My child has a special health care need. What should I do?

If your child is between the ages of 0-3, and you believe that he/she may have a developmental delay or disability, contact the New Jersey Early Intervention System Point of Entry toll-free at 888-653-4463 or go to www.nj.gov/health/fhs/cries to find out how to get your child evaluated. You can get information about early intervention on the SPAN website at www.spanadvocacy.org/content/parent-training-information-pit-center.

If your child is between the ages of 3-21 (or 0-3 if they are not eligible for early intervention), contact the New Jersey Department of Health Special Child Health Services at 609-777-7778 for information on your county SCHS Case Management Unit, or find them at www.state.nj.us/health/fhs/sch/sccas-s.html.

Through the Early Hearing Detection & Intervention Services Project, the Statewide Parent Advocacy Network (SPAN) provides support for families of children with deafness and hearing loss. Support includes Parent-to-Parent Support (see brochure), referral to Special Child Health Services (SCHS) Case Management Units, linkages with a "Medical Home," and referral to other support agencies.

Across all of our health-related projects, SPAN works to improve New Jersey’s performance on the six core outcomes for CYSHCN: (1) families are engaged at all levels and satisfied with services; (2) there is early and continuous screening to identify special needs; (3) children have access to comprehensive and culturally-competent care within a "medical home" that coordinates all their health needs and services; (4) families can access community services easily; (5) families have adequate public and private insurance to pay for services; and (6) youth receive services needed for effective transition to adult systems of care.

What Family Wrap Does

The Statewide Parent Advocacy Network (SPAN) provides comprehensive and coordinated services and supports to families, including families of children with special needs. Family Wrap provides one-stop, "wrap around" services, information, resources and support to families, combining four SPAN programs: SPAN Family Resource Specialist/Project CARE, Parent to Parent, Family Voices, and the Family to Family Health Information Center.

Through these four components, Family Wrap addresses family needs for emotional support, information on and connection to resources, knowledge and skills about child- and family-serving systems and how to navigate and advocate within those systems, and leadership development to help other families and contribute to system improvements.

Family Resource Coordination/Project CARE

SPAN Family Resource Specialists are stationed part-time at county Special Child Health Services Case Management Units. They provide information and advocacy on family rights to participate in decision-making concerning their children’s health and education, and resources such as support groups and respite care. They help families prepare for IEP meetings, health care appointments, and hospital visits, and resolve conflicts with school and health staff.

Parent to Parent

Regional Associates (Northwest, Northeast, Central, and South) and Project CARE, County Coordinator, match families of children with special needs with trained "support parents." They also conduct orientations for parent groups and parents interested in becoming "support parents," to build skills in effective listening, active communication, parent empowerment strategies, and ways to provide culturally responsive support.

Family Voices

The Family Voices coordinator provides telephone assistance and resources on health care, health coverage, and effective health advocacy and informed decision-making including healthcare financing fact sheet series, a "GPS for Families," Health Advocacy Toolkit, fact sheets on preparing for and follow-up from a hospital stay, information on health care transition including a Health Passport, and many more health and mental health resources available at www.spanadvocacy.org/content/family-family-health-information-center-family-voices-SPAN. SPAN is also a member of the National Federation of Families for Children’s Mental Health (see www.ffcmh.org).

Family to Family Health Information Center

Two Regional Coordinators (North and Central/South) provide telephone and in-person information, training, technical assistance and advocacy for families of children with special healthcare needs related to the Healthy People 2020 six core outcomes for CYSHCN. County workshops on Health Advocacy, the Health and Education Rights of CYSHCN in the Child Welfare and Juvenile Justice Systems, and Transition to Adult Systems of Care, and an annual teleconference series archived on the SPAN website, are provided at no charge to families.

Contact Information

Patricia Paraskevacos, Director of Family Wrap

For assistance from a Family Resource Specialist:
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(973) 523-6778 x2421 Fax (973) 523-7715
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For information about New Jersey Statewide Parent to Parent:
Brenda L. Figueroa (English & Spanish), Statewide Coordinator
(800) 654-SPAN x119
bfigueroa@spannj.org

For information about statewide Family Voices:
Lauren Agorats (English & Spanish) New Jersey Coordinator
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For information about the Family to Family Health Information Center:
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Program Funders

New Jersey Department of Health, Special Child Health & Early Intervention Services

U.S. Department of Health and Human Services, HRSA Maternal and Child Health Bureau

U.S. Department of Education, Office of Special Education Programs

Collaborating Agencies

Statewide Parent Advocacy Network Family Voices-NJ at SPAN
NJ Department of Health

Revised October 2016
New Jersey Statewide Parent to Parent

Family Voices New Jersey (FV-NJ)

Family Voices-New Jersey works to "keep families at the center of children's healthcare," particularly for families of children and youth with special healthcare needs. Our Family Voices Coordinator informs families and professionals about public and private health care resources and how to access quality, family-centered, culturally competent healthcare. We share the expertise and experiences of families with policy makers, the media, health professionals, and other families. We serve on state and local boards and task forces, bringing the family perspective to policy discussions and decisions. FV-NJ is New Jersey's State Affiliate Organization of National Family Voices. (For more information on National Family Voices, go to www.familyvoices.org).

Family to Family Health Information Center (F2F HIC)
The Family to Family Health Information Center's Regional Coordinators provide information, training, support, technical assistance, advocacy, and leadership development for families of children and youth with special healthcare needs and the professionals who work with them. The F2F HIC is funded by the U.S. Department of Health and Human Services, and is a part of a national network of F2F HICS. (For more information, go to www.fv-ncp.org and www.nchc.hrsa.gov/programs/familytofamily/).

Ways Family Voices & the F2F HIC Can Help
- Providing information and assistance in securing health coverage and accessing quality primary and specialty health care, including mental health care.
- Helping families to appeal denials of health coverage for needed services.
- Working with families and health professionals to improve family-professional collaboration.
- Guiding families and professionals toward resources, programs and services.

New Jersey Statewide Parent to Parent

Parent to Parent is a statewide network of parents (mothers, fathers, and caregivers) supporting families of children with developmental delays, disabilities, mental health challenges, or other special health needs. As trained "support parents," we offer families assistance in learning the skills they need to face the challenges of raising their child and connect them to critical resources. Our Regional Parent to Parent Associates connect families to Support Parents and provide orientations to parents who are ready to help other parents through their journey. Our goal is to offer parents moral support and to encourage them to feel optimistic about the future. New Jersey Statewide Parent to Parent is New Jersey's affiliate of Parent to Parent USA. (For more information on Parent to Parent USA, go to www.p2pusa.org.)

Ways Parent to Parent Can Help
- One-to-one matches of families with similar needs and experiences.
- Emotional support for the parent of a child with a special health/mental health need, developmental delay, or disability.
- Current local, state and national resources for the child and family on a variety of disabilities and health issues.
- Training for parents who would like to become "support parents".
- Biannual newsletter (English & Spanish).
- Annual conference for fathers of children with special needs.

Our goal
Is to give families the skills and support they need to help their children with special needs reach their potential.

Our hope
Is for families to feel less isolated and more confident about themselves. All information is kept confidential.

Parent to Parent is funded by the New Jersey Department of Health in cooperation with: