or the school year. For example, a student who needs extensive health care support services may need to have a full time aide with him or her during the school day, but that should not inhibit the student from participating in any appropriate school activity with non-disabled peers.

Program Development and Procedural Safeguards

Each student with a disability must have an individualized education program (IEP), a written plan designed

to deliver a free appropriate public education to the student. The IEP is developed, reviewed and revised in accordance with specific procedures set forth in federal and state laws that include provisions for parent involvement at every stage. Among other things, the IEP sets forth the specific special education and related services to be delivered to the student. An IEP may include services the student needs but are being provided by other providers, if those services must be coordinated with the educational services being provided by the school district. The IEP serves multiple purposes, including a teacher planning tool, an administrative form and a vehicle for parent involvement. The IEP is the cornerstone of the special education system. Once services are included in a student's IEP, the local educational agency is required by law to provide those according to the specifications of the IEP.

The law further provides procedural protections for students and families that help ensure that parents are able to challenge recommendations of local educational agencies on any decision made about their child's educational program, from evaluation to services and ultimately, even to where those services are provided. These are commonly referred to as "due process" rights.

Related Services

Students with disabilities, including those with complex health care needs, are also entitled under the IDEA to a wide array of "related services" to further support their access to and participation in public education. Related services, like special education services, must be provided at no cost to the parent and must be appropriate for the student [20 U.S.C. 1402(26)]. Further, "related services" are defined in the law as:

transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, *school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child*, counseling services, including rehabilitation counseling, orientation and mobility services, and *medical services, except that such medical services shall be for diagnostic and evaluation purposes only*) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in students [20 U.S.C. § 1402 (26)(A)] (revised 2004 language in italics).

It is important to note that the *term does not include a medical device that is surgically implanted, or the replacement of such device* [20 U.S.C. § 1402 (26)(B)].

The federal regulations further include "counseling" and "parent counseling and training" in the list of related services. Parent training could in many cases include training the parent in understanding and supporting the child's educational program through understanding of their complex health care needs. Many of the specific related services listed in the statutory definition are further defined in the regulations. It is important to keep in mind that this is not an exhaustive list, but rather that the definition suggests other developmental, corrective and supportive services may also be "related services."

Assistive Technology

Of special interest to families of students with complex health care needs is the right to assistive technology and services. In 1990, the IDEA was amended to include, among other things, a mandate for the provision of assistive technology services and devices, when appropriate, for students with disabilities as part of their IEP. The IDEA defines “assistive technology device” to mean:

Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain, or improve functional capabilities of a child with a disability [20 U.S.C. § 1402(1)(A), 34 C.F.R. § 300.5].

The Office of Special Education Programs and Services within the U.S. Department of Education (“OSEP”) has made clear that hearing aids and eye glasses are classified as assistive devices to which students with disabilities are entitled when the child needs the device to receive or benefit from, a free appropriate public education [*Bachus*, 22 IDELR 629 (OSEP 1995); *Seiler*, 20 IDELR 1216 (OSEP 1993)].

Assistive technology *services* are defined as any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device. Such term include:

- Evaluation of the needs of such child, including a functional evaluation of the child in the child's customary environment;
- Purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by such child;
- Selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing assistive technology devices;
- Coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs;
- Training or technical assistance for such child, or, where appropriate, the family of such child; and
- Training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of such child [20 U.S.C. §1402(2)].

These broad rights to assistive devices and services can be used to obtain essential services for students with complex health care needs during the time they are in school. Often the student is entitled to use the device at home and parents are further entitled to services to learn how to assist the student in using the device.

School Health Care Services

Students with complex health care needs and other students with disabilities are also expressly entitled to “*school health care services*” under the IDEA’s definition of related services. *School health care services* are defined as health care services provided by a nurse or other qualified person [34 C.F.R. § 300.24(b)(12)]. Congress only included *medical services* as related services when they are used for diagnostic and evaluation purposes and defined them as services provided by a licensed physician to determine the child’s medically related disability that results in the child’s eligibility for special education [34 C.F.R. § 300.24(b)(4)].

The Supreme Court has decided two significant cases that help distinguish school health services from medical services for students with disabilities. In *Irving Independent School District v. Tatro*, 468 U.S. 883, 104 S.Ct. 3371 (1984), the Court held that school health services that could be delivered by a school nurse or other qualified personnel in the school setting were indeed related services to which the student was entitled under the IDEA, while medical services that had to be provided by a licensed physician were not. In 1999, the Supreme Court further clarified this bright line distinction in the case of *Cedar Rapids Community School District v. Garret F.*, 526 U.S. 66, 119 S.Ct. 992 (1999), holding that under the IDEA, the district must furnish such related services (in this case, private duty nursing services) in order to guarantee that students like Garret are integrated into the public schools.

CURRENT AND EMERGING ISSUES

Current and emerging issues that most impact students with complex health care needs and their ability to be cared for at home, not surprisingly, focus on access to appropriate school health care services, the availability of qualified and trained professionals and an overarching coordination among various service providers, including family members.

Access to Appropriate School Health Care Services

School health care service or medical treatment? There is now a long history of Supreme Court cases and state and local policies that ensure that students with complex health care needs receive the health care services they need during school, except when such service must be provided by a physician. This “bright line” distinction between school health care and medical services still generates some controversy and concern. For example, in 2004, Congress amended the IDEA to include language that explicitly excludes from the list of assistive devices any “*medical devices that are surgically implanted*” or their replacement. Some legislative experts believe increasing costs associated with cochlear implants for hearing impaired students gave rise to this new, more limiting language. However, without further regulatory clarification, this language could also unintentionally exclude services involving other surgically implanted devices, such as gastrostomy and tracheotomy tubes, which may have to be replaced or maintained during the school day.

Availability of Qualified and Trained Professionals

Another emerging policy issue focuses on school nurses and the availability of competent health care during the school day. In 2004, Congress expanded the definition of “related services” to expressly include “school nurse services designed to enable a child to receive a free appropriate public education as described in the child’s individualized education plan” [20 U.S.C § 1402 (26)(A)]. Parents of students with complex health care needs are consistently interested in the quality and availability of school nurses and other professionals properly trained to provide health care services to their students during the school day. Some assert that more nurses are necessary and discourage delegation of school health services to non-health care professionals. Others, including the Consortium for Citizens with Disabilities (collaborative of national organizations), admit that more nurses are needed, but advocate focusing the discussion and policy changes on ensuring that

students with complex health care needs have a comprehensive school health plan that will support them daily and in emergencies and encourages proper delegating of basic health care tasks to other school personnel trained to perform these tasks safely.

Parent Involvement and Collaboration

Policy makers and educators and others often have to be reminded that legally parents are the ultimate health care decision makers for their children. The importance of the critical role of parents, in developing educational plans cannot be overstated. The school nurse is not the ultimate arbitrator of school health services—or the child’s health decisions in school, these decisions must be made according to law and most often by the child’s IEP Team, including the child’s parent. When possible, students should be active participants in the IEP process.

Interagency Collaboration

Equally important is collaboration and coordination among all service providers both within the school community and including those who serve the student beyond the school day. Students with complex health care needs often present schools with critical health issues where timely, accurate, information sharing is essential. There must be systems in place to facilitate the movement of information and appropriate responses. The IEP is the vehicle that can be used to ensure this collaboration takes place. It should set forth in detail the time, place and content of interagency and inter-personnel collaboration, with input and consent of the parents. Health care plans are emerging as part of IEPs and can be used as tools for coordinating services and school personnel both internally and with outside service providers.

Inclusion

Students with complex health care needs must be included in all public policy and advocacy strategies seeking to include children with disabilities in the regular education programs of public schools with their non-disabled peers. Too often, children with complex health care needs are left behind as “too fragile” or seen as having too many complex needs to be included in the activities of the regular education program. Efforts must be made to ensure that, whenever possible, with supplemental aids and services required by law, children with complex health care needs spend time in activities with children without disabilities to the maximum extent appropriate for the child with complex health care needs.

Academic Proficiency

With increasing attention to the academic proficiency of all students, and a renewed commitment to the education of children with disabilities, it is important to ensure that children with complex health care needs are included in all school reform efforts to increase academic proficiency. Policy makers and advocates should not lose sight of the academic goals for students with complex health care needs.

Pending Regulations

With the release of new federal regulations implementing Part B of the IDEA in August 2006, Pennsylvania and other states must now in turn revise and reauthorize their own State implementing regulations to ensure

compliance. With the development of new State regulations there will be opportunities for further policy analysis and systems change. It is important that interested advocates for students with complex health care needs continue to monitor these legal developments and continue to participate in the public debate on those issues most dear to students with complex health care needs and their families.

CONCLUSION AND RECOMMENDATIONS

Despite these moving tides of public education policy, the basic right to special education and related services first established in 1975 remains an invaluable, but underutilized community resource and support for students with complex health care needs and their families. Students with complex health care needs continue to find it difficult to enter school with their peers or remain in school for any significant period of time. They quickly fall behind. Some school districts attempt to provide services at home, but too often these services are at best inadequate and more often, inappropriate. As a result, students with complex health care needs are placed in congregate settings, including hospitals, residential settings, foster care and juvenile court placements, and often encounter even more obstacles to the receipt of an appropriate public education. This paper offers some suggestions about how parents, educators and policy makers can work together and within their fields to encourage and support access to appropriate public education services, with necessary health care support services for children with complex health care needs.

There is much work to be done to ensure that students with complex health care needs have meaningful access to public education and to the essential support services they need to make academic progress and to grow up and live as independently as possible. This discussion and specific recommendations are intended to help parents and policy makers take the steps necessary to ensure that students with complex health care needs have access to appropriate public education services that will enable them to live at home and benefit from school and their communities.

SPECIFIC POLICY RECOMMENDATIONS

Access to timely accurate legal information and advocacy support. Convince policy makers and state agencies to work to ensure that all families of children with complex health care needs have access to timely, accurate information about their legal rights and the support needed to advocate and obtain the services necessary for their children with complex health care needs to be educated in the least restrictive environments.

Meaningful access to advocacy training for parents. Convince policy makers and state agencies to work to ensure that parents of children with complex health care needs have meaningful access to the training and support they need to advocate and obtain the services necessary for their children with complex health care needs to be educated in the least restrictive environments.

Inclusion of comprehensive school health care plan in student's IEP. Through use of existing mandates and procedures, advocate at the state and local level for inclusion of a comprehensive school health care plan in each student's IEP. Help create and disseminate model plans and work to ensure that state and local agencies provide training and education to parents and school personnel on the plans.

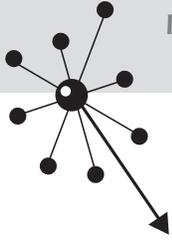
Strengthen state regulations in the area of school health care and other related services. Work with legislators and policy makers to strengthen state regulations in the area of school health care and other related services. While federal laws provide a “floor” of rights for students with disabilities and their families, states can provide additional and more extensive rights that meet the needs of their own unique populations. Parents and advocates can lobby Pennsylvania law makers to bolster and expand the rights of students with complex health care needs in upcoming revisions to Chapter 14 (the Pennsylvania regulations that govern special education and related services in conjunction with the IDEA).

Foster interagency collaborations between school districts, health care providers, and relevant government agencies. Convince State and local agencies to foster interagency collaborations between school districts, health care providers, and relevant government agencies and to create written agreements that provide structure and consistency to these agreements.

Fund and support research on best practices for supporting and including children with complex health care needs in regular school settings. Document what services and accommodations help students best achieve academic success in school and post school outcomes and improve the quality of their lives and the lives of their family members.

Foster recognition among families, school personnel and policy makers that it is necessary and important to ensure that students with complex health care needs maintain appropriate academic progress. Work to develop comprehensive academic planning models for children with complex health care needs that take into consideration long or intermittent absences and utilize current technology.

Promote and support state and federal policies that focus on adequate funding for schools to meet the needs of students with complex health care needs and provide appropriate services in an integrated setting. Current examples include an initiative by ELC (and two other collaborative groups) to secure a state-funded “costing out” study to determine the actual cost of meaningfully educating students and support pending federal legislation (“Protecting Children’s Health in Schools Act 2006), that seeks to ensure schools can continue to recoup certain costs under Medicaid.



IX. PERMANENCY PLANNING: THE STATE OF THE LAW AND POLICY IMPLICATIONS FOR PENNSYLVANIA

Arlene Kanter and Lesley Owens-Pelton

Introduction

Most children, with or without disabilities, live with their parents. For some parents of children with disabilities, particularly children with serious health issues, the challenge of raising and caring for a child at home may become too difficult without adequate financial and emotional supports. For these parents, an out-of-home placement may seem like the family's only option.

When children with disabilities are voluntarily placed out-of -the-home by their parents, the parents retain their parental rights. The state will and can not intervene because the parents have not violated any child welfare laws; they have not neglected or abused their child, and placement in an institution is not considered abandonment under federal or state law. In fact, most parents believe that their decision to place a child out-of-the-home is in the child's best interest as well as the best interests of other siblings (if applicable) and the parents themselves.

