

ORDINARY LIVES, EXTRAORDINARY NEEDS:

Assuring Family Life For Children with Complex Health Care Needs



EXECUTIVE SUMMARY

ORDINARY LIVES, EXTRAORDINARY NEEDS: **Assuring Family Life For Children with Complex Health Care Needs**

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.

See the full document for the following in-depth material

I. INTRODUCTION

II. LITERATURE REVIEW

Nancy Rosenau

What Do Children With Complex Health Care Conditions Need?

What Do Families Need?

How Do Services, Supports, Resources, System Designs, and Funding

Mechanisms Facilitate or Hamper Family Life for Children

with Complex Health Care Needs?

Overall Summary

PERSONAL PERSPECTIVES

III. FAMILY PERSPECTIVES

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

Assuring Family Life: Family Experiences

Key Themes and Issues

Summary of Key Strategies and Factors that Facilitate Family Life

Conclusion: Key Challenges in Supporting Family Life and Their Impact

IV. DIRECT STAKEHOLDER PERSPECTIVES

Dianna Ploof

What Does It Take? Essential Supports

Family Characteristics that Facilitate Care at Home

Summary

V. INDIRECT STAKEHOLDER PERSPECTIVES

Liz Healey

Challenges to Family Life

Steps Toward Assuring Family Life for All Children

Conclusion

VI. RESEARCH TEAM PERSPECTIVES

Nancy Rosenau

Issues and Framework for Supporting Family Life

Description of Status of Current Services to Children And Families

Description of Vision of Desired Service System

Goals, Action Strategies, and Opportunities

POLICY PERSPECTIVES

VII. HEALTH POLICY REVIEW

David Gates

Health-Related Services Families Need

Barriers to Obtaining Needed Services and The Related Policy Issues

Conclusion

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

Nancy A. Hubley and Shari A. Mamas

Legal Context for Public Education Policy in Pennsylvania
Educating Students with Complex Health Care Needs – The Law
Current and Emerging Issues
Conclusion and Recommendations

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

Arlene Kanter and Lesley Owens-Pelton

The Development of Permanency Planning Policies in Federal Law
Relevant Federal and State Case Law
State Permanency Planning Statutes
Recommendations
Conclusion

PRACTICE PERSPECTIVES

X. CULTURAL COMPETENCE

Susan Davis

Culture and Services Use
Disparities in Healthcare, Health Delivery, and Family Supports
Strategies to Address Cultural and Linguistic Competence
Tools to Use to Develop Cultural and Linguistic Competence

XI. PROMISING PRACTICES

Bonnie Shoultz and Perri Harris

Exemplar Pennsylvania Programs
Exemplar Programs in Other States
Exemplars of State Systems
Summary of Program Level Promising Practices
Summary of State System Level Promising Practices

SUMMARY

XII. KEY FINDINGS, CHALLENGES, AND RECOMMENDATIONS

Pam Walker and Nancy Rosenau

Essential Services and Supports
What Facilitates Family Life
Makes Care at Home Difficult: Findings, Challenges, and Recommendations
Conclusion

APPENDIX

Chapter I. Introduction References
Chapter II. Literature Review References
Chapter IX. Permanency Planning References
Chapter X. Cultural Competence References