

Health Advocacy Across the Lifespan

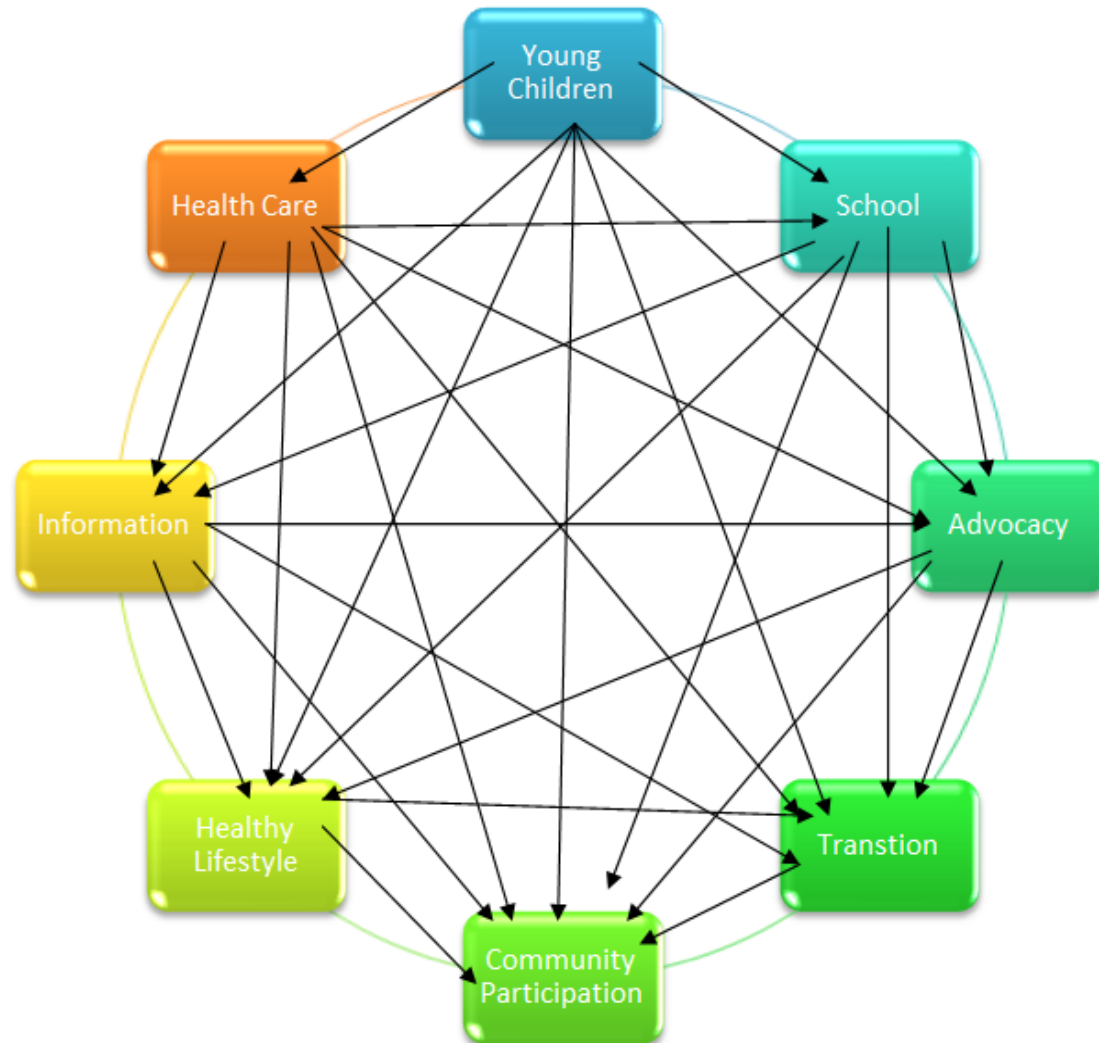
Part II: Partnerships, Advocacy, Appeals, & Resources

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*Statewide Parent
Advocacy Network*

A GPS for Families of Children, Youth and Adults with Disabilities & Special Healthcare Needs



How to use the Advocacy Manual

- Developed *by* families of and individuals with disabilities *for* families and individuals with disabilities & special healthcare needs
- Includes health advocacy information & tools from early childhood through adulthood
- Families and individuals with disabilities can review the entire manual or just those sections that are of interest to them

Welcome letter to families

I wrote this manual to help other families of children with special needs and the professionals who work with them. My daughter now has 5 life-threatening conditions, and autism just to keep things interesting. We have been through everything from early intervention to currently going through transition to adult care. I hope this helps you on your journey.

Lauren Agoratus

NJ Coordinator-Family Voices @ SPAN





- The Maternal & Child Health Bureau has identified six core outcomes for children and youth with special healthcare needs
- Each state including NJ must report on its performance on these six core outcomes every year as part of their MCH Block Grant application, & identify strategies to improve

MCH Core Outcomes for CYSHCN

- Families are engaged at all levels & satisfied with services
- Early & continuous screening to identify all special needs
- Access to a medical home to coordinate all needed care
- Adequate public & private health insurance & healthcare financing
- Access to community-based services organized for easy use
- Effective transition to adult healthcare & other services

6 Core Outcomes of DSCSHN's System of Services



Partnerships



*Partnering with
providers improves
health outcomes and
patient and provider
satisfaction*

Learn More about Partnering
with Providers

- Family-professional partnerships with:
 - Healthcare providers (primary care & specialists)
 - Health insurers
 - Other professionals

Family-Professional Partnership

- Families & health professionals work together in the best interests of the child/youth/young adult
- As the child grows, s/he becomes part of the partnership team
- Everyone respects the skills & expertise brought to the relationship by each partner



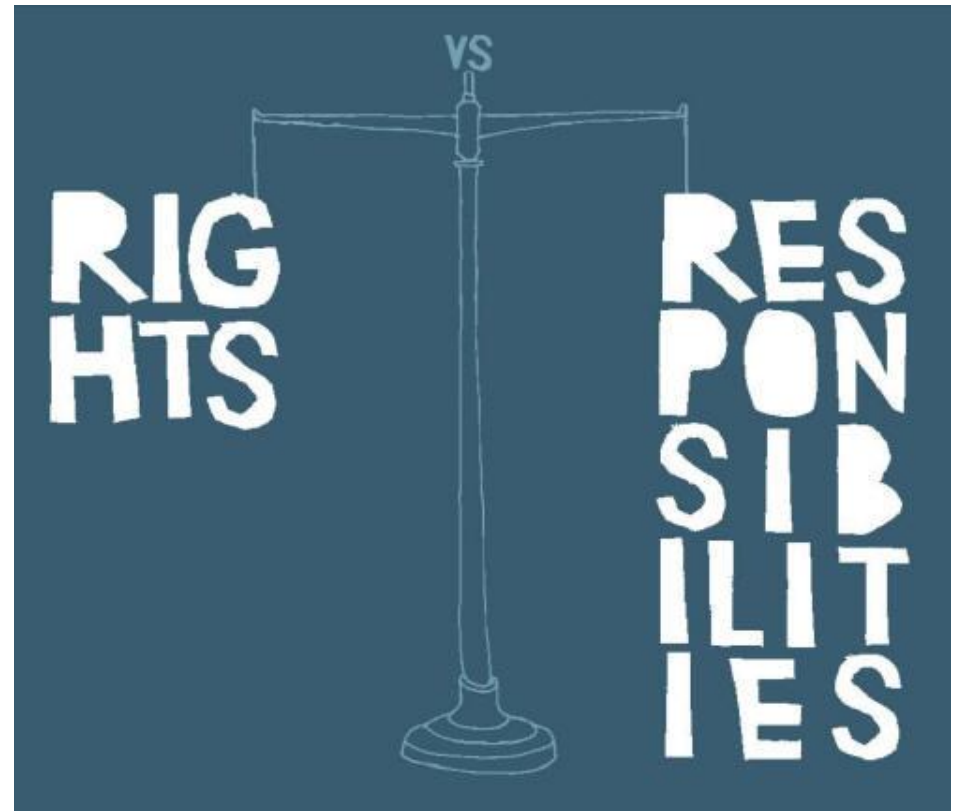
Why build relationships?

- With strong, trusting relationships, health providers really stand behind you, your child, and your family
- Good relationships with committed providers relieve you of some of the stress of coordinating all the services your child needs, and provide support for problem resolution



Understand your entitlements

- Read your member handbook to learn
 - your rights and responsibilities
 - which services are available to your child
 - which services require referrals or prior authorization
 - how *and where* to order medications and durable medical equipment
 - who to call with questions or complaints



It helps providers when you...