When children have been abused or neglected by their parents, the state, not their parents, becomes entitled to make all decisions on behalf of the child, including where the child will live and with whom. Further, under federal law, the state also must develop and implement a "permanency plan" for every child who has been removed from the home due to parental abuse or neglect. The goal of such permanency planning is to assure that a child has a permanent, nurturing family by safely rectifying the situation to prevent removal, reunifying the family as soon as safely feasible, or to terminating parental rights and placing the child with another family through adoption. Central to the concept of permanency planning is the belief that all children, regardless of abilities and disabilities, belong in families.

All states have some form of permanency planning legislation, as a result of the federal mandates contained in federal laws. However, these laws apply only to children within the child welfare system. Texas is currently the only state that has applied its permanency planning law to children with disabilities served outside the child welfare system.

Regular contact, and a loving relationship between children and their parents is a given (or at least an expectation) for most children who live at home. Children whose parents voluntarily place them in institutions, often are deprived of regular and meaningful contact with their parents. Even for the most committed and devoted parents, maintaining daily contact with a child in an institution is difficult, if not impossible.

In her book, A Family for Every Child: Family Based Alternatives for Children with Disabilities (2005), Dr. Nancy Rosenau identifies options for parents of children with a disability who are unable to care fully for their child in their own homes. Instead of institutional care, Rosenau describes family-based alternatives, including “shared parenting” and “support families” for children with disabilities to assure every child the right to grow up in a family. Rosenau proposes expanding the application of permanency planning to children with disabilities whose parents retain legal custody, but who live away from home in institutional settings. This paper explores the legal basis for such expansion.

THE DEVELOPMENT OF PERMANENCY PLANNING POLICIES IN FEDERAL LAW

Background

The concept of “permanency planning” was first introduced by Joseph Goldstein, Anna Freud, and Albert J. Solnit in their 1973 book, Beyond the Best Interests of the Child. The authors “challenged the then-current, transient nature of the child placement system” and presented the concept that the “law must make the child’s needs paramount” (Goldstein, Freud, & Solnit, 1973).

Enactment of Federal Laws

The Adoption Assistance and Child Welfare Act of 1980. Shortly after the book, Beyond the Best Interests of the Child, gained prominence, a national movement developed to either return children in foster care to their biological families or to terminate parental rights and place the children up for adoption. As a result of this movement, Congress enacted the Adoption Assistance and Child Welfare Act (AACWA) in 1980, which mandated permanency planning for all children removed from their homes due to parental abuse or neglect. Importantly, the law requires states to use “reasonable efforts” to prevent the removal of a child from the home, and to return of a child to the home, or to seek adoption if return cannot be achieved on a timely basis [42 U.S.C. §671 (1999)].

A decade after the enactment of the AACWA, it became apparent that the law was not working to accomplish its goal of either returning children in foster care to their homes or placing them in permanent family homes. The number of children in foster care had exploded, as did the costs associated with the foster care system. In 1984, the cost of foster care was under half a million dollars; by 1996 the cost had risen to 3.1 billion dollars (Ramsey, 2005).

Compounding financial concerns was difficulty implementing “reasonable efforts” to prevent a child’s removal from the home or to make it possible for a child to return home.

The Adoption and Safe Families Act of 1997. The next major foster care reform occurred in 1997 with the Adoption and Safe Families Act (ASFA). The ASFA sought to add safety and permanency for children in foster placement by providing federal matching funds for adoption subsidies for children with “special needs” placed in out-of-home placements (Taylor, Lakin, & Hill, 1989).

The ASFA served as an impetus to states to reform their child welfare practices. In particular, the ASFA shifted its focus away from AACWA's focus on family preservation and family reunification, to a renewed focus on the long term health and safety of children. At the time of its enactment, ASFA was seen as ending the practice of keeping children within foster care for extended periods of time. ASFA makes it clear that while good foster care provides important safe havens for children, it is, by definition a temporary, not a permanent, setting (Klee, 2002). Opponents of ASFA, however, believe that its provisions encourage adoption as a permanent solution in lieu of supporting and strengthening biological families and family preservation (Klee, 2002).

Limitations of the Protections Provided in Federal Law For Families with Children with Disabilities

Children with disabilities whose parents are unable to find adequate support, who are subsequently placed voluntarily in institutions or institution-like settings are not protected by either the AACWA or the ASFA. Neither the AACWA nor the ASFA provides assistance to families of children with disabilities whose parents retain legal custody. Even with little or no contact with their biological families, or the psychological safety and support of a nurturing family, children who have been placed in institutions by their parents are not considered neglected or abandoned under federal law. Since the parents who voluntarily place their children in a facility remain the child's legal guardians, the state has neither jurisdiction nor the legal right to investigate the reasons for the placement out-of-the-home, or to find an alternative family-based placement for the child. No federal law prohibits parents from placing their children in such facilities. To the contrary, treating professionals and state agencies sometimes encourage such placements for parents who express fears or concerns about keeping a child with a disability at home.

Moreover, federal law provides no specific help to families who would prefer to keep their children with disabilities at home rather than place them in institutions. In fact, parents who wish to keep their children at home face a myriad of obstacles under federal law. Although federal Medicaid funds support children in institutions regardless of parental income, Medicaid federal funds are only available under waivers to states in certain circumstances in limited numbers to help a family care for a child with a disability at home (Shoultz, O'Connor, Hulgin, & Newman, 1994). For example, funds to retrofit a home for a child who uses a wheelchair, or to enable a family to move to a larger apartment to make room for necessary medical equipment for a child with serious health problems, or to secure in-home support and regular respite care for families with children with disabilities who live at home are generally not available without a waiver. Therefore, even where *some* federal funds are available for support services or home improvements for *some* families, there is not enough funding or support for all the families who want to keep their children at home but find it financially or practically impossible to do so.

Another significant obstacle for parents who wish to keep their children with disabilities at home is administrative and bureaucratic hurdles. The family may not be aware of what services are available or may not meet the narrow criteria for particular programs. For example, children with functionally similar care needs will be covered with one diagnoses but not with another (Rosenau & Walker, 2002). Further, the increasing numbers of single parent families, the transient nature of society in which extended family members are not

available locally to provide support or assistance, together with the unavailability of well-funded support, may cause families with children with disabilities to believe that their only option is to place their child out-of-the-home in an institution or other congregate living setting.

RELEVANT FEDERAL AND STATE CASE LAW

United States Supreme Court Case

The United States Supreme Court has never decided a case which directly addresses the issue of permanency planning for children with disabilities whose parents place them in institutions. There is no case law around “reasonable efforts” to prevent placement or to reunify where no abuse or neglect is threatened. However, the Court has addressed some related issues. For example, in 1983, in *Lehr v. Robertson*, the Court ruled that a state court is not always required to honor a biological parent’s wishes regarding a child’s best interests, especially when the parent has had little or no interaction with the child [*Lehr v. Robertson*, 463 U.S. 248, 262 (1983)]. In this case, the Court observed that:

[t]he significance of the biological connection is that it offers the natural father an opportunity that no other male possesses to develop a relationship with his offspring. If he grasps that opportunity and accepts some measure of responsibility for the child’s future, he may enjoy the blessings of the parent-child relationship and make uniquely valuable contributions to the child’s development. If he fails to do so, the Federal Constitution will not automatically compel a State to listen to his opinion of where the child’s best interests lie [*Lehr v. Robertson*, 463 U.S. 262 (1983)].

This case provides a basis for a state legislature to enact a law that would permit a court to limit the parental rights of parents who voluntarily place their children in institutions and who, after so doing, have little or no regular interaction with their children. In such cases, a law may be written authorizing a court to order an alternate family placement.

The California Case of Guardianship of Phillip B.

The most instructive case for advocates seeking to establish court-sanctioned permanency planning for children with disabilities is the California case of *Guardianship of Phillip B.* [*Guardianship of Phillip B.*, 139 Cal. App. 3d 407; 188 Cal. Rptr. 781, 783-94 (1983)]. In this case, Phillip Becker, is a child with Down syndrome whose parents placed him in an institution as an infant at the recommendation of his pediatrician. While his biological parents maintained minimal contact with him, another family, who volunteered at the institution, developed a close personal relationship with Phillip. They brought Philip to their home for overnight visits, and he called them “Mama Heath” and “Dada Heath” and called the Heath’s home, “my home.” When Phillip was diagnosed with a heart defect which needed medical treatment, his biological parents refused to consent to the procedure. The Heaths intervened in the case, and their attorney presented a novel argument to the court, that the Heaths were Phillip’s “second set of parents,” and as such, should have a say in the decision regarding his surgery. The court awarded the Heath’s legal guardianship for Phillip and although the parents retained legal custody, the Heaths became responsible for making decisions for Phillip in his best interest.

The *Becker* case did not involve a situation in which the state had intervened because Phillip's parents had voluntarily relinquished their parental rights or because the state had terminated their rights due to abuse or neglect under the state's child welfare laws. To the contrary, Phillip's biological parents wanted to retain custody; yet, the court chose to acknowledge the interests of the Heaths. As a result, Phillip ended up essentially with two sets of parents. The trial court judge based his decision on what he thought Philip would have wanted and the decision that would be in Phillip's best interest. In his decision, the judge literally placed himself in Phillip's shoes and based on the evidence presented, decided that if Philip could express his opinion, he would choose to live with the Heath family rather than in the institution.

Unlike a typical case involving termination of parental rights in which the rights of one set of parents are severed so that another set of parents may gain legal custody, the *Becker* case broadens the concept of custody and authorizes shared parenting among two sets of parents. Although the case itself is binding only in the state of California, a growing number of cases elsewhere have adopted similar reasoning or have relied specifically on the *Becker* case to expand the concept of parenthood beyond the traditional two parent nuclear family. The Supreme Court has specified that neither the traditional "boundary of the nuclear family" [*Moore v. City of East Cleveland*, 431 U.S. 494, 502 9 (1997)] nor the existence of blood relationships [*Smith v. Organization of Foster Families*, 431 U.S. 816, 843-44, 53 L. Ed. 2d 14, 97 S. Ct. 2904 (1977)] nor the legitimacy of a family arrangement under state law (id. at 845 & n.53) defines the boundaries of family rights. Lower courts are thus free, within the limits marked out by the Court, to determine that a particular non-nuclear or non-biological family merits constitutional protection.

As one Pennsylvania court has acknowledged, "needs and welfare' is a legal concept that denotes certain minimum requirements that all children are entitled to: adequate housing, clothing, food, and love." [Involuntary Termination Re ASJ, 19 Fiduciary 2d 415 (1999); In re Adoption of Michael J.C., 326 Pa Super. 143, 463 A.2d 1021 (1984), rev'd on other grds., 506 Pa 517, 486 A. 2d 371 (1984)] Advocates in Pennsylvania may consider litigation options to pursue a child's right to live with a family including one other than his or her own as an alternative to institutionalization (Garrison, 1983).

Pennsylvania Case Law

According to our research, no Pennsylvania court has ruled in a case which involves permanency planning for children with disabilities in institutions, nor has any Pennsylvania court ever cited the *Guardianship of Phillip B.* decision, discussed above. From a legal perspective, therefore, courts in Pennsylvania are free to apply the *Becker* reasoning (or not) in any future case. Further, because there is no case law to the contrary, Pennsylvania courts also are free to uphold a permanency planning law that would include shared parenting without running afoul of established legal precedent.

In fact, courts in Pennsylvania have decided a variety of cases which arguably support the right of a biological parent to share some of his or her parental rights with respect to a child with a disability as an alternative to institutionalization, or to forfeit some or all rights if the parent has been found to have effectively "abandoned" the child in an institution.

The Pennsylvania Custody Act, recognizes the possibility of a variety of custodial arrangements. For example, it recognizes partial or shared custody, specifically with respect to divorcing parents or grandparents seeking custody. One could argue that such partial or shared custody arrangements under Pennsylvania law may be applied to cases involving a parent of a child with a disability who seeks to share custody with another family to provide the necessary supports to allow a child to live in a home rather than in an institution.