- treat them with the same **respect** you expect them to give you
- give them all the **info** they need to give your child the best care
- **honestly** express your concerns
- **listen actively**; take notes to help understand
- **ask** questions when you don't understand

How to ask questions

- Always keep a record of phone calls and correspondence. Make copies of everything!
- Keep a logbook next to your phone and record the date, name, position/title, and answer to your questions
- Use a care notebook
- Be persistent, but try to remain polite!



It helps providers when you...

- use resources wisely (e.g. use 24 hour hotline for urgent, not routine, questions)
- keep or reschedule appointments
- **thank** them when you like what they do



Expect your primary care provider to...



- See to your child's basic health needs
- Coordinate medical care, including routine, preventive, urgent, & specialty
- Make referrals (& standing referrals)
- Take care of prior authorizations
- Help with appeals or fair hearings

Expect yourself to...

- Keep your PCP informed of contacts with other provider visits, including emergency room visits
- Ask questions
- Follow health instructions



Getting a care manager

If you are enrolled in Medicaid Managed Care, you should call your care manager to get a basic care plan started soon after HMO enrollment.



Expect your care manager to...

- have experience with people with special needs
- probably be one of your best troubleshooting resources
- coordinate all your child's services & needs
- develop an IHCP with you and your child
- help with referrals & locating specialists



Medical Systems: Making them Work for You and Your Family!



Medical Appointments



Photo www.friendshipcircle.org

Families need to be organized to make the most out of doctor's appointments. From being prepared with questions, to coordinating specialists to avoid multiple visits, to the era of managed care where providers are rushed so families need to use time efficiently, there are many resources to address these issues.

Medical Decision-Making

Shared decision-making is one of the key concepts in healthcare. When patients partner with their health providers, they get better outcomes.



Photo www.aboutkidshealth.ca

Medical Decisions

- Parents need to decide if and when their children are capable of making medical decisions.
- The individual with disabilities should maximize their independence, including medical decisions.
- One of the most difficult decisions for parents of children with special needs is how much they need to be involved in medical decisions as their child grows older.



Self-Advocacy:
Know Yourself,
Know What You
Need, Know How
to Get It

Medical Home



The medical home isn't a place but the approach of having all of a child's medical care information together. This is especially important for children with complex needs.

Photo www.fmstudented.org

Partnerships lead to Medical home!

Your medical home is the **place** where you can take your child for all their health care needs. This includes:

- Checkups/well visits
- Sick visits
- Accidents
- Special health needs
- Immunizations (shots)

Your medical home is an **approach** that emphasizes partnership between families & providers. It includes:

- Preventive care
- Staff know you & your child
- Available 24/7
- Connection to specialty care
- Connection to community services



What should you look for in a medical home?



Medical Home

Family-Centered Care

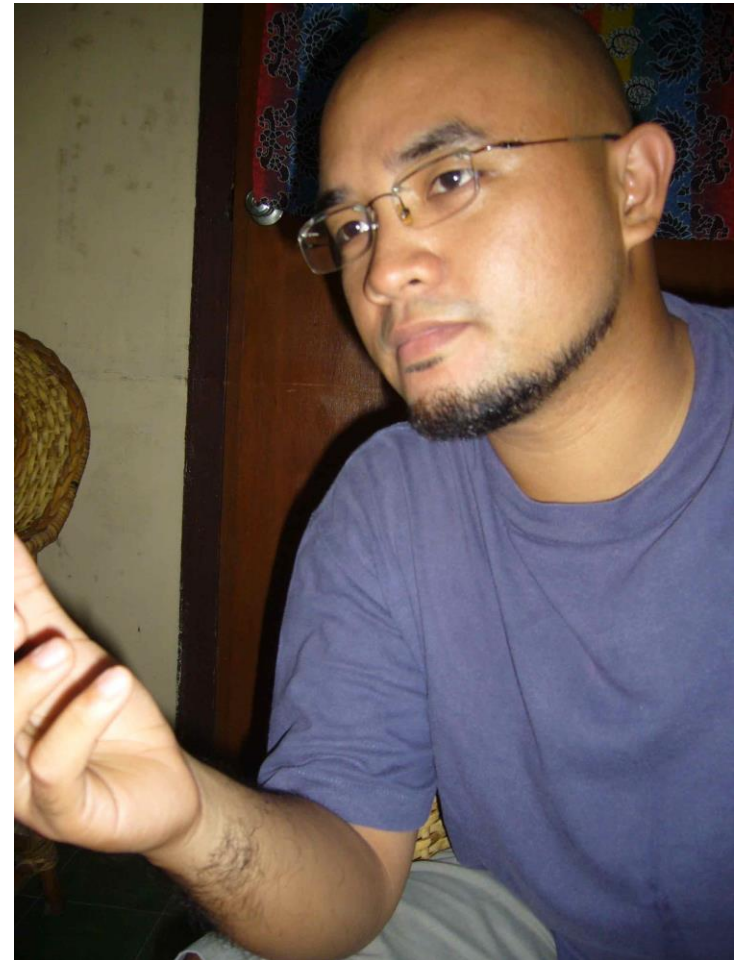
- Family-Centered Care Self-Assessment Tool

www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf



Effective Communication & Advocacy Skills

- Decide what you want to achieve
- Prioritize what you want
- Explain to others what you want and why: the reasons behind what you are asking for (your interests)
- Express yourself without being rude or aggressive
- Understand others' perspectives & points of view



When You Disagree



- Maintain respect
- Find out the policy & procedures to resolve disagreements
- Use discretion about when & where disagreements - or the people you disagree with - are discussed
- Talk directly with those involved first
- Check the facts

When you disagree



- If you have a problem with:
 - A provider, talk to your care manager or PCP
 - Your care manager or your PCP, call your plan's member services

Resolving Disputes

- If you can't prevent or immediately resolve a problem to your satisfaction, call member services and make a complaint. Be specific.
- If member services can't solve the problem in 24 hours, you may register a grievance with your plan by phone or letter (procedure in member handbook)



Appeals



- HMOs must notify you in writing before they deny or limit covered services.
- You may file an appeal of the denial with the HMO.
- Sometimes appeals are resolved easily, but the process can become complicated, so you may want to turn to your care manager, DRNJ (Protection & Advocacy), or Legal Services

Appeals

- Internal (within insurance plan):
two stages
 - With plan's medical director or MD who denied services
 - With physicians not involved in 1st internal appeal who might care for children like yours
- External (if internal gives unsatisfactory results)
 - To appropriate entity within your state who deals with health appeals



Appeals



- At each stage, if the plan continues to deny services, it must inform you in writing within a specified time, giving you
 - reasons for denial and
 - how to proceed to the next appeals stage
- At any time during the appeals process, Medicaid recipients may request a Medicaid Fair Hearing.
- Ask for an immediate review in any urgent situation!
- Keep good records of all interactions.

Advocacy

Being an advocate for your child means doing what is necessary to make sure your child gets what he or she needs and that your family gets what it needs to care for your child.





Advocacy

Photo-sicklecellbodypolitics.wordpress.com

Along with exercising civil rights to access healthcare, families may need to advocate both for their child as well as themselves, for example for family support services to help maintain the child at home. Family Support Services range from home or vehicle modification to respite, which is a break for family caregivers from what could be 24 hour care. A good overview is “Health Care Advocacy Across the Lifespan” at

http://www.hinkle1.com/pdf/FV_HC_Book_web.pdf

Your child and advocacy

- Help your child become a self-advocate at whatever developmental level she's at; don't always speak for her. Let her do it herself if she can.
- Other than your child, you know your child best and are his best advocate; don't be afraid to speak up for him.



Self-advocacy



Photo-autisticadvocacy.tumblr.com

In addition to advocacy by families, children with special needs will need to learn how to advocate for themselves. Some tools are:

- Wyoming Council on Developmental Disabilities coloring book for children <http://ddcouncil.state.wy.us/KidsCRSpring12.pdf>
- For older children, “It’s My Future” is available at http://ngsd.org/sites/default/files/its_my_future.pdf or “My Health, My Choice, My Responsibility” <http://www.ablelinktech.com/myhealth/> (both have iPad apps)
- “This is Your Life! Creating Your Self-Directed Plan” which also includes mental health and is available at <http://www.cmhsrp.uic.edu/download/sdlifeplan.pdf>

Remember: Keep the end in mind!
Get your child what s/he needs today to lead to
a successful transition to adulthood tomorrow!



From diagnosis to transition



Starting with Screening

- Families often have concerns about their child's development
- Screening should routinely be done by:
 - Primary care providers
 - Early childhood providers
 - Home visitation programs
- Screening should be done using standardized tools recommended by AAP on a periodic schedule
- Screening is reimbursable under Medicaid, SCHIP, & Affordable Care Act (ACA) (see Health Insurance)



Screening Resources

Parents can find checklists on screening and information on how to talk to their doctor at:

- Act Early at <http://www.cdc.gov/NCBDDD/actearly/milestones/index.html>.
- “What to Expect & When to Seek Help” <http://www.brightfutures.org/tools/>
- American Academy of Pediatrics screening recommendations <http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Description-and-Policy.aspx>
- First Signs tips on discussing with the pediatrician <http://www.firstsigns.org/concerns/if.htm>.



Let's start at the beginning...diagnosis

Where can families find information on their child's special needs?



Photo www.cdc.gov

A resource guide which lists all the national organizations for specific conditions is Exceptional Parent at www.eparent.com.

The Maternal & Child Health Bureau (MCHB) has “Knowledge Paths” on some conditions at <http://www.mchlibrary.info/KnowledgePaths/index.html> and resources for families at www.mchlibrary.info/families/index.html.

The Parent Center Hub has information on specific disabilities at <http://www.parentcenterhub.org/repository/specific-disabilities/> or Spanish <http://www.parentcenterhub.org/repository/aprendizaje/>.

How to explain the diagnosis to your child

Families will know when their child is ready to find out about their diagnosis when they start asking questions. Here are some places to begin.

Kids Health <http://kidshealth.org/parent/medical/>

For older children: “Accepting My Disability”
<http://www.going-to-college.org/myplace/disability.html>

You have a diagnosis-now what?

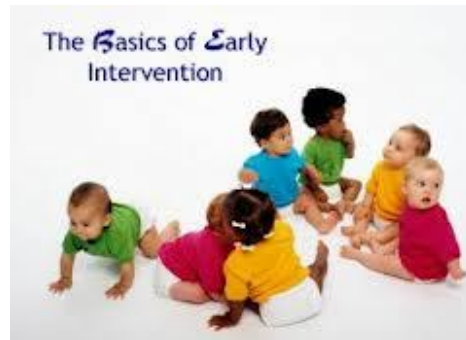


Photo-NICHCY.org

Families of children from birth to three can get help from the NJ Early Intervention System to help their child reach their best potential.

- ❖ NJEIS <http://www.state.nj.us/health/fhs/eis/index.shtml>
- ❖ Regional Early Intervention Collaboratives <http://www.njeis.org/>
- ❖ Parent Center Hub-early intervention overview <http://www.parentcenterhub.org/?s=early+intervention>

Another consideration-genetics



Photo-teachersnetwork.org

There are many good resources available and families may feel as if their child's symptoms finally "have a name." These are:

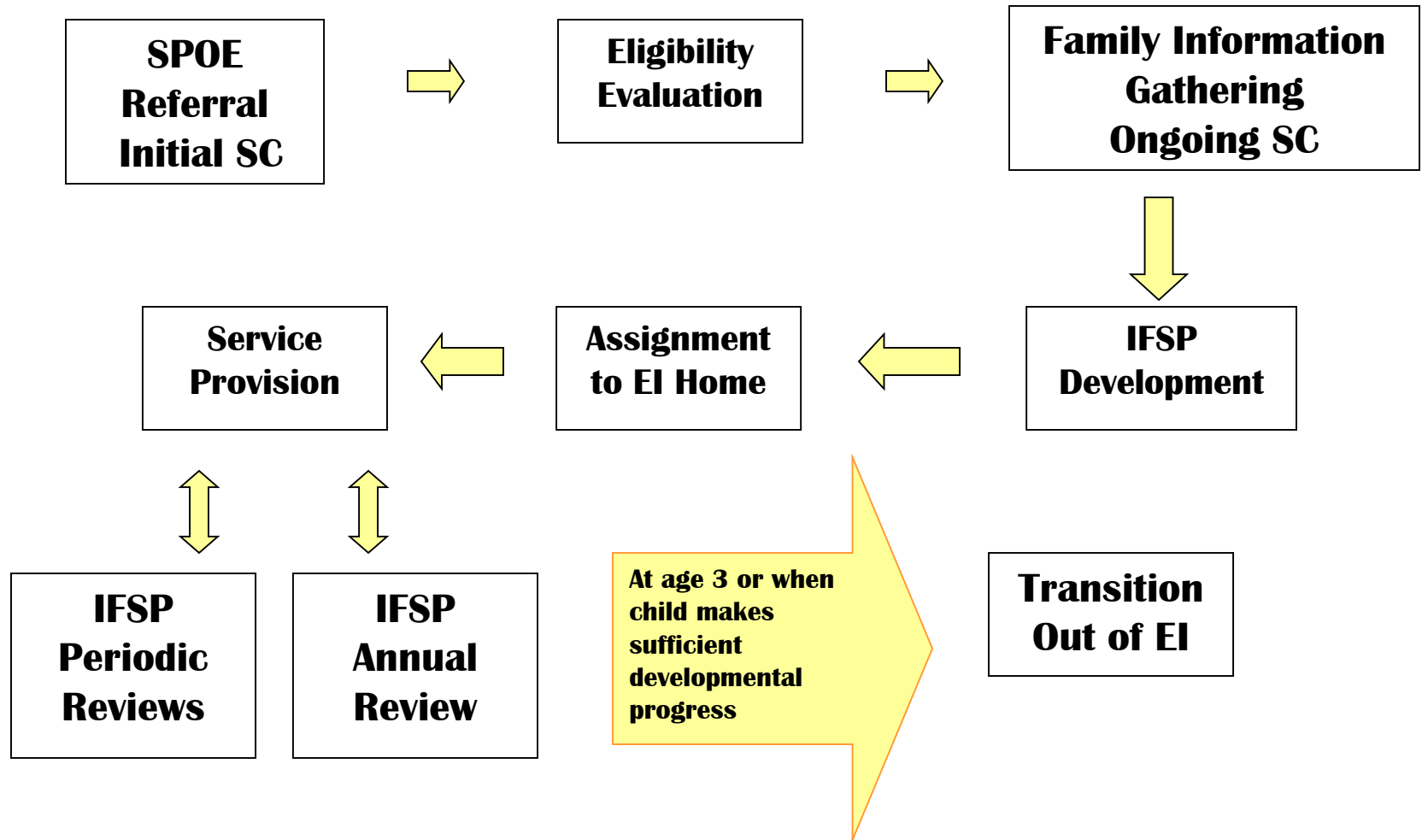
- Genes in Life explains the basics of what genetics means for families at <http://genesinlife.org/genetics-101/why-learn-about-genetics>
- "Children and Youth with Special Healthcare Needs in Healthy People 2020: A Consumer Perspective" at <http://www.geneticalliance.org/publications/healthypeople>

Early Intervention

- For infants & toddlers 0-3 years old with disabilities & developmental delays
- Required under the Individuals with Disabilities Education Act (IDEA)
- Administered by the NJ Department of Health Division of Family Health Services-Special Child Health & Early Intervention Services-EI System
- Call 888-653-4463 (single point of entry) to refer
- Parent consent for evaluation, IFSP implementation, sharing family/child information
- Evaluation, eligibility determination, development & implementation of Individualized Family Services Plan (IFSP) completed within 45 days from referral
- No cost to families:
 - Child find
 - Service coordination
 - Evaluation, eligibility, IFSP development & transition
 - Procedural safeguards
- Sliding fee scale for services (no cost up to 300% of FPL)



Early Intervention Flow for Families of Eligible Children



Who is Eligible for EI Services?

In NJ Jersey, infants & toddlers who have a 33% delay in 1 or a 25% delay in 2 of the following developmental areas:

- Gross motor skills – crawling, walking, jumping
- Fine motor skills – using hands to play or eat
- Communication – speech and language
- Sensory – vision and hearing
- Cognitive – thinking and learning
- Social or Emotional – interaction with others and the environment
- Adaptive – self-help skills, i.e. eating, dressing



Presumptive Diagnoses

Children diagnosed with the following are automatically eligible to enter the EI system even if not yet showing a developmental delay:

- Down Syndrome
- Fetal Alcohol Syndrome
- Hearing Impairment
- Vision Impairment
- Autism/ PDD
- Spina Bifida
- Cerebral Palsy
- Trisomy 13, 18, etc.
- Fragile X
- Hydrocephalus
- Other physical or mental diagnoses with signed statement from a physician indicating the diagnosis typically results in developmental delay such as genetic disorders, congenital abnormalities, etc.