Courts in Pennsylvania have acknowledged that a parent's right to custody of a child is not absolute. Each case "must finally rest on and be determined by its own facts" [Republican College Council v. Winner, 357 F. Supp. 739 (E.D. Pa. 1973)]. While the Commonwealth places great importance on biological ties, it does not do so to the extent that the biological parent's right to custody will trump the best interests of the child. Pennsylvania courts have felt free to decide that the parental rights of a biological parent will not always prevail, especially if there has been an affirmative showing that the biological parent has abandoned the child. When a parent places a child with a disability in an institution as a last resort when unable to secure adequate support, however, a court would likely not terminate a parent's right on that basis alone. In Pennsylvania and elsewhere parents are granted enormous autonomy with respect to decision-making on behalf of their children. In fact, the United States Supreme Court has often upheld the right of parents to make all sorts of decisions about their child without state interference, including decisions about placing a child in an institution for mental health treatment (*J.R. v. Parham*) to not placing them in a public school (*Wisconsin v. Yoder*). It is well established that the US Constitution protects "a private realm of family life which the state cannot enter" [see *Prince v. Massachusetts*, 321 U.S. 158, 166, 88 L. Ed. 645, 64 S. Ct. 438 (1944)]. Further, living arrangements of parents and children have historically been protected from various forms of state intrusion [see, e.g., *Moore v. City of East Cleveland*, 431 U.S. 494, 499, 52 L. Ed. 2d 531, 97 S. Ct. 1932 (1977) (plurality opinion by Powell, J.)], and the associational freedoms of the First Amendment are also thought to protect the integrity of families against the state [see *Roberts*, 468 U.S. 609, 618-20 (1984)]. Accordingly, it is unlikely that any Pennsylvania court would invalidate a parent's decision to place a child out-of-the-home.

Nonetheless, in the "right" case, in which two sets of parents are willing to share responsibilities for a child with a disability who otherwise would face institutionalization, a Pennsylvania court may be willing to consider a mechanism to allow the biological parents to share parenting or enter a shared custody arrangement. In addition, based on this brief review of Pennsylvania case law, it appears that advocates for children with disabilities who live in institutions may consider bringing a "test" case challenging the parental rights or custody of a parent who has placed a child in an institution and failed to maintain meaningful contact with the child.

STATE PERMANENCY PLANNING STATUTES

In addition or as an alternative to litigation strategies, advocates may wish to pursue legislative strategies to assure the right to permanency planning for children outside the child welfare system. Such a strategy would involve appealing to the Pennsylvania legislature to enact a new law or to amend the current law to provide all Pennsylvania's children the right to live in a loving home.

Components of Permanency Planning

Before examining the state laws in greater detail, it is important to become familiar with the five common components of permanency planning: (1) family support (2) family reunification efforts (3) pursuit of adoption (4) provision of foster care and (5) post-adoption supports (Shoultz et al., 1994).

Family Supports. Some states have enacted policies in their disability services based on the belief that they must do “whatever it takes” to help children grow up in families and to avoid institutional placement. The most effective policies offer flexible, family-centered support programs which seek to meet the needs of the families. Such policies for families not involved in the child welfare system may include cash subsidies, voucher programs, and programs which are run by family counselors. Family activists have advocated for “family driven” programs in which the family determines what the family needs (Shoultz et al., 1994).

Family Reunification Efforts. Sometimes families are not able to keep their children at home. As a result, such families may find it necessary to accept placement for their child outside of the home. Historically, some agencies have gone so far as to discourage a family’s involvement after the child is placed. The concept of permanency planning challenges this practice as it sees family ties as critical to the development of a child. Accordingly, even after placement, the responsibility of the state is to use resources effectively to try to reunite children and families.

Adoption. Sometimes families are unwilling to parent a child with a disability but are nevertheless concerned about the child’s welfare. Adoption is an option that seeks to assure permanency. There are two methods of adoption, “closed” and “open” adoptions. The former envisions no contact between the child and the biological parents; however, the latter permits contact between the child and his or her biological parents, even after the adoption is finalized. For children with disabilities, whose parents voluntarily place them out of the home, adoption is generally not an option because the parents retain parental rights and legal custody. Some proponents of permanency planning suggest that parents should relinquish their parental rights if they do not intend to resume care of their child after placement to allow their child to be legally adopted. Others suggest the option of continued parental involvement with placement in long-term foster care. For those parents who believe that their decision to place their child out-of-the-home is in their child’s best interest and who want to maintain a meaningful relationship, they would, understandably, take offense at and resist suggestions of terminating their parental rights. Such experiences are explored in Rosenau’s *A Family for Every Child* (2005).

Provision of Foster Care. According to the concept of permanency planning, children who can not remain in their homes should be placed temporarily in foster care as an alternative to an institution or group home setting, and only while reunification efforts are pursued. “Foster care,” as used in permanency planning for children with disabilities whose parents want to maintain a meaningful relationship, may not be what we typically think of as foster care. Foster placements for children with disabilities may include an agreement between the biological family and a “foster” family allowing for the child to live with the foster family for an extended period of time and for the biological parents to “share parenting.” Such “shared parenting” allows the biological and foster families to share responsibility for raising the child whose parents, for one reason or another, are unable to raise the child alone (Shoultz et al., 1994).

Post-Adoption Services. Successful adoptions (as other alternative family placements) depend on the careful selection and preparation of the adoptive families and the support available post-adoption. Post-adoption services vary greatly from state to state. The ASFA provides federal funds for special needs adoption subsidies, although the amount and availability vary from state to state.

Selected State Laws

The following is a summary of the state permanency planning laws of three states: Pennsylvania, Texas, and Michigan. Each state's laws address the issue of permanency planning for children with disabilities in different ways.

1. Pennsylvania. The Pennsylvania laws governing termination of parental rights and permanency planning for children who are removed from their parents' home are typical of most state laws enacted to conform to the federal ASFA. The Pennsylvania law is intended to effectuate the following purposes:

- To preserve the unity of the family whenever possible or to provide another alternative permanent family when the unity of the family cannot be maintained.
- To provide for the care, protection, safety, and wholesome mental and physical development of children coming within the provisions of this chapter.
- To achieve the foregoing purposes in a family environment whenever possible, separating the child from parents only when necessary for his welfare, safety, or health or in the interests of public safety.
- To provide means through which the provisions of this chapter are executed and enforced and in which the parties are assured a fair hearing and their constitutional and other legal rights recognized and enforced.

The Pennsylvania statute has been interpreted to apply permanency planning only to children who have been removed from their homes because of abuse or neglect. Pennsylvania does not have a statute equivalent to the Texas law nor does it have the alternative family placement considered in the Michigan ASFA statute described below.

Although there is no legislation in Pennsylvania that specifically applies the concept of permanency planning to children who have been placed for reasons other than abuse or neglect, there is no legislation that would prevent it, either. Therefore, the enactment of a new law or an amendment to the current law, similar to the permanency planning law that was enacted in Texas, would provide the necessary mandate for Pennsylvania state agencies to work with advocacy groups to further the goals of permanency planning for children with disabilities.

2. Michigan. Michigan has been at the forefront of implementing permanency planning policies for children, with and without disabilities, and within and outside of the child welfare system. It has done so without specific legislation for children outside the child welfare system. Only Michigan has interpreted the ASFA requirement of permanency planning as applying to children in mental health/mental retardation system as well as the child welfare system.

Michigan's law requires the state to develop "an alternative plan, including, but not limited to, long-term foster care" for children who no longer live at home with their families. Accordingly, Michigan's law appears to be the most conducive to shared parenting. It provides for long-term foster care as an alternative to institutional care if termination of parental rights is not in the child's best interest. This law was enacted in response to ASFA for TPR (Termination of Parental Rights) proceedings, yet lists an alternative to the TPR. It acknowledges that a child may need alternative family, which can allow the statute to be used in the context of more than just one set of parents.

One of the most positive and innovative aspects of the Michigan law is that it has been interpreted to apply the concept of permanency planning to the various rules, practices and funding for services for children served outside the child welfare system. All children receiving services through MH/MR must have an ISP (Individualized Plan of Services). As part of the state's permanency planning mandate, the ISP for those children who do not live with their biological or adoptive families must include a written permanency plan (Shoultz et. al, 1994). This permanency plan is designed to ensure that the child has the opportunity to live with a family, preferably with the child's biological parents, but if not, with parents who are members of the extended family, or a foster or adoptive family. An option for parents of children with disabilities in Michigan is "open adoption" in which two families who know each other agree to allow one family to adopt the other families' child and thereafter to allow the biological family to maintain ties with the child. Michigan programs also include the option of "shared parenting" in which biological and co-parent families make a joint commitment to share the care of a child with developmental disabilities (Rosenau, 2005).

Although permanency principles are embedded in Michigan policy, it has had its share of problems in implementation, demonstrating that policy alone is not sufficient to assure permanency. For example, birth families report that they have to "fight" for the support they receive from the State, and that such support is likely less than that received by foster care or adoptive families. While Michigan has a family subsidy program which provides financial support to families with children with severe disabilities, it covers only limited eligibility based on specific school classifications. Even though a child has a severe disability, the family may not receive the family support subsidy if the school classification does not meet the established criteria. Finally, many more families apply for services than can be served. Accordingly, families who wish to keep their children with disabilities at home may have to threaten to place their child in order to receive one of the limited number of waivers that provides funding for services at home. Furthermore, even if a family does receive a waiver, families in low income areas report that the waiver is difficult to use because many providers do not accept Medicaid or are unwilling to go into homes their neighborhoods.

Despite its implementation struggles, Michigan policies may suggest ways to promote permanency planning for children as an alternative to in institutions in other states.

3. Texas. Texas has the most comprehensive permanency planning legislation that specifically addresses children with disabilities placed voluntarily in institutions in the disability services system. The legislation requires identification of all children who live in non-family residences and engagement of their parents in

permanency planning every six months. The Texas law may serve as a model for other states considering a legislative solution to the problem of permanency planning for children with disabilities in institutions or institution-like settings.

Texas responded to ASFA by enacting a state law requiring permanency planning for children within the child welfare system. However, unlike other states, Texas adopted a second piece of legislation that extended similar protections to children with disabilities whose parents retain legal custody after voluntarily placing them in an institution. No other state law, as far as we are aware, has expanded the application of ASFA's permanency planning mandate to children who are voluntarily placed in institutions and whose parents retain legal custody and all parental rights.

Even with such a comprehensive law, however, children with disabilities in Texas may remain in institutions for a lifetime. A variety of reasons for this apparent inconsistency between the law and state practice have so far prevented the law from being effectively implemented. Lack of training on permanency planning, resource limitations, waiting lists, unwillingness to terminate rights of absent parents, and willingness to accept parental choice of institutional care have been problematic.

In sum, Pennsylvania, Michigan and Texas each have enacted state laws implementing the ASFA mandate to provide permanency planning for children who are removed from their homes. Michigan has voluntarily expanded the permanency mandate to children in the MH/MR system without specific legislation; Texas has enacted specific legislation applying this mandate to children with disabilities whose parents voluntarily place them in institutions but has had difficulty fully implementing it; Pennsylvania has no current law or policy requiring the state to provide permanency planning for children with disabilities whose parents place them in institutions. None of the states compel the "reasonable efforts" standard in the voluntary disability services sector to prevent placement or seek reunification afterwards.

RECOMMENDATIONS

In Rosenau's book, *A Family for Every Child: Family Based Alternatives for Children with Disabilities*, she suggests that an alternative to placing children in institutions is (1) for parents to receive the support they need, but (2) when they cannot maintain their child at home to be offered a "shared parenting" arrangement or a "support family." According to this model, instead of placing a child with a disability in an institution, the birth family retains parental rights and involvement and agrees to allow a second family to help raise their child. Instead of two parents, the child with a disability has the advantage of being raised by additional parents and two families. And, instead of placing the child in an institution, the birth parents have the help and support they need to keep the child in a family home—either their home or the home of the second family. Although many obstacles must be overcome before a shared parenting arrangement may be finalized—not the least of which are convincing the birth family to share parenting and finding a second family—this model has enormous potential in Pennsylvania and elsewhere. Research shows that there are willing families who would take a child with a disability into their homes and care for and nurture the child, particularly where 1) state legislation is

in place; 2) preparation, training, and support is available to assist them; and 3) state agencies' philosophies embrace the concept of permanency planning and facilitate the process with the biological parents, institutions, the state, and co-parenting support families (Rosenau, 2005).

Rosenau's arguments in favor of programs that first support families to maintain their children, and secondly provide an alternative "support family" as a way to make permanency planning work for children with disabilities, are persuasive. Some federal funding may be available (through Medicaid waivers for example). To what extent such funding has been used nationally to promote programs for support families or shared parenting, is unclear.

If such programs could be funded and even mandated through legislation, or required by a judge in a given case in state court, the problem of permanency planning for children with disabilities could be more effectively addressed. However, to date, no state except Texas has adopted such legislation, and unfortunately, in Texas, the law has not yet been applied to prevent institutional admissions and has been only partially effective in reuniting families or encouraging shared parenting or use of support families.

In order to convince legislators in Pennsylvania to enact a Texas-type permanency planning law, the legislators must be convinced that the concept of permanency planning is feasible and affordable. In the authors' view, it is, for the following reasons. First, in Pennsylvania, the concept of "permanency planning" already exists in state laws. Accordingly, no new law (or new state agency) is needed to protect the right of children with disabilities to have a permanency plan developed on their behalf. Instead of enacting an entirely new law, the Pennsylvania legislature may be approached to expand the current state permanency planning mandate to children whose parents voluntarily place them in institutions or institution-like settings.

Although amending a current Pennsylvania law seems more efficient than seeking to create a new law, Pennsylvania lawmakers may nonetheless consider enactment of a new law modeled after the Texas Law [Tex. Gov't Code Ann. (2001) §531.151 et. seq.]. Such a law would require permanency planning for children with disabilities who are at risk of being placed, or who already live in institutions or other non-family settings. For either legislative approach, state legislators must be convinced that an amendment or a new law is not only practical but also affordable.

Funding may be the state's concern, understandably. One of the advantages of the "shared parenting" or "support family" model is that such home-based care may be less expensive than institutional care because, among other reasons, the love and support which is the primary "service" provided to the child by the family is less expensive than the 24-hour staff of institutions, and the cost of facility infrastructure (e.g., buildings, cooks, janitors) is greatly reduced. Therefore, such a proposal may not only be consistent with current Pennsylvania law, it may also be financially feasible.

Since Pennsylvania law has already established that all children are entitled to love and physical and mental well-being, it follows that a new law would simply extend permanency planning to a new group of children—

children with disabilities who do not live at home. Since the Pennsylvania law already recognizes the right of all children in the Commonwealth to love, advocates for children with disabilities may argue that to comply with Pennsylvania's Child Welfare Law, the state should work to create support for family-based alternatives so that children in institutions can be placed in loving homes, which may involve the home of one or more sets of parents.

Further, under Pennsylvania law, a state may award shared custody between two parents, such as in the case of divorce [Pa. Consolidated Statutes, Title 23 Section 5304 "Award of Shared Custody"]. Among the factors considered by a court in awarding shared or partial custody under Pennsylvania law, is whether or not both parents are fit, capable of making reasonable child rearing decisions, and willing and able to provide love and care for their children. In addition courts will consider whether or not both parents evidence a continuing desire for active involvement in the child's life, if they are a source of security and love to the child, and if there is at least a minimal degree of cooperation between the parents [see e.g., *Wiseman v. Wall*, 718 A.2d 844 (Pa. Super. Ct. 1998)]. Although we have not found any case in which a Pennsylvania court has awarded shared or partial custody to non-relatives, Pennsylvania courts have acknowledged situations in which parenting can be shared between parents in different households. Therefore, an argument may be made that a court or the legislature would not be overreaching to authorize shared parenting by two sets of parents for children with disabilities who otherwise face institutionalization.

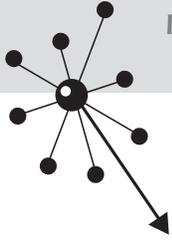
CONCLUSION

The concept of permanency planning for children was first introduced in the 1970s and was soon thereafter incorporated into federal law. Permanency planning has been applied under federal law only to children who are removed from their homes due to parental abuse or neglect. As a result of the federal mandate, states enacted their own permanency planning laws. Texas is apparently the only state to date which has expanded permanency planning to children who are not part of the child welfare system, but who have been placed in institutions, voluntarily, by their parents who retain legal custody. Despite the laudable language and breadth of the Texas law, however, it has not been pressed on behalf of institutionalized children whose parents continue to choose institutional care despite an available family-based alternative. By contrast, Michigan has adopted permanency planning without legislation for children outside the child welfare system. While permanency planning is not required by state law and is therefore generally unenforceable, state leadership and wide scale development of family-based alternatives over many years has reduced the number of children with disabilities in institutions to near zero.

Pennsylvania now has the opportunity to follow Texas' lead and adopt specific legislation authorizing permanency planning for children in institutions and/or to follow Michigan's lead in implementing practices that fit the philosophy. A legislative initiative may take two forms—either the enactment of a new separate law, or the enactment of an amendment to Pennsylvania's current child welfare laws. In addition to a legislative strategy, courts in Pennsylvania may be willing to award shared or partial custody to parents who are not the biological parents of a child with a disability, but who are willing to support the family by having the child live with them.

Finally, advocates for permanency planning for children in institutions in Pennsylvania may wish to partner with like-minded advocates in other states to amend the federal ASFA. An amendment to the federal law would extend ASFA's permanency planning mandate (and the innovative arrangements that it may authorize) currently applied only to children who are removed from their homes due to neglect or abuse, to include reasonable efforts to prevent placement, to reunify institutionalized children with their families, or to seek alternate families for children with disabilities who will otherwise remain in institutions.

Pursuit of a federal legislative strategy relates to ongoing actions in states throughout the country, and on the national level, to implement the Supreme Court's 1999 decision in *Olmstead v. L.C.* which held that it is discrimination under the Americans with Disabilities Act to keep people in institutions who could live in the community. The anti-discrimination principles of *Olmstead* may also be applied in support of permanency planning by federal lobbying efforts to mandate non-institutional options for children with disabilities [*Olmstead v. L.C.*, 527 U.S. 581 (1999)].



X. CULTURAL COMPETENCE

Susan Davis

In developing this section of the report, we were aware of the importance and need for cultural competence and sought reputable tools and resources to offer to assist in its development.

Culture is reflected in everything we do. Culture is reflected in behaviors, values, and beliefs that are learned through a process of socialization and transmitted through our families; our educational, political, economic and religious systems; the media; and other symbols (National Medical Association). It is more than race or ethnicity. The National Center for Cultural Competence (NCCC) defines culture:

Culture is an integrated pattern of human behavior which includes but is not limited to thought, communication, languages, beliefs, values, practices, customs, courtesies, rituals, manners of interacting, role relationships, and expected behaviors of a racial, ethnic, religious, spiritual, social, or political group; the ability to transmit the above to succeeding generations; and dynamic in nature (Bronheim, Goode, & Jones, 2006).

CULTURE AND SERVICES USE

Culture affects the ideas and behaviors of families who use services as well as the practitioners who provide them. Culture defines how information is received, what is considered a problem, what type of services should be provided, and who should provide them (U.S. Department of Health and Human Services, 2001). Organizations providing or coordinating family supports face the need to understand and address a multiplicity of cultures, languages, and values of the families they serve. The U.S. population is growing more diverse. Racial minorities grew at a rate six times that of non-Hispanic whites between 1990 and 2000 and are projected to exceed 47% by 2050 (National Medical Association, n.d.). According to the last census, African Americans make up 13% of the population and Hispanics make up 14.2%. Immigration grew by 50% between 1990 and 2000 (Bronheim et al., 2006). The number of foreign-born Americans more than tripled in the last three decades reaching 28.4 million in 2000 (Flores, 2003). Over 48 million people speak a language other than English at home (Bronheim et al., 2006).

Cultural competence

To effectively address such diversity requires cultural competency. Cultural competence requires that organizations have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge, and (5) adapt to diversity and the cultural contexts of individuals and communities served (see National Center for Cultural Competence website at <http://gucchd.georgetown.edu/nccc>).

Linguistic competence

In addition to cultural competency, organizations need to be linguistically competent. The NCCC defines linguistic competence:

Linguistic competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities (Bronheim et al., 2006).

In addition to addressing a variety of spoken languages, organizations must further be able to address diversity of literacy. The National Assessment of Adult Literacy indicates that 14% of adults in the U.S. demonstrate skills at the lowest levels of reading. The Institute of Medicine estimates that nearly half of all American adults, or 90 million people, have difficulty understanding health care information (Bronheim et al., 2006). Health literacy has been defined in Health People 2010 by the Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (Bronheim et al., 2006).

Cultural and linguistic competence with families with children with complex health care needs

Families in general provide 80% of long-term care across the life-span for members with disabilities (Bronheim et al., 2006). According to the U.S. Census, 2.8 million families are raising a child with a disability (Wang, 2005). These families require more intensive and specialized interactions with health and health-related care systems in carrying out daily routines including:

- managing complex and atypical physical and medical problems
- providing medical treatments, operating medical equipment, managing complex medical regimens that require a high degree of skill and related training
- attending frequent appointments and meetings related to services and care plans for their children
- learning about and accessing community resources
- keeping records about treatments and services across multiple systems
- dealing with fragmented, complex systems of services and supports
- experiencing financial difficulties due to lack of insurance or underinsurance for the child’s health and other service needs
- providing care and support beyond the traditional childhood years

(Bronheim et al., 2006).

Families raising children with complex health care needs often interact with multiple systems including health, education, developmental disabilities, mental health, and child welfare. The systems that families need to support them in caring for their children are complex, fragmented, and difficult to navigate. Given the great and growing diversity in the U.S., providing families with support that respects their culture, values, preferences, linguistic and literacy capacities, presents challenges to the multiple service systems with which they interact.

To support families requires that organizations and their staff to adapt approaches and communication to ensure that they understand families and to ensure that families have the information and the resources they need to care for their children with special health care needs. Unfortunately, limited cultural competence throughout systems of care makes it difficult to offer culturally responsive services, do outreach, and build connections to communities (Bronheim et al., 2006; National Medical Association, n.d.).

DISPARITIES IN HEALTHCARE, HEALTH DELIVERY, AND FAMILY SUPPORTS

While systems struggle to meet the needs of families with children with special health care needs generally, research indicates they have more problems meeting the needs of culturally diverse families. The National Survey of Children with Special Health Care Needs in 2001 found disparities in health care delivery reported by families from culturally and linguistically diverse groups.

- Black and Hispanic families with children with special health care needs are significantly less likely to report that they are partners in decision making.
- Black, Hispanic, and multicultural families with children with special health care needs are less likely to report that they receive coordinated, ongoing, comprehensive care in a medical home.
- Black and Hispanic and families with children with special health care needs are significantly less likely to report that community-based service systems are organized for easy use (Bronheim et al., 2006).

Providers of services acknowledge difficulty in addressing diversity. A survey by the Administration on Developmental Disabilities found 23% of programs reported difficulty in providing support in a culturally competent manner. Programs reported difficulty in (1) identifying, involving, and serving culturally diverse, underserved, and unserved families, and (2) recruiting bilingual and culturally diverse staff (Bronheim et al., 2006). The Sullivan Commission on Diversity in the Health Workforce (2004) found that while Blacks, Hispanics, and Native Americans make up more than 25% of the US population, they represent only 9% of the nations' nurses, 6% of doctors, and 5% of dentists.

Inequities within the health system reflect larger social, environmental, and economic issues. Minority families who have children with special health care needs are disproportionately represented at lower socio-economic levels (Bronheim et al., 2006). The 2003 National Healthcare Disparities Report (U.S. Department of Health and Human Services, 2003) found racial and ethnic groups, and poor and less educated patients, are more likely to report:

- poor communication with their physician
- problems with some aspect of the patient-provider relationship
- greater difficulty accessing health care information
- less likelihood of being involved in preventative or screening and treatment activities.

Cultural competence in the patient-physician relationship can have important clinical consequences. Failure to understand and address a patient's cultural and linguistic needs can result in (1) inaccurate histories, (2) non-adherence to treatments, (3) poor continuity of care, (4) less preventative screening, (4) miscommunications,

(5) difficulties in assuring informed consent, and (6) a lower likelihood of having a primary provider (Flores, 2003).

The National Medical Association (NMA) represents over 25,000 African American physicians committed to improving health care status and outcomes of minority and disadvantaged people. The Association's members serve a disproportionately high number of poor minority families who are uninsured or underinsured. The NMA suggests that health providers who lack understanding of a family's home, community, and available resources contribute to negative consequences. Minority families who live in lower socio-economic neighborhoods often experience differential treatment based on practitioners' erroneous assumptions, negative perceptions, and misinterpretations that lead to unnecessary child protective services referrals (Flores, 2003; National Medical Association, n.d.). The NMA has developed training for health care providers and recommends that health care professionals invest time and effort to gain some basic understanding and familiarity of the ethno-cultural and racial groups they can expect to encounter in their practice.

Some of the interviews with families and stakeholders done for the present study provided examples of the kinds of concerns identified in the literature:

1. Parents and stakeholders reported that uneducated parents were given less information.
2. Parents and stakeholders reported that children were given less assertive treatment when families had low incomes or represented minority groups.
3. Parents and stakeholders reported discriminatory treatment because the practitioner did not share their values regarding their child with a cognitive disability or shortened life expectancy.
4. Parents and stakeholders reported that the national nursing shortage was accentuated for families who live in poor neighborhoods that are perceived as dangerous.

STRATEGIES TO ADDRESS CULTURAL AND LINGUISTIC COMPETENCE

To address disparities will require attention at three levels: systemic, organizational, and individual.

Strategies to address cultural and linguistic competence at the systemic level

The 2003 National Healthcare Disparities Report suggests quality performance measures for priority populations including individuals with special health care needs. Some key recommendations were:

1. Eliminate disparities in access of health insurance by expanding public health programs and work towards universal health coverage.
2. Improve health care in medically underserved areas, which are often communities of color, by supporting community health clinics that provide high quality care.
3. Develop health care institutions that are welcoming and respectful to people of different races and ethnicities.
4. Track racial disparities in health care provision to help in making institutions more accountable.
5. Provide medical interpretation services for all clinical encounters.
6. Support programs that incorporate cultural traditions.