Service Coordination

- Service Coordinator assigned, completes referral process
- SC coordinates evaluation/assessment, eligibility
- SC assists in identifying service providers
- SC coordinates IFSP implementation
- SC provides info about resources
- SC facilitates annual IFSP review
- SC facilitates transition meeting



Some Types of Early Intervention Services

- Developmental Intervention
- Occupational Therapy
- Speech-Language Therapy
- Physical Therapy
- Family Training & Counseling
- Assistive Technology Devices & Services
- Social Work Services
- Audiology
- Health Services
- Nursing Services
- Social Work
- Service Coordination

Transition from EI

- The child and family will exit from Early Intervention into new activities in the community and possibly new education services and programs through the local school district.
- The service coordinator will work with the family to develop a transition plan.
- A child may Transition because:
 - Child turns age 3**
 - Child has progressed and no longer meets the eligibility criteria for Early Intervention
 - Move within the state or to another state

** Family Support Coordinators conduct detailed workshops on the topic of Transition to Preschool

Resolving Disputes

- Discuss with service provider(s)
- Discuss with service coordinator
- Discuss with Family Support staff at Regional Early Intervention Collaborative
- Discuss with EI Procedural Safeguards Coordinator
- Request mediation, complaint investigation, &/or due process (877-258-6585)

Who will provide childcare?

Another concern for families of children with special needs is finding someone to care for their child when they work during the day or before or after school. Families need to know that the child care provider can accommodate their child.

- Americans with Disabilities Act (ADA) requires child care providers to provide reasonable accommodations
 - Physical accessibility
 - Modification of activities
 - Provision of services such as toileting
 - Administration of medication
- Families may advocate for EI and/or preschool special education providers to collaborate with child care providers to provide services in the early childhood setting



Inclusive Child Care Resources

- Inclusive Child Care Project

<http://www.spanadvocacy.org/content/inclusive-child-care-project>

- Map to Inclusive Child Care Team

<http://www.state.nj.us/humanservices/clients/family/special>

- Add an Individual Health Plan to an IEP/504 plan which could include afterschool care

http://www.spannj.org/Family2Family/individual_health_plan.htm

- NJ Law Against Discrimination

http://www.state.nj.us/humanservices/clients/family/special/10_Child_Care_NJLawAgainstDiscrimination_columns%20.pdf

Other Accessibility Issues

Accessibility can include everything from getting into the door to being able to get on the exam table. Access also includes interpreters if needed. Resources on accessibility are:

- ❑ “Access to Medical Care for Individuals with Mobility Disabilities”

http://www.ada.gov/medcare_mobility_ta/medcare_ta.pdf

- ❑ “Healthcare Accessibility Toolkit”

http://www.equalrightscenter.org/site/DocServer/Accessible_Healthcare_toolkit.pdf?docID=2181



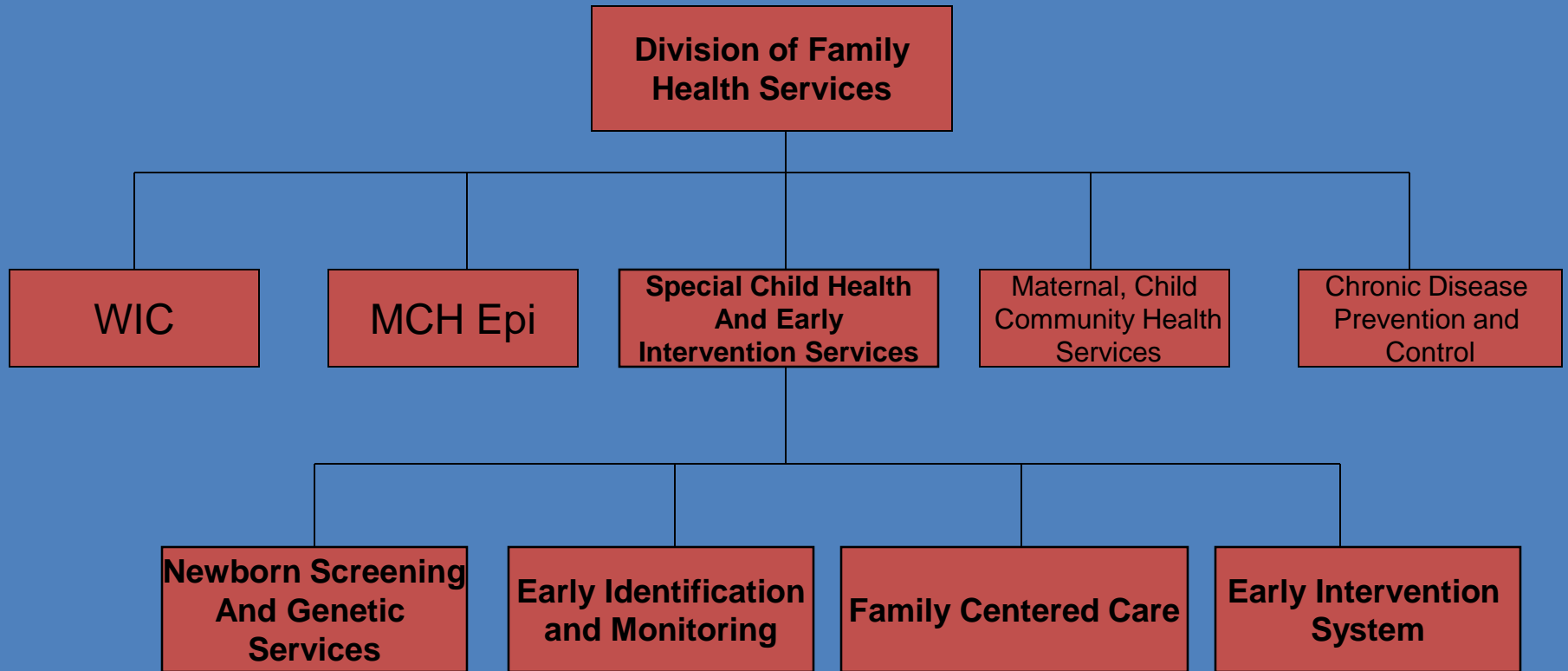
Title V

According to the MCHB, Title V “as a Federal-State partnership,... acknowledges the uniqueness of each State and...maternal and child health program and the differing needs of their individual populations.”