Strategies to address cultural and linguistic competence at the organizational level

The National Center for Cultural Competence (NCCC) provides a comprehensive framework, materials, policy briefs, training, technical assistance, consultation, and exploration of promising practices for achieving cultural competence. The NCCC suggests that organizations address (1) policies and procedures, (2) workforce development, and (3) quality improvement (Bronheim, n.d.).

The NCCC website offers concrete activities that organizations have employed to address cultural competence.

1. Convene a cultural competence committee, work group or task force with representation from every level of staff and administration working together, with an emphasis on including staff that reflect the population and communities served.
2. Ensure that the organization's mission statement commits to cultural competence as an integral component of all of its activities.
3. Determine the racial, ethnic, cultural, and linguistic groups of people served and then find ways to assess their satisfaction with services.
4. Conduct a comprehensive program or organizational cultural competence self assessment.
5. Encourage partnerships to share training resources at the local, state, or regional levels and utilize a network of community informants who have first-hand knowledge of the people served.

The NCCC also suggests organizational activities to support linguistic competency:

1. Provide intake forms and procedures that capture the communication needs and special accommodations of individuals served.
2. Build in extra time for appointments and meetings for individuals with disabilities.
3. Provide training for all staff, consultants, and volunteers in how to work effectively with individuals who have a range of communication needs.
4. Ensure that all consultants and contractors adhere to stated policies and procedures. (Bronheim et al, 2006)

A critical first step to ensure delivery of culturally competent care is to achieve buy-in that cultural competency is a valid health issue that affects outcomes for children, quality, costs, and family satisfaction. Families should be involved in and play important roles in organizations' efforts to ensure that all staff use culturally and linguistically competent practices through participation on advisory committees and collaboration in over-all organization functions. Including families and communities in a collaborative process of learning, by having patients and their families directly discuss their cultural issues and concerns, can be one of the most powerful tools to affect change (Flores, 2003).

Strategies to address cultural and linguistic competence at the individual level.

Ultimately, it takes the motivation, commitment, and knowledge of each person in an organization to make culturally competent responsiveness a part of everyday practice. The NCCC has identified critical knowledge necessary for individuals to provide culturally competent services including knowledge of:

1. socio-economic backgrounds of patients, their families, and their communities;

2. beliefs, values, traditions and practices of a culture;
3. culturally-defined, health related needs of individuals, families, and communities;
4. culturally-based belief systems about illness and disease, and health and healing;
5. attitudes toward seeking help from health care providers.

The National Medical Associations offers some recommendations for personal practice:

1. Avoid generalizations based on race, gender, health insurance, job, and/or economics.
2. Engender trust and be trustworthy.
3. Listen.
4. Never minimize or dismiss expressed concerns.
5. Do not assume that, because you are the same race or have the same ethnic background, you are culturally competent.

Importantly an organizational plan to improve cultural and linguistic competency needs to include individuals at every level, including non-professionals well as professional. Susan Bronheim, Director of the NCCC, draws attention to the negative consequences when front desk staff are not culturally competent (Bronheim, n.d.). She emphasizes that many interactions precede any contact with professionals, as families make appointments, ask questions about insurance, check in and provide information. Families who encounter insensitivity, lack of courtesy or respect, bias and discrimination in their experiences at the front desk may feel insulted, fear further contact, become confused about appointments and treatments, and generally not feel valued. Parents with those experiences may not keep follow up appointments, may not follow through on treatment instructions, or may not obtain adequate information for treatment of their child.

Increasing competency requires, learning, listening, self-reflection, and developing relationships. Increasing cultural competence requires individual attention in four areas: (1) awareness, (2) knowledge, (3) attitudes, and (4) behavior. Culturally competent practitioners need first to be aware of their own culturally-bound values and communication limitations; to learn about and understand the views and experiences of others; to use awareness and knowledge to modify their attitudes and behaviors; and to engage in relationships with people of different cultures in order to practice responsibly.

Both individuals and organizations need to examine their values and practices to align how services are conceptualized, designed, and delivered (Bronheim et al., 2006). A variety of tools are available that can help individuals and organizations in developing cultural and linguistic competence.

TOOLS TO USE TO DEVELOP CULTURAL AND LINGUISTIC COMPETENCE.

National Standards for Culturally and Linguistically Appropriate Services in Health Care. Office of Minority Health, U.S. Department of Health and Human Services (available at www.nhmamd.org/pdf/CLASfinalreport.pdf). This is a set of 14 standards developed with broad stakeholder engagement for policy makers, families, advocates, and the health care community generally. The standards are organized around themes:

- Culturally Competent Care
- Language Access Services
- Organizational Supports for Cultural Competence

An Organizational Cultural Competence Assessment Profile. In Indicators of Cultural Competence in Health Care Delivery Organizations: A Cultural Competence Assessment Profile (Linkins, McIntosh, Bell, & Chong, 2002), Health Resources and Services Administration, U.S. Department of Health and Human Services (available at <http://www.hrsa.gov/culturalcompetence/indicators/>).

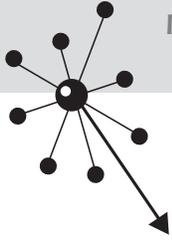
The Profile builds on the National Standards for Culturally and Linguistically Appropriate Services and is intended to be used within an organization to define expectations and standards and assess staff levels of understanding and development. It looks at organizational values, governance, communication, and infrastructure. The Profile emphasizes that assessment of cultural competence is not an event, but rather a continuous process that is integrated into all activities.

The National Center for Cultural Competence. Georgetown University Center for Child and Human Development, Washington, D.C. (Website: <http://guchd.georgetown.edu/nccc>). The NCCC has provided national leadership in developing a body of knowledge on cultural and linguistic competency within systems and organizations. It offers web-based materials, training, technical assistance, and consultation to assist organizations to assess their policies and practices and to develop strategic plans to improve. The NCCC makes available a variety of checklists and assessment tools. Some examples relevant to families with children with complex health care needs that can be accessed from the NCCC include:

- Policies to Promote and Sustain Cultural and Linguistic Competence in Family Supports
- A Guide to Planning and Implementing Cultural Competence in Organizational Self-Assessment
- Getting Started: Planning, Implementation, and Evaluating Cultural and Linguistic Competent Service Delivery Systems for Children with Special Health Needs and Their Families
- Planning for Cultural and Linguistic Competence in Systems of Care

NCCC checklists developed in collaboration with the Georgetown National Center for Child and Human Development (Goode, 2004) provide concrete examples of the kinds of values and practices that foster a culturally competent environment. Complete checklists are available through links on the NCCC website. Some examples of items from these checklists addressing service delivery for children with special health care needs include:

- I display pictures, posters, and other materials that reflect the cultures and ethnic backgrounds of the children and families served by my program or agency.
- I understand that it may be necessary to use alternatives to written communications for some families, as word of mouth may be a preferred method of receiving information.
- I recognize and accept that folk and religious beliefs may influence a family's reaction and approach to a child born with a disability or later diagnosed with a physical/emotional disability or special health care needs.
- Even though my professional or moral viewpoints may differ, I accept the family/parents as the ultimate decision makers for services and supports for their children.



XI. PROMISING PRACTICES

Bonnie Shoultz and Perri Harris

This section is intended to look at encouraging examples of actual programs and systems that have facilitated family life for children with complex health care needs. We looked for strategies, approaches, or processes that are recognized by families and leaders in the field as being effective in supporting families. We sought examples where suggestions that were raised in the family and stakeholder interviews conducted as part of this study, were being implemented. Importantly, we were not looking to endorse programs, but rather to identify the specific practices that earned a reputation for success. Also of note, the included examples are not intended to be exhaustive or to be without flaws, but rather are suggestions of what is possible.

In developing this section of the report, we identified two types of promising practices. First, we sought programs that had the reputation of being effective in supporting families well, providing a range of supports to families, and putting families at the center of the decision-making process. Second, we identified state systems that have worked to ensure that all or most of that state's children with complex health needs are able to live in families—birth, foster, or adoptive—rather than in congregate care settings such as nursing homes, children's residential programs, group homes or ICF/MR settings, or hospitals.

In choosing the exemplars described below, we looked at programs that were identified during the interviews, we asked experts in the field to nominate candidates, and we used our own prior research with the Center on Human Policy which has included extensive site visits across the country. We subsequently searched the Internet for information about nominated programs or states, we interviewed individuals with intimate knowledge of the nominated practices because of their positions of responsibility or “on the ground” experience, and we interviewed advocates who are knowledgeable about the identified programs or state practices. Below are descriptions of ten exemplars: three are direct service delivery programs in Pennsylvania, three are service delivery programs in other states, and four represent states which have implemented systemic or statewide approaches.

EXEMPLAR PENNSYLVANIA PROGRAMS

Ventilator Assisted Children's Home Program, Pennsylvania (VACHP)

Background

This program was established by Children's Hospital of Philadelphia and the Pennsylvania Department of Health in 1979. The program promotes high quality, cost-effective care of ventilator assisted children in the home and supports their families in coping with this extraordinary endeavor. The program is funded by the

Department of Health. By 2004, it had served more than 600 infants and children under 21 and their families. Referrals are made by hospitals, community agencies, and individual families. Today, children are served by staff based in Philadelphia or Pittsburgh.

The program consists of three multidisciplinary teams that include physicians, pediatric nurses with respiratory critical care experience, and social workers. Each team serves 75 families at one time, and the program is limited to serving 225 families statewide. Teams collaborate to provide:

- Consultation and support to families and institutions considering home care
- Advocacy to achieve effective utilization of available funding sources
- Post hospital discharge follow-up with families including home visits, advocacy and coordination of services
- Assessment, recommendations, and evaluation of the child's safety and clinical status, the caregivers' knowledge and skills, and community resources
- Funding for respite care
- Education for nurses
- Transition planning

Much effort is made to maintain children in their birth family, but it is not always possible to do so. Many of the families served are adoptive or foster families. Interestingly, some of the staff members in the program have personal experience in home care for children with complex needs as foster or adoptive parents of ventilator-assisted children.

Promising Practices

This program is highlighted because of its efforts to provide supports based on the unique needs of each family and because of families' consistent characterization of interactions with the program as positive, personal, and effective. Staff play multiple roles such as helping families with "hands and feet" work, helping families identify need resources, and helping families advocate for needed supports. Interactions are based on face-to-face contact with families and the development of emotionally supportive relationships. Additionally, the program addresses system level issues, such as the provision of training for nurses.

The following promising practices are in evidence in this program:

- The program employs a "**whatever it takes**" approach, finding practical ways of assisting families such as attending hospital discharge planning meetings with families, helping families to fill out paperwork, and maintaining a supply closet filled with donated or used items for families where no other sources of funding are available.
- Program staff serve as **information resources** for families and as **advocates** for services when needed.
- The program provides **training for nurses** so they are well-prepared to care for children with complex medical needs, especially those who use ventilators and trachs.
- The program **demonstrates cost-effectiveness** with data that shows that hospital discharge is much faster for families involved in the program, and that hospital admissions of enrolled children are much lower than for those who are not enrolled.

Diagnostic & Referral Centers—Pennsylvania

Background

The Children’s Hospital Diagnostic Center at Children’s Hospital of Philadelphia (CHOP). This center is designed to meet the needs of children with complex or hard-to-diagnose illnesses. Doctors and staff at the Diagnostic Center collaborate with referring physicians in managing and coordinating children’s care and helping them to meet the needs of children with special health care conditions. The Diagnostic Center provides subspecialty consultations, evaluates findings, reports to the referring physician and parents, and assists with inpatient care involving multiple subspecialties.

Children’s Hospital of Pittsburgh: The Paul C. Gaffney Pediatric Diagnostic Referral Service. This center helps families and supports primary care physicians by identifying a child’s specialized medical needs and coordinating advanced treatment. The service is staffed by full-time physicians with special interest in diagnostic challenges, who specialize in multi-system diseases and complex single-system problems. The Diagnostic Referral Services is available to assist pediatricians and primary care physicians in helping young patients and their families. Staff have many years of experience in diagnosing and managing a wide variety of the most complex pediatric medical conditions. That experience supplements a referring physician’s knowledge of the patient and provides a fresh perspective on what may present a challenging diagnosis or care management. The Diagnostic Referral Service provides rapid access to a complete range of services within Children’s Hospital, including access to subspecialty services and technologically advanced equipment and facilities.

Promising Practices

Diagnosis and treatment is often challenging; however, parents reported that it is most effective when there is communication and collaboration among specialists and between specialists and the family. Parents who have used these centers consistently identify the following elements of promising practices:

- The staff **work collaboratively with one another and with families.**
- The staff are **responsive to families.**
- The approach is **holistic**—interest is taken in the parents as well as the child in developing care management plans.

Every Child, Inc., Pittsburgh, PA

Background

Every Child, Inc. is a non-profit social service agency in Southwestern Pennsylvania whose mission is to serve the most vulnerable children and families, with the goal of removing barriers to full family and community life for each child served. Every Child believes that all children deserve the opportunity to live, play, and develop with a family, hopefully their birth family. If living with the birth family is not an option, Every Child recruits and supports adoptive families. Every Child provides services and resources to support children with

disabilities (ages birth to 24), with a particular interest in children with complex medical conditions, to grow up in a nurturing, safe, healthy and lasting family. Ninety-eight percent of the children and families served live at the poverty level and utilize medical managed care for their physical and behavioral services. All of the children the agency serves have either a chronic physical, developmental, behavioral, or emotional condition. Many of the children have experienced long hospital stays, multiple placements, and trauma.

Every Child uses a planning process called “Family Centered Futures Planning” to create an ongoing plan which the family can use over time to organize the daily complexities of caring for their medically fragile child. Every Child has developed what it calls “Medically-Related Wrap-Around Services” to support children who are medically fragile and their families. These services include an array of supports to families dealing with the transition of their child from the hospital to home, or intervention for families whose children have previously transitioned home without the necessary support and education for the parents to insure the child stays healthy and in the home. Supports are family driven and individualized according to the child’s and family’s needs and may include: assessment and planning, identification of potential resources in the community, transportation, daycare for other children in the household so parents can visit and prepare for the child’s return, identification and support of in-home nursing and/or other therapeutic services, reinforcement of child specific health related procedures, identification of tangible resources required by the child’s condition but not covered by any insurance coverage, and emotional and peer support.

Promising Practices

The following promising practices are identified in the approaches used by the program:

- **Coordination, communication, and collaboration** are emphasized between all of the providers of service, the family and friends, and other person’s involved in the child and family’s life.
- A **partnership** is developed and maintained with the family, their social support network, health care practitioners, therapists, nurses, social service staff, educators, and other individuals and organizations vital to the child’s and family’s emotional, social and physical health.
- Services are **holistic** and consider children and families as a whole rather only addressing the child’s health care condition.
- Staff interactions are personal including visiting families at home, hearing family needs, identifying needs the family may not aware of, and finding ways to meet those needs through referrals to other resources or by direct service to the family.
- An emphasis is placed on **multiply-trained staff** and **continuity** with the child and family over time.
- Coordinators do **hands-on work with families** such as driving them to appointments, helping them to design schedules for care of the child, preparing them for medical appointments, working with the nurses who come into their homes, and helping parents learn to “read” signs of impending medical crises in their child.

EXEMPLAR PROGRAMS IN OTHER STATES

The Coordinating Center—Maryland

Background

The mission statement of the Coordinating Center is: “to partner with families, children and adults with special health care needs and disabilities and those who support them in the community to achieve their aspirations for independence, health, inclusion, dignity and quality of life.” The Coordinating Center implements the Maryland Medical Assistance Model Waiver that provides medically necessary home care services and case management for children and young adults under age 22 with complex health care needs. This waiver supports families who have no other funding source, or whose private insurance coverage is exhausted or inadequate. The Coordinating Center is required to show cost effectiveness by demonstrating that the cost of care at home would be less than or the same as the projected cost of long term hospital care. The Center serves approximately 200 children and young adults.

Promising Practices

The Coordinating Center believes it is not their job to move the hospital into the home or to set families up to function like a hospital; instead, they work to help the family function like a family. In creating family life, the Center has used the following promising approaches:

- Case managers develop close, positive **relationships with families**.
- Case managers **visit families in their homes** to be able to know first hand how things work and what they need.
- Staff provide families with **information, resources, and assistance in advocating** for needed services.
- Staff are engaged in training, technical assistance, and consultation to affect **systems change that promotes full inclusion**.

EveryChild, Inc.-Texas

Background

[Note: EveryChild, Inc. of Texas is not affiliated with Every Child, Inc. of Pennsylvania. Both organizations involved a parent/advocate coalition which used similar names, but the two coalitions were not affiliated.]

EveryChild, Inc. of Texas was formed in 2000 as the result of activities of a coalition of parents of children with disabilities and child advocates who were concerned about the large number of children with developmental disabilities living in institutions and nursing homes. The common interest of the group was the belief that every child deserves to grow up in a loving and nurturing family. The group formalized its common interest in the Every Child Coalition and expanded participants to include state agency staff, legislative staff, and providers of services. The early work of the Coalition, supported by grants from the Texas Department of Health and the Texas Council for Developmental Disabilities, included educating policy and decision makers, creating a strategic plan, developing training guides, researching systemic barriers, performing a needs assessment, and creating a best-practices model of family-based alternatives for Texas.

As a result of the Coalition's activities, legislation was passed that requires "permanency planning" for children with developmental disabilities living in all congregate care settings under any state agency. Permanency is a guiding policy and process that seeks to assure family life for children and support for families as an alternative to congregate care. The legislation further authorized the Texas Health and Human Services Commission (HHSC) to contract with a community entity to develop a system of family-based alternatives to institutions.

The Every Child Coalition spawned the incorporation of EveryChild, Inc. which was awarded the HHSC contract in May 2002 to implement the Family-Based Alternatives Project. The Project assists institutionalized children and young adults to return home to their birth families with support; or when return home is not possible, recruits alternate families called "Support Families" who are carefully matched with children and their birth families to care for children long-term in a relationship characterized by "shared parenting." Unlike foster care, birth families retain their rights. This shared parenting relationship enables birth families to remain actively engaged in their child's life even if circumstances prevent them from caring for their child at home. The two families develop a shared parenting agreement outlining expectations, schedules, decision-making, and responsibilities based on their individual circumstances and preferences.

EveryChild does not provide direct services or service coordination; rather the Project is responsible for identifying institutionalized children and contacting their families to discuss possible options to residential facility care. They actively recruit potential alternate families and work closely with disability provider agencies and traditional foster care agencies to embrace children with disabilities and the concept of shared parenting as an alternative to traditional foster care or congregate care.

Promising Practices

EveryChild, Inc. was chosen because it is implementing permanency principles as an alternative to congregate care for children with complex health care needs. Texas is one of the few states to apply permanency planning to children served in the disability and health services sector rather than solely in the child welfare sector.

Following are promising practices in EveryChild's approach.

- A **parent-driven** coalition has shaped system change.
- **Legislation** requires that every child in congregate care is tracked, that a permanency plan that is developed and reviewed every 6 months, and that the state reports to the legislature what families need to care for their children at home.
- The permanency planning process **identifies unavailable resources for the legislature** that are needed to help support families to keep their children at home.
- Staff engage in **relationship-based practice** that takes the stance that the trust of families is earned by developing close, personal relationships in combination with offering practical real-life help that fits what families identify.
- Staff are guided by a "**whatever it takes**" approach—for example, sending gas cards so families can visit their children, or working evenings and weekends to fit the family's preferred schedule.

- Family support **coordinators are themselves often parents of children with disabilities** who share personal experience with families they serve.
- Where children cannot live with their birth families, **shared parenting** (like extended family or amicable step family relationships), allows children to enjoy family life who would otherwise be placed in congregate settings.
- **Providers are viewed as allies** and engaged in rethinking their current service array to more fully embrace family support.

SKIP of New York

Background

SKIP stands for Sick Kids need Involved People. SKIP is a service coordination agency which provides advocacy and support for families who care for children with complex health care needs. SKIP's Care at Home Program began in 1985 with New York's Katie Beckett waiver. The program provides nursing, co-payments for medication, and comprehensive case managers with 24 hour access. The emphasis of the organization is to provide case managers who are compassionate, knowledgeable, flexible, creative, and persistent. Case managers make home visits, help with insurance and Medicaid problems, and help with education issues. The focus of case managers is to form a partnership with the family, assisting to guide them through the "maze" of services and paperwork. Case loads are small (20-25 families per case managers), so case managers can get to know families well and provide significant assistance.

Promising Practices

SKIP is recognized for providing responsive coordination and support to families. SKIP finds that access to and relationships with case managers are crucial. Promising practices in evidence at SKIP have the following characteristics:

- **Positive relationships with families** are developed and maintained.
- Families are **equal partners** in collaboration about a child's best interest.
- Staff provide **practical assistance** such as helping with paperwork and exploring how to maximize insurance coverage.
- **Coordinators make home visits** to assure an accurate understanding of what families need on a daily basis.
- **Coordinators assist families through the maze** of services and payment mechanisms.
- **Case management is independent** of service provision.
- The organization creates a supportive atmosphere of **working with families rather than managing them**.

EXEMPLARS OF STATE SYSTEMS

Minnesota

Background

Minnesota's family advocacy organizations, state departments, universities and county programs have worked together to create a system that provides assistance to families so that children with special health care needs can remain at home. Minnesota lessened its reliance on institutions after the Welsch consent decree in 1980, closing its last state institution in 2001. Almost all of Minnesota's children with complex medical conditions are living with families—birth, foster, or adoptive.

Some of the services and resources that make up the system in Minnesota include multiple waivers located in multiple state agencies which provide funding for services and supports in the recipients' home. A state website listing state-level and community resources provides information to families and practitioners. The University of Minnesota School of Nursing is home to the Center for Children with Special Health Care Needs, a partnership with the Department of Health to prepare advanced practice nurses to fulfill leadership roles in interdisciplinary clinical care and policy.

Promising Practices

A family-valuing professional and advocacy culture has developed in Minnesota that works to ensure that children with developmental disabilities will grow up in families rather than in congregate care facilities.

Promising practices in evidence in Minnesota include:

- **Partnerships** with families as key stakeholders.
- A **holistic** approach to care of children and adolescents with a focus on family life and community participation.
- **Information and access routes to resources** provided to physicians, early childhood program staff, and families.
- **Cross system collaboration.**
- **Attention to transition to adulthood** for youth with special health care needs.

Wisconsin

Background

Stakeholders in Wisconsin have been working for many years to redesign the system that supports children with disabilities, including those with complex medical needs. In 1998, the Children's Long Term Care Support Committee developed a report that included recommendations and best options for children. This report set out a guiding philosophy, central to which is the belief that children belong in families. Years of system redesign work followed, as the committee asked "What isn't working? What needs to change?" The committee included parents, providers, county representatives, and state department staff. Parents comprised two-thirds of the committee. Families reported to this planning body that they need a person who gives them information, refers them to needed services; helps them with planning, and helps with locating providers for needed services.

With the redesign, a set of Medicaid Home and Community-Based Services waivers were developed for children that added to the services that already existed. Three Home and Community Based Waivers for children, called the “sister waivers,” provide family support services for families of children with developmental disabilities, severe emotional disorders, and physical disabilities. A statewide Family Support program pays families up to \$3,000 per family for services and items that cannot be purchased through Medicaid or other sources. The program includes involvement by a family support coordinator, who together with the family develops a service plan that addresses the family’s unique situation, identifying support needs and setting priorities. Also available in Wisconsin are five Regional CYSHCN (Children and Youth with Special Health Care Needs) Centers which provide free and confidential information and assistance to providers and children with special health care needs and their families.

In January 2005, the Council for Children with Long-Term Support Needs (CLTS) was established by the Secretary of the Department of Health and Family Services, and charged with providing recommendations regarding infrastructure, accountability measures and mechanisms, financing systems, training programs, and program design elements necessary to implement service delivery systems in communities throughout the State to address the needs of children with long-term support needs and their families. The Council is working toward a system that provides a constellation of services from which families can access different supports at different points in time, can get what they actually need, and where services are driven by a child’s functional needs rather than diagnosis.

Promising Practices

Promising practices in Wisconsin include:

- A continuing **partnership** between state departments, families, providers, and counties.
- Organization of state agencies to **combine programs and funding streams** across child protection, mental health, disability services, health, and Medicaid.
- **Work across programmatic and regulatory boundaries** to establish a more coordinated system of supports.
- A standardized web-based **eligibility determination process for all services based on functional needs** rather than multiple separate processes and diagnosis-based eligibility.
- A voucher program that provides funds to families that allow very **individualized, flexible responses to their needs**.

Michigan

Background

Michigan has developed multiple ways of supporting families of children with complex health care needs. Services for children with developmental disabilities and special health care needs are administered by the Michigan Department of Community Health (MDCH) and funded with state and federal Medicaid dollars including waivers designed to provide in-home services and supports to children who would otherwise be at risk of out-of-home placement. In 1983, Michigan enacted the Family Support Subsidy bill which provides discretionary cash to families with children with severe disabilities.

MDCH uses a network of Community Mental Health Services Programs which act as a single entry point into services and provide or contract for a full range of services for families. Community Mental Health Services Programs have independent family service coordinators who arrange needed services and assistance through private insurance or access to public funding.