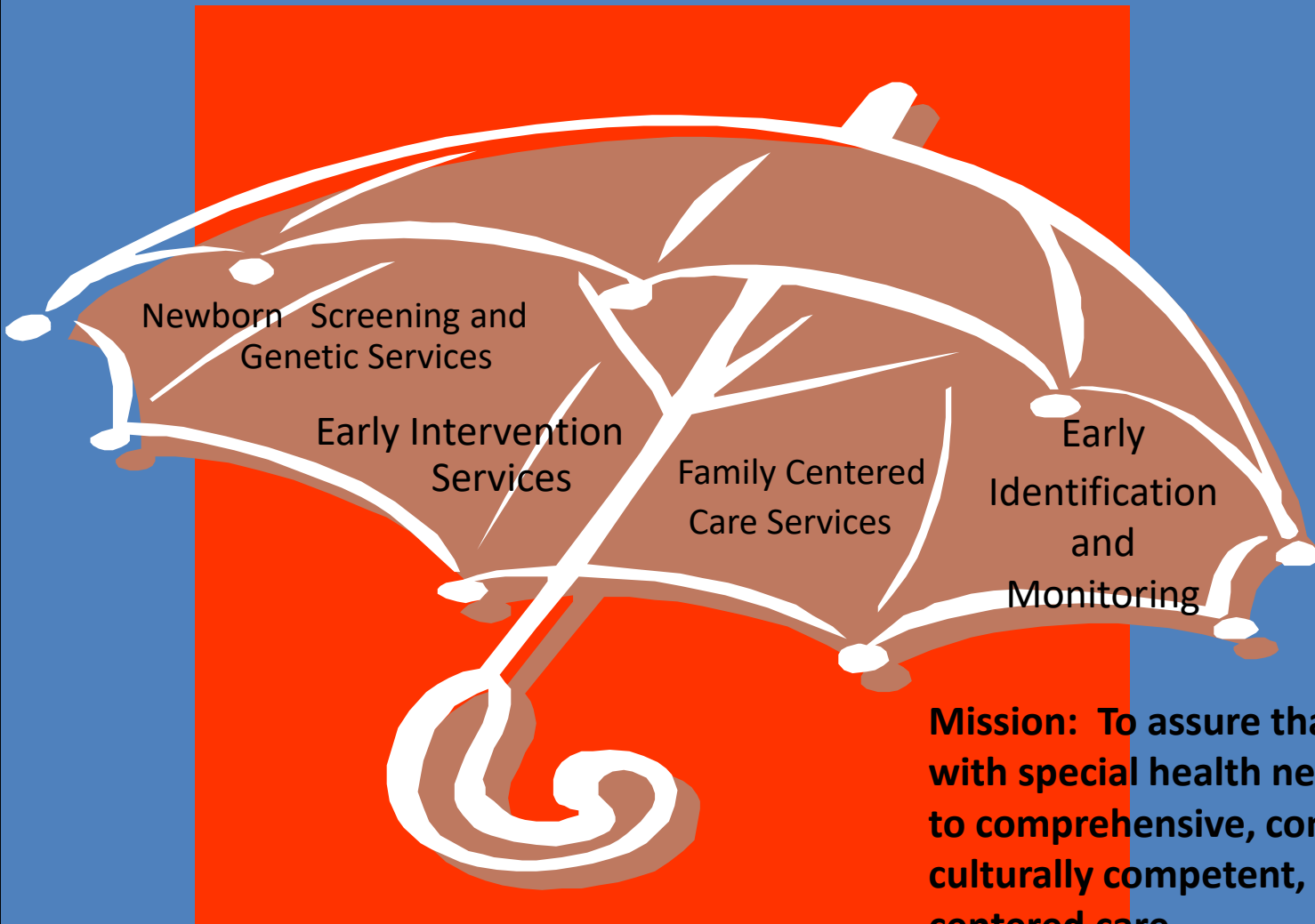


Photo www.mchb.hrsa.gov

Special Child Health and Early Intervention Services



Special Child Health and Early Intervention Services



Mission: To assure that all children with special health needs have access to comprehensive, community based, culturally competent, and family centered care.

Special Child Health and Early Intervention Services

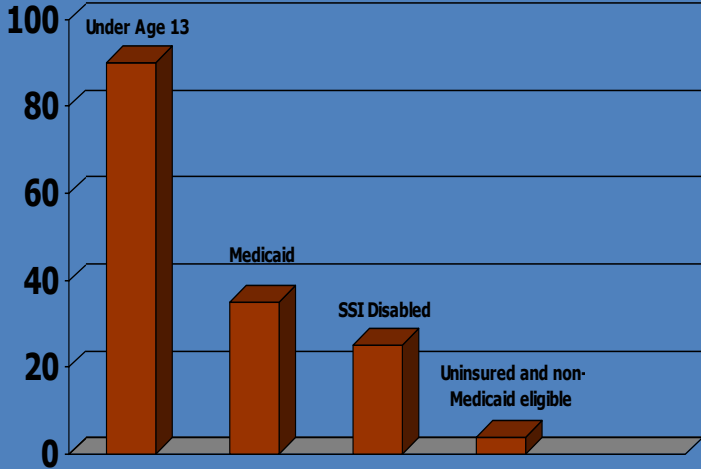
Family Centered Care Services

MISSION

Assist children age birth to 21 years to access comprehensive family centered culturally competent care, and serve as a point of entry for Early Intervention System.

- Case Management
- Child Evaluation Centers/
Tertiary and Cleft Lip/ Palate Services
- Ryan White Part D

Client Statistics



STATISTICS:
90% are under age 13 years
37% Medicaid
26% SSI Disabled
3% Uninsured and non-Medicaid eligible

SCHS Case Management

Focus – Children with special needs, birth to age 21

- Primary care provider and/or other health and social service providers contacted to coordinate services
- Referrals made for identified needs
- Individual Service Plans developed
- Help families to advocate through various agencies

Programs, Services, and Supports

Information and referral to State, Federal, and charitable programs, examples include

- Early Intervention Services
- Child Evaluation Centers
- Family Centered HIV Care Network
- Catastrophic Illness in Children Relief Fund program
- NJ FamilyCare
- Division of Developmental Disabilities
- Division of Medical Assistance and Health Services Medicaid and/or Waiver programs
- Health resources
- Social Security
- SPAN, Elks, Lions, etc....



Case Management

Linkage with Birth Defects & Autism Registry (BDARS)

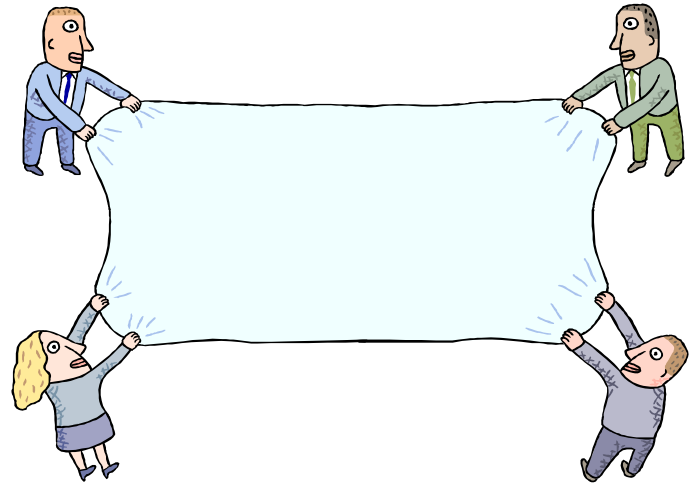
- SCHS Registry refers children to case management within 10 days of receipt of registration
- > 90% of case load referred by the SCHS Registry
- Families are contacted within 7 days of referral

Focus

- Primary care provider, specialty care, & other involved professionals contacted in order to coordinate services
- Referrals made for identified needs
- Individual Service Plans developed
- Help families to advocate through various agencies

Specialized Pediatric Services Centers of Excellence

- Child Evaluation Centers
- FASD Centers
- Newborn Hearing
Follow-Up
- Craniofacial Centers
- Tertiary Care Centers



Specialized Pediatric Services

Child Evaluation Centers, Tertiary & Cleft Lip/Palate Services

10 Child Evaluation Centers; Cooper University Hospital, Jersey City Medical Center, Jersey Shore University Medical Center, John F. Kennedy Medical Center, St. Joseph's Children's Hospital, Morristown Memorial Hospital, Children's Seashore House of the Children's Hospital of Philadelphia, Children's Hospital of New Jersey at Newark Beth Israel, Children's Specialized Hospital, UMDNJ New Jersey/New Jersey Medical School

3 Tertiary Centers; Cooper University Hospital, The Children's Hospital at Newark Beth Israel, UMDNJ/Robert Wood Johnson Medical School Children's Health Institute of New Jersey (CHINJ)

5 Cleft Lip/Palate Craniofacial Centers; Cooper University Hospital, Monmouth Medical Center, St. Barnabas Ambulatory Care Center, St. Peter's University Hospital, St. Joseph's Regional Medical Center

Child Evaluation Centers

Ten hospital based grantees serve clients in all 21 counties.

- Jersey Shore Medical Center
- Children's Seashore House (CHOP)
- Children's Hospital of New Jersey at Newark Beth Israel
- UMDNJ/NJ Medical School
- Children's Specialized Hospital
- Cooper Hospital/University Medical Center
- Jersey City Medical Center
- John F. Kennedy Medical Center
- St. Joseph's Children's Hospital
- Morristown Memorial Hospital



FASD Diagnostic Centers

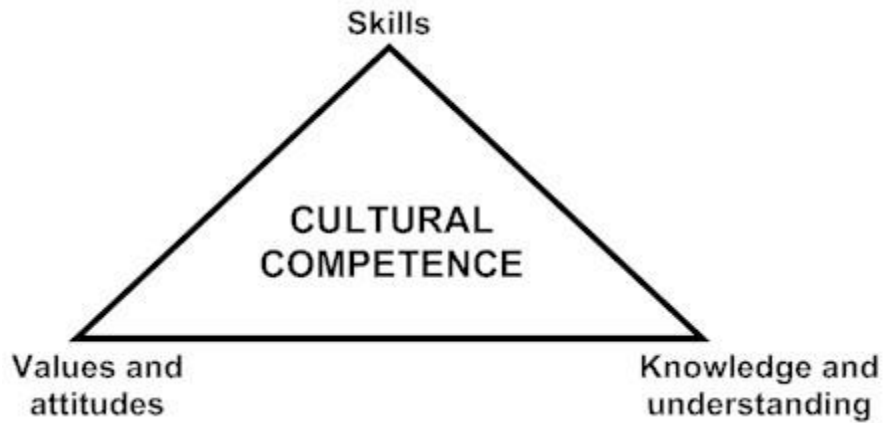


- Jersey Shore Medical Center
- Children's Seashore House (CHOP)
- Children's Hospital of New Jersey at Newark Beth Israel
- UMDNJ/NJ Medical School
- Children's Specialized Hospital