Over the years, Michigan has demonstrated a commitment to permanency planning for children with developmental disabilities and complex health care needs. In the 1970s, Michigan was an early leader in deinstitutionalization and the development of community-based services. For children, the development was directed at family-based alternatives (birth, foster, or adoptive) rather than in group settings, and it extended to children with special and complex health care needs living in nursing homes. After Congress passed Public Law 96-272, the Adoption Assistance and Child Welfare Law of 1980 which mandated permanency planning for children in foster care and other out-of-home settings in the child welfare system, Michigan obtained federal grant money to initiate a Permanency Planning Project in the disability sector. Guided by the principle that all children belong in families, Michigan was the first state to apply the permanency planning philosophy to children with disabilities outside the child welfare system. The goal was to ensure that every child with developmental disabilities lived with a permanent family. The project staff developed strategies to achieve this goal, including services and supports to help children stay with their birth families, family reunification efforts for children who had previously been placed, and an emphasis on recruitment of foster and adoptive homes for children who couldn't live with their families.

Michigan also developed “gate-keeping” policies to control admissions of children to nursing homes and other congregate care facilities including small group homes. The philosophy behind permanency planning is widely held by policymakers, parents, and providers.

Promising Practices

Michigan has been successful in supporting children in family settings. Promising practices that have contributed to successful support of family life include:

- A **holistic approach** to service delivery for children and their families that recognizes that supports and services impact the entire family.
- **Family choice and control** through mandating of person-centered planning.
- **Flexible funding** provided directly to families through cash subsidies and vouchers.
- **Collaborative planning efforts including parents**, advocates, and the multiple state agencies which are involved in the lives of children with developmental disabilities and special health care needs.
- **Independent service coordination** with allegiance to the family.
- **Commitment to a common value** that children belong in families.
- Demonstration of **permanency planning** outside the child welfare system.
- Development of **shared parenting** arrangements whereby families are recruited to care for children who cannot live with their birth families without relinquishment.

Colorado

Background

In the 1980s, when Colorado began to bring people out of the institutions, children were first to leave. In contrast to many other states, few congregate care options for children with disabilities were developed in Colorado. While a few small group homes were developed, the “host home” was the model most used in the state, and this was the model most frequently used for children. In the early 1980s, Colorado began to offer waivers to assure services were made available to children living in family homes. At present, no children under 18 reside in the remaining state institution (which is being closed), nursing homes are not allowed to admit children, and there are no private congregate care facilities for children in the state.

Developmental disability services in Colorado are provided through Community-Centered Boards, which are private, non-profit agencies designated by the Colorado Division for Developmental Disabilities to determine eligibility for services, act as the single point entry point for persons to receive developmental disabilities services, provide case management/service coordination, and authorize services and supports either directly or through purchase from service agencies.

Colorado has three waiver programs for children and two more that are soon to be implemented. These five waivers are:

- 1) The Children’s Home and Community Based Services waiver (formerly known as the Katie Beckett waiver) for children who require a nursing home or hospital level of care.
- 2) The Children’s Extensive Support waiver for children with developmental disabilities or delays who are most in need due to the severity of the disability.
- 3) The Children’s Habilitation Residential Program waiver for children and youth in foster care in the child welfare system who have a developmental disability and extraordinary needs.
- 4) An autism waiver (new) for children with autism who are up to 6 years of age.
- 5) A pediatric hospice waiver (new), for children requiring hospice level of care.

Promising Practices

For many years, concerted and coordinated efforts have been made to respond to the needs of these children and their families. Promising practices in Colorado include the following:

- A **held-in-common philosophy** that children with special health care needs and/or developmental disabilities should live with families.
- **Collaboration** across state departments, together with the Community-Centered Boards, parent advocates, and other advocacy groups.
- Very **active and informed parent advocacy** groups.

SUMMARY OF PROGRAM LEVEL PROMISING PRACTICES

There are several commonalities in key aspects of the promising practices of the programs we have highlighted. Importantly, promising programs address children with complex health care needs **holistically**. They

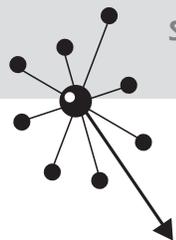
recognize that children with complex health care needs are not simply medical conditions to be dealt with; they are children who have families, many of whom need support to be able to function as families. Successful agencies stressed the importance of **understanding** individual families' needs personally, **listening** to their dilemmas, and **working together** to create support around these needs. Because systems are often complex mazes, successful programs include **care coordination** to ensure that the child's needs are met and understood in relation to the family. Coordinators do more than provide information and referrals; they are **actively involved** with families. They **provide practical, hands-on help** in addition to formal services, for example, driving families to appointments, helping nurses and families acclimate to each other, or making contacts on a families' behalf. Coordinators do not simply fill out paperwork and sit in front of a computer screen, they have **face-to-face relationships** and **visit families in their homes** which helps to assure that families will not only have individualized support, but also have the **emotional support** of feeling understood.

SUMMARY OF STATE SYSTEM LEVEL PROMISING PRACTICES

States reviewed for this report were states that had undertaken system-level family support by adopting a value system that emphasizes the belief that children should grow up in families and that families need support to ensure that this value system is fulfilled. Each state where promising practices are in evidence developed **partnerships with parents in system design and development**. States that successfully support families have **planning bodies** made up of stakeholders that include families in examining the programs and practices that affect children with disabilities and that have the ear of senior policy and decision makers. These states have active **parent and disability advocacy organizations**. They nurture positive relationships with people working **across state government departments** that affect children with special health care needs and disabilities.

Many of these states have created sets of waivers that work together to meet as many needs as possible, and provide a wide array of supports which can be **tailored to fit individual families**. They use **independent care coordinators** whose allegiance is to families. They utilize subsidies and vouchers to increase flexibility and family choice and control. They also have worked to create **information and referral mechanisms**, including web-based resources, so that families, practitioners, and coordinators can learn about programs. Some of these states have worked to augment the supply of medical professionals, especially nurses, by offering **specialized training**. These states **keep good data** to track where children live and what effect support has on maintaining children at home. They have clearly defined **policies regarding admission of children to congregate settings**—in some states the doors are closed on such admissions, and in others such admission cannot take place without state-level review. In particular these states also **actively develop family-based alternatives** to congregate care by recruiting families for children with special health care needs who cannot remain with their birth families.

Importantly, programs and states which support children with complex health care needs in family homes have expressly **articulated policies that state children belong in families** to guide their efforts.



XII. KEY FINDINGS, CHALLENGES, AND RECOMMENDATIONS

Pamela Walker and Nancy Rosenau

The wide range of families and stakeholders who provided input to this study shared remarkably similar views of services for children with complex health care needs and their families. Furthermore, their views are consistent with the perspectives of the policy analyses and literature reviewed for this study. Collectively, they provide a picture of the essential services and supports that families need, what facilitates home care, and what makes it more difficult for families to care for their children with complex health care needs.

ESSENTIAL SERVICES AND SUPPORTS

First, there is a broad consensus that children need to grow up in well-supported families for optimal well-being and development. In general, families and stakeholders, and reviews of literature and promising practices, suggest the following are essential supports for families:

- Information about their child and about services and resources
- Practical help
- Emotional support
- Access to services and supports that are individualized to fit their unique needs and circumstances
- Being understood by those who design, deliver, and evaluate services

WHAT FACILITATES FAMILY LIFE

There was broad consensus that *how* services and supports are provided is as important as *what* services and supports are provided. The following elements were identified as characteristics of systems that facilitate home and family life:

- Systems that are family-centered and collaborative and see families as partners in designing, planning, developing, and evaluating their services and supports, both at the individual level and at the system level.
- Interactions with system representatives that are built on relationships that are personal, face-to-face, in-home, and hands-on to assure that families' daily lives and experiences are truly understood.
- Systems that have family-valuing and child-valuing cultures, see families holistically, and are willing to explore creative and flexible ways to use existing resources.
- Systems that recognize their own complexity and provide a coordinator to families whose allegiance is to assisting the family in whatever ways necessary and who is knowledgeable or willing to learn about ways to meet families' needs and committed to find them.

- Systems that connect families to supports based on their functional needs, that are available as needed, when needed, in adequate amounts, for as long as needed.

Unfortunately, what clearly emerged from the participants in this study was the distance between these facilitating characteristics and families' experience with the current systems of services and supports. Below is a description of factors that make it difficult for families to care for their children at home.

WHAT MAKES CARE AT HOME DIFFICULT: FINDINGS, CHALLENGES, AND RECOMMENDATIONS

The findings presented below with regard to factors that make home care difficult represent common themes that were identified across multiple sources described in the previous separate sections of this report. The basis for each finding is presented followed by a description of the key challenge presented as well as recommendations to address this challenge.

1.

Finding: Families lack adequate amounts and types of supports and are fearful about the long-term stability of supports. Families characterize life as a constant battle to get the amounts and types of services they need. Funding to provide essential supports to families is insufficient. Bureaucratic rules and regulations (e.g., regarding how families obtain supports and who can provide support) foster inflexible services that do not very well meet the needs of unique children and families. In-home care is inadequate due to difficulties finding and funding nurses, particularly those who are well-trained and comfortable caring for children with ventilators and trachs, and due to insurance restrictions on nursing hours. Services and supports tend to focus on the child rather than the child within the context of his or her family. Finally, not enough attention is given to families' need for emotional support.

Challenge: To increase capacity and access to timely, adequate, individualized supports to families and explore creative ways to use existing resources more flexibly.

Recommendation: Holistically support children and their families with family-determined supports. Characteristics of programs that successfully support children and their families holistically include: family involvement in determining supports; individualized, flexible supports based on the unique needs of children and families; supports that are developed based on face-to-face interaction and in-depth understanding of children and families; and supports that are provided within the context of positive, emotionally supportive relationships. Support must take into account the needs of other family members in addition to the targeted child with health care needs, and support for the targeted child must encompass medical as well as nonmedical needs.

Recommendation: Develop an adequate pool of trained nurses. An increased supply of nurses who are skilled in care of children who use ventilators and trachs is needed. Some organizations in Pennsylvania, such as the Ventilator Assisted Children's Home Program, are experienced in preparing nurses for work in homes of

children with ventilators and trachs, and their experience could be drawn upon to increase the availability of such training. Collaborative efforts are needed to tackle the complex issues involved in addressing the nursing shortage, with particular attention to assuring that home care is competitive with other nursing jobs.

Recommendation: Further develop and promote other options for in-home support. Some families and young adults with disabilities do not specifically need a nurse for all of their in-home support. Some families appreciate the flexibility of being able to hire friends, neighbors, or other community members for some or all of their support needs. There are some families and young adults in Pennsylvania who have had very positive experiences hiring community members as personal care assistants, and hiring friends and neighbors as respite providers. In addition, there are some families who prefer to arrange and manage their own supports with the assistance of fiscal intermediaries or service brokers. The option of family management is available through the Person/Family Directed Support Waiver and through self-determination initiatives. With further development and promotion of these options, many other families may benefit from them.

Recommendation: Ensure that sufficient funding is available to provide adequate supports to families. States that have had success with supporting families utilize a number of strategies, including: (a) closing congregate facilities and using the funding instead to support families; (b) development of noncategorical funding; (c) flexible funding pools to supplement what is not covered by Medicaid or insurance; and (d) collaborative constituencies advocating for increased funding.

2.

Finding: Families' voices are not heard and their experiences are not widely understood. At many levels, family voices are not heard or their day-to-day lives are not well-known. Many of those who determine policy, who make decisions about resource allocation, and who provide or oversee services do not seem to have an in-depth understanding of families' lives and perspectives. Families experience significant stress, and this lack of understanding compounds their frustration and sense of isolation.

Challenge: To increase understanding and awareness of the general public and decision makers about the daily lives and experiences of families who are raising children with complex health care needs.

Recommendation: Promote awareness and understanding of families' lives and issues. It is critically important that family voices are heard and collected, that there are forums for families to express themselves and tell their stories, and that links are made between these stories and key policy and practice issues. Families have a great deal to teach the system about what amounts and types of services they need and how to stretch limited resources. The service system needs to find ways to hear their experiences and utilize their experiences and skills as partners in shaping a more responsive service system. In addition, those who control resources and make decisions about policy need to meet families and hear their stories in order to fully understand the impact of policy and resource decisions on the lives of children and families.

Recommendation: Include families in all levels of planning and decision making. Families report that

they do not feel that they are considered to be partners in collaborating to solve problems at the individual level or at the system level. It is positive that families are involved in Title V planning in Pennsylvania. It is essential that this type of involvement be expanded, in order to best create an effective, responsive service system. In interviews for this report, the Every Child Deserves a Home Coalition was identified as a source for the collection of family stories and voices. Support of such a forum to represent the perspective of a range of families with children who have complex health care needs may provide a vehicle for increased family involvement in state level planning.

3.