Contact Information

<p>Birth Defects and Autism Registry Mary Knapp, Coordinator 609-292-5676 mary.knapp@doh.state.nj.us</p>	<p>NJ Ryan White Part D Program Jane Caruso, Project Director 609-777-7748 jane.caruso@doh.state.nj.us Web site: http://www.state.nj.us/health/fhs/hivcare/index.shtml</p>
<p>Family Centered Care Services Pauline Lisciotti, Program Manager 609-777-7778 pauline.lisciotti@doh.state.nj.us</p>	<p>New Jersey Early Intervention System Terry Harrison, Part C Coordinator 609-777-7734 terry.harrison@doh.state.nj.us http://www.state.nj.us/health/fhs/eis.shtml</p>
<p>Special Child Health Services – Case Management Bonnie Teman, Coordinator 609-777-7778 bonnie.teman@doh.state.nj.us Suzanne Canuso, RN, MSN 609-777-7778 suzanne.canuso@doh.state.nj.us Felicia Walton 609-777-7778 felicia.walton@doh.state.nj.us</p>	<p>Specialized Pediatric Services Program Jo-Ann Ayres, Coordinator 609-777-7778 joann.ayres@doh.state.nj.us Suzanne Canuso, RN, MSN 609-777-7778 suzanne.canuso@doh.state.nj.us Web sites: http://www.state.nj.us/health/fhs/sch/cec.shtml http://www.state.nj.us/health/fhs/sch/scclft.shtml http://www.state.nj.us/health/fhs/sch/scpats.shtml</p>

Other Critical Issues





Cultural Competence

Photo-mocmh.org

All children and adults with disabilities and special healthcare needs deserve to have healthcare access in a culturally competent manner. NJ was the 1st state to require cultural competency training for providers and has a listserv.

- cultural competency helps eliminate health disparities (see <http://www.spanadvocacy.org/content/unfair-access-healthcare-affects-our-families-lauren-agoratus>)
- Family Voices national has “Diversity & Cultural Competence” at <http://www.familyvoices.org/work/diversity>
- The National Center Cultural Competence has “In Their Own Voices: Cultural Competence and Health Promotion” at <http://nccc.georgetown.edu/features/voices.html>.
- NJ Statewide Network for Cultural Competence (see <http://www.state.nj.us/njsncc/> and <https://www.facebook.com/NJStatewideNetwork>)

Immigrant Issues



Photo-ijpc-cincinnati.org

Closely related to cultural competency are issues affecting immigrant families.

- Immigrant families may be eligible for health care coverage (see <https://www.healthcare.gov/what-do-immigrant-families-need-to-know/>)
- See details on how immigrant status affects eligibility for health plans in the Marketplace at <http://www.fv-ncfpp.org/blog/how-immigrant-status-affects-eligibility-health-plans-marketplace/>
- The National Immigration Law Center has an excellent “Quick Guide to Immigrant Eligibility for ACA (and other national programs)” at http://www.spanadvocacy.org/sites/g/files/g524681/f/files/imm-eligibility-quickguide-2013-01-29_0.pdf.



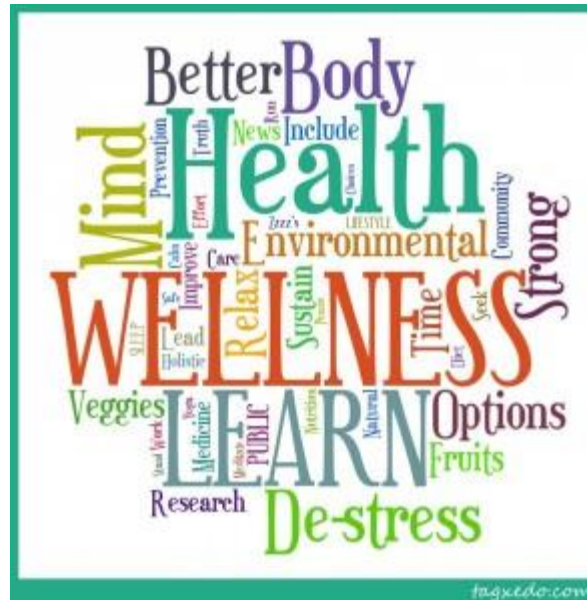
Stigma

Photo-peaceproject.com

Besides cultural competency, there must be no stigma for physical and mental health conditions. People first language means the person comes first, then the description. A variety of resources are listed below:

- Disability Etiquette <http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>
- People First Language- Disability is Natural
<http://www.disabilityisnatural.com/images/PDF/pfl09.pdf>
- Those of Us DisLabeled <http://www.hdi.uky.edu/Media/Default/Documents/DisLabeled.pdf>
- People First Language
http://www.sabeusa.org/user_storage/File/sabeusa/People%2520First%2520Language%2520Manual.pdf
- Stigma: Language Matters
<http://www.onourownmd.org/wp-content/uploads/2011/12/LM-Flyer-Artwork207.pdf>

Wellness, Health Promotion, & Prevention: Important for *All* Children & Adults!



Wellness & Prevention

- Care for CSHCN must include:
 - Well-child care
 - Preventive care
 - Health promotion
 - Coordination of health care services related to special healthcare needs





Dental care

Photo Vanderbilt Kennedy Center

Dental care is an important component of health care. Oral health can adversely affect physical health.

- Families can find out if dental benefits are included in their medical plan at <https://www.healthcare.gov/find-premium-estimates/>. Parents can also get information on available stand-alone dental plans at <https://www.healthcare.gov/dental-plan-information/>.
- Medicaid also has dental coverage.
- If your child is uninsured, Donated Dental Services provides free care and can be found at <http://nfdh.org/donated-dental-services-dds/state-dds-programs/new-jersey/>. If your child needs braces, Smile for a Lifetime has free orthodontics at <http://slf.memberclicks.net/zip-code-search>.

Dental care & CSHCN

Dental health could also be affected by special needs. This could be due to the child's poor motor skills or sensitivity to touch. Special needs resources are:

- “Oral Health Tips” at http://kc.vanderbilt.edu/kennedy_files/OralHealthTips.pdf.
- “Dental Tool Kit” at <http://www.autismspeaks.org/family-services/tool-kits/dental-tool-kit>.

Emergency care preparedness



Photo www.nhpediatricems.org

Families of children with disabilities need to be prepared in an emergency. There are things parents can do ahead of time that will make it easier. Some tips are available:

- “Emergency Information for children with special needs” at <http://www.acep.org/content.aspx?LinkIdentifier=id&id=26276&fid=896&Mo=No>
- “To Go” Kit http://www.nhfv.org/files/To_Go_Kit_brochure.pdf

Emergency Preparedness

Hopefully information on natural disasters won't be needed but it's better to know what to do.

- The child could wear a medical id bracelet (caregivers can too)
- Parents can also carry a paper copy of essential information in their wallets
- Good sample forms: universal health record <http://www.state.nj.us/health/forms/ch-14.pdf> and the care plan for children with special needs <http://www.state.nj.us/health/forms/ch-15.pdf>

Emergency Preparedness

- Sign up for the NJ Special Needs Registry at <https://www13.state.nj.us/SpecialNeeds/>
- Register with the county Office of Emergency Management at <http://www.ready.nj.gov/about/association.html>
- Consider an emergency generator if the child has equipment or refrigerated medicine.



Photo www.gahcd.org

Hearing Issues

Hearing, dental, and vision care are important components of overall health for growing children. Hearing issues that aren't discovered quickly could be misinterpreted as behavioral, affecting speech and development. Resources for families include:

- ❖ Early Hearing Detection & Intervention program information for families
<http://www.state.nj.us/health/fhs/ehdi/parentinfo.shtml>
- ❖ “Opening Doors: Technology and Communication Options for Children with Hearing Loss”
http://www2.ed.gov/about/offices/list/osers/products/opening_doors/index.html

Nutrition



Photo www.abilitiesexpo.com

According to the Centers for Disease Control (CDC), 18% of children and 21% of teen are obese (not just overweight.) Obesity causes children to get “adult” diseases like diabetes, high blood pressure, high cholesterol etc.



Photo www.mychildwithoutlimits.org

Physical Activity

Closely related to nutrition and obesity prevention is physical activity. There are resources on wellness and prevention from Bright Futures, endorsed by the American Academy of Pediatrics.

Physical Activity

The U.S. Department of Health and Human Services has special guide on physical activities for girls at <http://www.girlshealth.gov/fitness/index.html>.

“Body & Mind: Physical Activity “ is found at <http://www.cdc.gov/bam/activity/index.html>.

“14 Weeks to a Healthier You” is found at <http://www.ncpad.org/14weeks/>.

Parents' Role

- Support healthy eating behaviors
- Facilitate regular physical activity
- Reduce sedentary activity
 - Watching television & videos
 - Playing computer games



Tips for Parents

- Focus on good health, not a certain weight goal
- Teach and model healthy and positive attitudes toward food and physical activity without emphasizing body weight.



Tips for Parents



- Focus on the family.
- Do not set overweight children apart.
- Involve the whole family and work to gradually change the family's physical activity and eating habits.

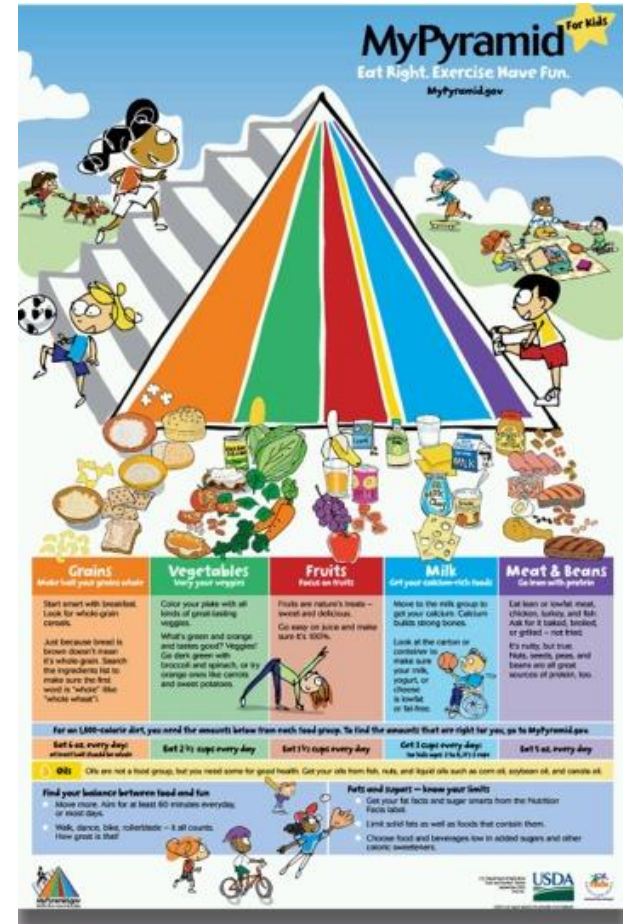
Family meals



- Establish daily meal and snack times, and eat together as frequently as possible.
- Make a wide variety of healthful foods available based on the Food Guide Pyramid for Young Children.
- Determine what food is offered and when, and let the child decide whether and how much to eat.

Food Guide Pyramid

- Plan sensible portions. Use the Food Guide Pyramid for Young Children as a guide.
- Don't make changes to a child's diet based solely on perceptions of overweight



Teach children



- Involve children in planning, shopping, and preparing meals.
- Use these activities to understand children's food preferences, teach children about nutrition, and encourage them to try a wide variety of foods.

Healthy shopping

- Buy fewer high-calorie, low-nutrient foods.
- Help children understand that sweets and high-fat treats (such as candy, cookies, or cake) are not everyday foods.
- Don't deprive children of occasional treats. This can make them more likely to overeat.



Snacking



- Make the most of snacks. Continuous snacking may lead to overeating.
- Plan healthy snacks at specific times.
- Include two food groups, for example, apple wedges and whole grain crackers.

Snacking



- Focus on maximum nutrition - fruits, vegetables, grains, low-sugar cereals, low-fat dairy products, and lean meats and meat alternatives.
- Avoid excessive amounts of fruit juices, which contains calories, but fewer nutrients than the fruits they come from

Screen Time

- Limit the amount of time children watch television, play video games, and work on the computer to 1-2 hrs./day.
- Keep TVs out of the bedroom!
- Reducing sedentary activities helps increase physical activity.



Eating & TV watching



- Discourage eating meals or snacks while watching TV.
- Eating in front of the TV may make it difficult to pay attention to feelings of fullness and may lead to overeating.

Physical activity



- Encourage physical activity.
- Participate in family physical activity time on a regular basis, such as walks, bike rides, hikes, and active games.
- Support your children's organized physical activities.
- Provide a safe, accessible place outside for play.

Help your children re: obesity



- Discuss your daily activities and time spent with your children
- Brainstorm ideas about how to use available time, current family routines, & resources, to increase exercise, reduce screen time, & eat healthier

Help your children re: obesity



- Identify local sources of healthy food & try to figure out how to access those sources
- Get connected to sources of healthy, “fast,” culturally relevant recipes
- Brainstorm how to cook healthy with limited time

Sexuality



Photo www.butterflywheel.com

Parents need to remember that children with disabilities have the same feelings as everyone else. Even if the child has delays, they may just act younger than their age and maybe catch up later. Some children may need help in understanding what is happening as they grow up.



Photo www.mybergen.com

Vaccine Preventable Disease

Families need to make sure that their children do not get illnesses that could be prevented by vaccines.

The AAP list of recommended immunizations is found at <http://www2.aap.org/immunization/izschedule.html>. There is also a family page, including making educated decisions on vaccines and safety, at <http://www2.aap.org/immunization/families/families.html>.

Vision Care



Photo www.downsyndromedaily.com

Vision care is an essential component for overall health. Children with poor eyesight may experience headaches, or miss out academically in school.

In NJ, the Commission for the Blind & Visually Impaired does free screenings and also works with schools on IEPs for low vision tools like slantboards etc.

An overview is found at

<http://www.state.nj.us/humanservices/cbvi/services/prevention/screening/>

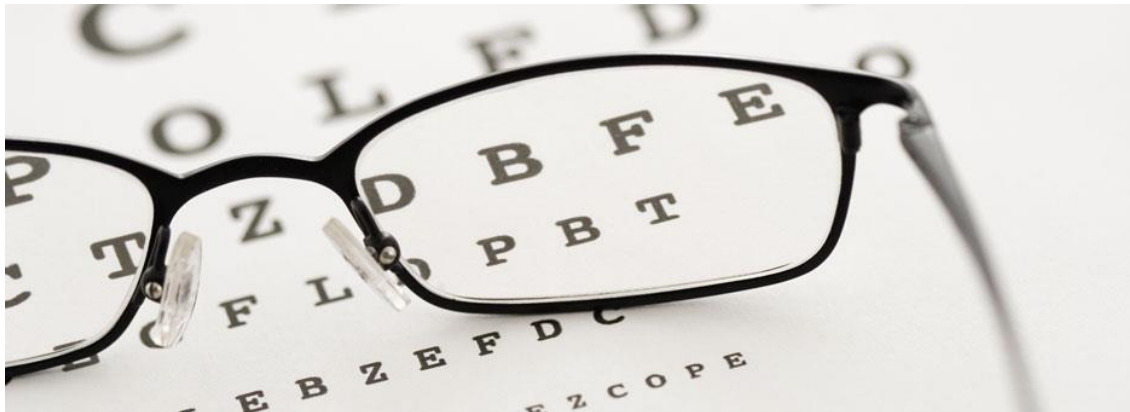
More information about services for children is available at

<http://www.state.nj.us/humanservices/cbvi/services/services/>.

Vision Services

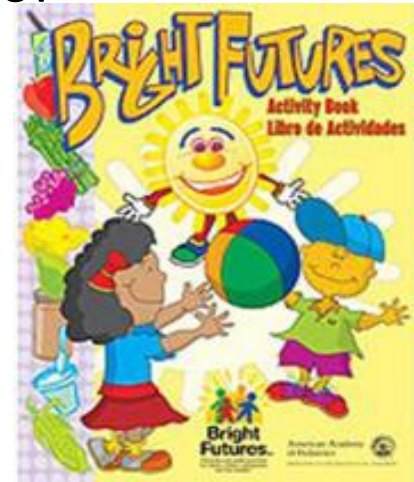
Pediatric vision & dental care included as
Essential Health Benefits under ACA

NJ FamilyCare also covers eyeglasses.