Finding: Families characterize many of their interactions with the service system as negative, impersonal, and problematic. Families report that they are often not listened to and not responded to; that their children are not valued; and, that they sometimes experience racism and discrimination. They feel that people within the service system often make negative judgments about them and their children. They experience long delays in getting answers, are shuffled between staff or systems, and have difficulty understanding the logic of decisions that are made.

Challenge: To develop partnerships with families in planning and development of services and supports.

Recommendation: Foster positive, collaborative relationships between families and the service system. When families report positive experiences with the service system, it is characterized as individuals who take time to listen to them and get to know them, who respect them, and who work collaboratively with them.

Recommendation: Provide services in a nondiscriminatory manner. Because families' stories and voices are not widely heard, positive as well as negative experiences are not known. The joy families find in their children with challenging needs is not appreciated. Negative assumptions are not reflective of their full range of perspectives or competencies.

Recommendation: Provide services in a culturally competent manner. Given the well-established link between poverty, disability, and race, attention to services to racial and ethnic minority groups is needed. In terms of promoting better understanding of cultural and ethnic diversity, the Office of Minority Health in Pennsylvania is an existing resource. In addition, this report has identified numerous other national resources for developing and promoting cultural competence.

4.

Finding: Services for families having children with complex health care needs are characterized as a “fragmented maze.” Families often receive services from various systems (e.g., health, education, disability systems), and sometimes fall through the gaps between systems. Service gaps are exacerbated by eligibility based on diagnostic categories rather than functional needs. There is lack of coordination for families between the medical services system and the disability services system. Workers within one system sometimes do not

inform families of services they are eligible for within another system. Though families may have more than one case manager, each one typically offers compartmentalized information and no one assists with overall coordination. Families feel that case managers' orientations are more geared toward resource constraint than to assisting them to get what they need.

Challenge: To increase cross system collaboration and integration and learn from promising practices that offer family-centered coordination and have moved from categorical to functional needs based services.

Recommendation: Provide service coordination that is based on in-depth knowledge of the family, allegiance to the family, and that helps them navigate the service system maze. Families report what has been, or would be, most helpful to them is an overall service coordinator who: knows their child and family well based on face-to-face contact; helps them locate resources across service systems; offers emotional support; remains consistent over time; and helps them advocate for needed services. There are at least a small number of organizations in Pennsylvania (e.g., Ventilator Assisted Children's Home Program, Every Child) that have case managers or social workers whose roles are broadly defined and incorporate these preferred aspects. Based on visits and personal contact with families, these coordinators help identify resources; they help families through the steps necessary to gain access to those resources; and they assist with appeals and advocate for and with families for needed resources. The emphasis of their interaction with families is not on cost containment, but on doing whatever it takes to help families find and obtain support.

Recommendation: Provide an integrated set of services that is easily accessible for families. The categorical boundaries characterized by current systems need to be removed or more easily bridged. Within Pennsylvania, a variety of forums for interagency coordination already exist such as the Department of Health Title V planning process, the Interagency Coordinating Committee, and the Children's Cabinet. Examples from other states include the Council for Children with Long-Term Support Needs in Wisconsin, as well as efforts by states like Minnesota or Michigan to create some noncategorical funding streams to cover individuals who fall through the gaps within traditional funding streams.

Recommendation: Promote collaboration across specialties and organizations. Families report that they benefited at the time of diagnosis and in the years following diagnosis when there was personal collaboration among the various specialists involved in their child's life. The diagnostic centers at the Children's Hospital of Philadelphia and the Children's Hospital of Pittsburgh provide examples of efforts to promote such collaboration. Other examples include the medical home grant initiatives underway through a collaboration between the Department of Health and the American Academy of Pediatrics.

5.

Finding: Information and resources are very difficult for families to obtain. Families have great difficulty obtaining information. They report that they most often obtain information on their own, with the assistance of other families, or by chance rather than through the service system.

Challenge: To improve timely and adequate access to accurate and comprehensive information for families.

Recommendation: Provide useful, timely information about resources to families. While a number of existing resources in Pennsylvania have attempted to provide information to families, too many families have not been reached by their efforts. Their approaches should be examined to understand the limits of their outreach and their positive contributions that can be built on. These resources include The Special Kids Network, as well as Parent to Parent and other similar programs.

Recommendation: Ensure information is comprehensive and easily accessible. Information that is specific to individual children and families is most useful. The lessons being learned through pilot efforts in Pennsylvania to create medical home programs to provide parents with information and resources through physician's offices should be examined and helpful approaches should be applied across the system.

6.

Finding: Families, children, and young adults are often socially isolated, housebound, or interact only with health care or disability service providers. Children and their families, particularly mothers, are sometimes isolated and homebound due to lack of in-home care, transportation, and respite. Young adults also are often homebound and socially isolated due to lack of transportation and lack of access to community places where their friends spend time after school and upon graduation. Families and young adults express concerns about the lack of comprehensive, individualized planning for adult life including supports for community living, employment, and social relationships. They fear a reduction in supports when moving from children's services to adult services and the possibility of institutionalization due to lack of adequate supports in the community. One young adult we interviewed who lived in nursing homes for much of his childhood because his parents were unable to care for him, described the isolation of these settings and confirms the fears of other young adults and their families regarding what they will lose if community support is inadequate.

Challenge: To promote inclusion and participation of all family members in their communities.

Recommendation: Provide supports that promote inclusion in community life for families, children, and young adults. Services that promote inclusion include transportation, adequate nursing hours, and flexible use of resources. Policies that focus on the child, or only on the child's medical needs, are not holistic enough to include social needs. Policies that prohibit available nurses from transporting children and young adults into the community prevent socialization and community participation. Policies that prohibit available nurses from caring for siblings in the home prevent parents from having the respite break they need.

Recommendation: Provide individualized, coordinated planning for transition to adult life. Where effective transition planning occurs, the family and/or young adult is at the center of the process and it is based on promoting imagination of possibilities and close collaboration between various systems such as education, vocational rehabilitation, and other disability service entities. The young adults who we interviewed report that maintaining the necessary supports to fully participate in community life requires significant time and effort

fighting for what they need and requires assistance from their families. They are fearful about the possibility of being placed in a nursing home because of inadequate support from the adult service system. In order to address these transition issues, some states have developed diverse sets of waivers in order to incorporate community supports for young adults with complex health care needs. In relation to the needs of youth with disabilities, the Pennsylvania Youth Leadership Network is an important resource, as it gives voice to the issues of youth with disabilities.

Recommendation: Offer the opportunity for all children to be included in their local school. School represents a major part of a child's life. Some school districts have made significant efforts to fully support and integrate all children, including those with complex health care needs. For example, the Pittsburgh school district utilizes specially designated staff to coordinate educational services and health care services. Methods of successful school districts could serve as examples to struggling school districts.

Recommendation: Assure that adequate Individualized Education Plans (IEPs) are developed and implemented. Children need the socialization with age peers that inclusive schools offer and families need the break that a full school day offers. Available educational supports are frequently not understood or fully utilized to assure school participation of children with complex health care needs. The Education Law Center and the PEAL Center are two Pennsylvania resources that could assist in promoting inclusion and assuring the necessary supports to make it viable at both the individual child level and at the system level.

7.

Finding: Insurance and Medicaid require hours of work from families and are a source of “constant battles” for families to obtain covered services. Families are faced with continuous cutbacks in services and seemingly illogical denials (e.g., nursing hours that have been prescribed by doctors, therapies that maintain skills, and equipment that promotes good health and independence are determined to be not medically necessary). Some denials are based on uncovered services, while others are based on inadequate documentation to approve covered services. Some denials are based on unrealistic restrictions or unreasonably frequent reconfirmation of permanent conditions. Families have difficulty getting coverage for needed services such as transportation and respite because they are not defined as medically necessary and therefore fall outside the range of covered services. Some determinations of medical necessity by the treating physician are overturned by non-physician review teams or by physicians who do not know the family or child or their circumstances. In addition, funders often constrain families' choices of service providers. There is a sense that those who control resources and make decisions about resource allocation do not understand family life and conversely, that families do not understand their insurers' coverage and rationale. In addition, as noted above, families are not fully informed about what services are covered (e.g., diapers, transportation), and have to discover this on their own or through other families. Both lack of access to funded services and funding restrictions lead to significant financial hardship for families, and their battles for funding are a source of significant stress. Financial hardships and stresses are exacerbated for families with low incomes, single parent families, or families in which a parent also has a disability or special health condition.

Challenge: To provide personalized assistance to families in obtaining covered services, managing denials and appeals, advocating for needed services, and finding ways to obtain uncovered services.

Recommendation: Educate funders about the types and quantities of services needed by families' and their experiences with system barriers in meeting their needs. As noted above, those who make decisions about resource allocation need to hear the voices of families and invite them to partner in mutual problem solving, both to obtain adequate funding and to use existing funding more effectively. Forums like the Title V planning process or the Every Child Deserves a Home Coalition may provide vehicles for bringing together families and decision makers.

Recommendation: Provide personalized, hands-on help to families to assist in obtaining and coordinating needed services and supports. There are many resources in Pennsylvania that can be drawn upon to provide expertise in advocacy at the individual level as well as the systemic level including the Health Law Center, the Education Law Center, the Protection & Advocacy Disability Law Project, and the PEAL Center. In addition, over time, families gain experience in advocacy and strategies for obtaining resources, and these families can be used as resources, as well, through organizations such as Family to Family.

8.

Finding: There is no comprehensive, cross system policy articulating a commitment to family life for all children and support families to provide it. Permanency policy is not applied to children with complex health care needs in Pennsylvania. Children with complex health care needs are at risk for placement in nursing homes and other congregate care facilities unless there is adequate planning and support for their families. While permanency needs of children placed in the child welfare system are protected by federal legislation, no such protection exists in disability and health services.

Challenge: To articulate and implement a cross system policy that establishes and commits to the idea that children should grow up in families and that families need support to care for children.

Recommendation: Apply permanency policy in principle and practice to children with complex health care needs by providing support to birth families and alternate families for children who cannot live with their birth families so that all children can grow up in families instead of congregate facilities. Some states such as Michigan and Texas have applied permanency policy to children with disabilities and complex health care needs. These states have embraced a value system emphasizing the belief that children should grow up in families and that families need to be supported, and have articulated these values in policy and/or legislation. Some states have clearly defined policies regarding admission of children to congregate settings; in some, the doors are closed to such admissions, and in others such admission cannot take place without state level review.

Recommendation: Recruit and support alternate families for children who cannot live with their birth families. In states with permanency policies in their disability sectors, energy and resources are directed to the recruitment of shared parenting arrangements, foster care, and adoption so that when children cannot remain with their birth families, they can live with another family instead of a congregate setting.

Recommendation: Shift from a medical model that focuses on the health care needs of the child, to a family support model that focuses on the child's developmental need for family life and provides holistic support to families. States that have been successful in developing family support have embraced support that moves beyond the child-as-patient/case. Successful family support requires that children's developmental needs receive as much attention as their health care needs, and that families are recognized as integral to meeting developmental needs.

CONCLUSION

Findings from the various sources informing this study reveal significant challenges to assure family life for all children. Overall, the participants concurred that children with complex health care needs have a right to grow up in a growth-promoting family, with the relational security of well-supported parents, embedded in supportive communities and service system environments. Given that the most important developmental need of a child is the secure, emotional base of a loving, lasting family, it is essential that families with children who have complex health care needs be provided support. Families with children with complex health care needs have tremendous resilience and strength; at the same time, they are frequently exhausted, isolated, and financially strained. There was consensus that the current systems, including health, education, mental retardation, and child welfare, fall short of providing the desired and needed service system environment.

The findings indicate that there are many resources and innovative efforts in Pennsylvania and nationally to build upon. In working toward a more responsive system, families and young adults are underutilized resources. Family support planning, development, and delivery should be guided by the disability ethos, "Nothing about us without us." If families and young adults with complex health care needs are integrally involved in planning and designing services, there is increased likelihood that efforts will better address their issues. Families are motivated and energized by the strength and resilience of their children; the support of family and friends; and support from particular exceptional service providers. This positive energy and these examples of what is feasible lay the groundwork for solving the problems that hamper families and promoting approaches that facilitate families raising children with complex health care needs.

The participants had numerous suggestions and recommendations about how to build a more responsive system, emphasizing work in the areas of policy development; awareness and understanding of families' experiences; dissemination of knowledge and information; and, most importantly, ready access to individualized supports. The participants agreed that strategies for cross system involvement of families and stakeholders offered some of the best opportunities for learning and problem-solving to make the changes necessary to create "real life" supports that would more effectively promote family life for children with complex health care needs.

APPENDIX

CHAPTER I. INTRODUCTION

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CHAPTER II. LITERATURE REVIEW

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NOTE: The report provided here is based on a more in-depth literature review available by contacting nancy@everychildtexas.org or Every Child, Inc. at East Liberty Station, 6401 Penn Ave, Suite 300, Pittsburgh, PA 15206.

CHAPTER IX. PERMANENCY PLANNING

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