Wellness-general

There are other general resources on prevention and wellness which are beneficial to families of children with special needs.



Bright Futures even has a children's activity book at

http://brightfutures.aap.org/pdfs/BFActivityBook_L%200626.pdf?Site=nf.aap.org&WebKey=68530b27-2adb-43ae-9c87-2fa20cb86cae&url_keyword=Bright+Futures+Activity+Book

Other Important Topics



Photo www.kidslinkcares.com

Abuse/Trauma

Unfortunately, children and adults with special needs are more likely to experience trauma and abuse.

Our focus group of self-advocates asked for information on this topic.

Abuse Prevention

Building family skills and preventing crisis is the key to success. Getting help when needed is a sign of strength, not weakness.



Alternative Medicine



Photo www.organicgardening.com

There are some other health related concerns for families of children with special needs. According to the National Institutes of Health, almost 24% of children with medical conditions have been given an alternative medicine product.

Alternative Medicine

Alternative medicine use for children with autism is even higher at 40% (see www.healthline.com.)

It is essential that families inform their healthcare providers of any therapies, herbs, vitamins etc. they are using as it may affect other health care such as prescription medication.

Families can find research on effective therapies from the National Center for Complementary and Alternative Medicine (NCCAM) at <http://nccam.nih.gov/health/atoz.htm>.



General



There are various resources for families of children with special needs if they need more information or assistance.

NJ was the first state to have the Parent Training and Information Center (PTI), Family Voices/Family-to-Family Health Information Center (FV/F2FHIC), and Parent-to-Parent (P2P) in one location and an overview is found at

<http://www.spanadvocacy.org/content/family-wrap-project-care>

General

Other resources include:

“What Do Families Say About Health Care for Children with Special Health Care Needs?” at

<http://www.familyvoices.org/admin/miscdocs/files/National-Famrpt-1.pdf>

“Finding Your Way” at

http://www.waisman.wisc.edu/cedd/pdfs/products/community/FYW_e.pdf

Roadmap to Success” at

<http://www.familyconnectionsc.org/resource-roadmap.html>

Quality Assurance



An important component of health care for children with special needs is access to quality care.

“Best Practices for Children and Youth with Special Health Care Needs” is available at http://nhfv.s481.sureserver.com/wp-content/uploads/2013/07/best_practices.pdf.

“Enhancing Quality: Standards and Indicators of Quality Care for Children with Special Health Care Needs” is found at http://www.neserve.org/neserve/pdf/NES%20Publications/Enhancing_Quality.pdf

Support: Individuals/Families

Lastly, but perhaps most importantly, is family support for parents of children with special needs. There are many different kinds of resources available to parents.



Family Support

NJ is fortunate in now having a Department of Children and Families. For information on developmental disabilities and/or mental health for children, see <http://www.state.nj.us/dcf/families/csc/>.

Children with developmental disabilities will be transitioned to adult services when needed. The Division of Developmental Disabilities is launching the new Supports Program and information can be found at <http://www.state.nj.us/humanservices/ddd/programs/supportsprgm.html>.

Family Support

Families of children with disabilities need to recognize that they have an extra role as caregiver.

The Caregiver Action Network has a Family Caregiver Toolbox found at <http://caregiveraction.org/resources/toolbox/>. Here families can find information on communicating with health professionals, technology assists with caregiving, financial planning etc.

Family Support

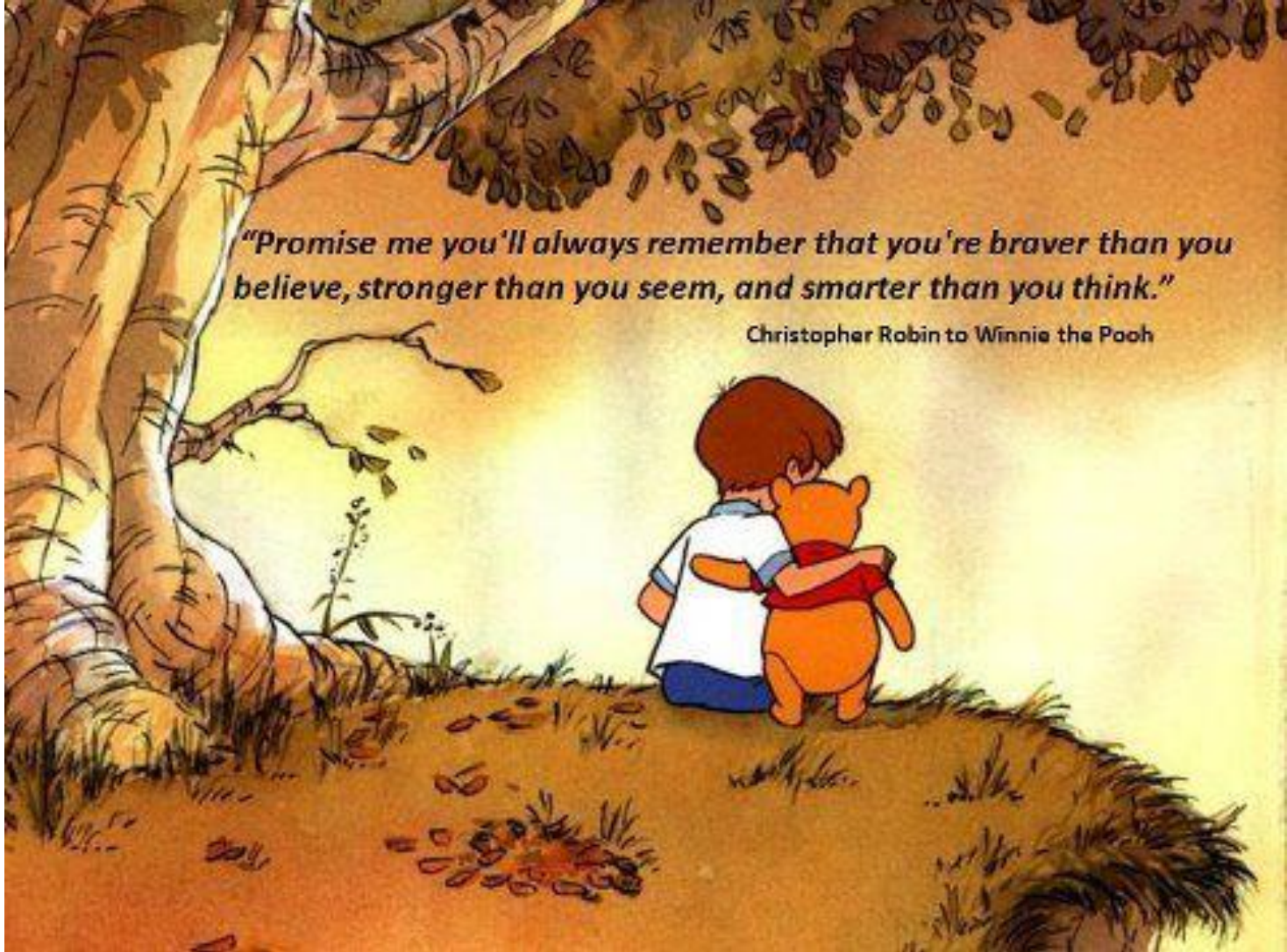
Sometimes parents just need to talk to another parent who has experienced similar issues. NJ Parent-to-Parent matches trained volunteer parents to families of children with the same condition at

<http://www.spanadvocacy.org/content/nj-statewide-parent-parent>



Family Support

Families need to remember that they are the best advocates for their children because they have a personal stake in the outcome. In addition, because parents are with their child with special needs 24-7, they need to realize that *they* are the experts in their child.

An illustration of Christopher Robin and Winnie the Pooh sitting on a grassy hillside. Christopher Robin is on the left, wearing a white shirt and blue pants, with his arms around Winnie the Pooh. Winnie the Pooh is on the right, wearing his signature red shirt. They are both looking towards the right. A large, gnarled tree trunk is on the left side of the frame, with some leaves falling from its branches. The background is a soft, yellowish glow, suggesting a sunset or sunrise. The overall style is classic and whimsical.

"Promise me you'll always remember that you're braver than you believe, stronger than you seem, and smarter than you think."

Christopher Robin to Winnie the Pooh

Contact Information

Statewide Parent Advocacy Network

(800)654-SPAN (7726)

Website: www.spanadvocacy.org

