Medical Home Toolkit

The Medical Home Toolkit was organized and translated in partnership with the New York-Mid Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC) based on the Medical Home Learning Collaborative Curriculum developed by the Statewide Parent Advocacy Network, American Academy of Pediatrics-New Jersey Chapter, and New Jersey Department of Health Special Child Health and Early Intervention Services.

Medical Home Project Team Members:
SPAN-NJ Team:

Malia Corde
Director, Medical Home Initiatives
Program Coordinator, NJ Parent to Parent,
Statewide Parent Advocacy Network
Chair, NYMAC Primary Care and Linkages
Workgroup

Ayomipo Bajomo
Administrative Assistant
Statewide Parent Advocacy Network, NJ

Iliana Cheveras
Team Member,
Statewide Parent Advocacy Network, NJ

Diana MTK Autin
Executive Co-Director
Statewide Parent Advocacy Network, NJ

NYMAC Team:

Kunal Sanghavi
Patient/Family Project Coordinator, NYMAC
Sr. Research Program Coordinator, McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins School of Medicine

Joann Bodurtha
Co-Director, NYMAC
Professor of pediatrics and oncology,
McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins School of Medicine

Beth Vogel
Program Manager, NYMAC
New York State Department of Health
Wadsworth Center

Michele Caggana
Project Director, NYMAC
Director, NBS Program New York State
Department of Health Wadsworth Center

Bonnie Fredrick
Project Coordinator, NYMAC
New York State Department of Health
Wadsworth Center

We would like to thank the members of NYMAC Primary Care and Linkages Workgroup for their feedback on the medical home project. We extend our gratitude to the participants and speakers of the Medical Home Learning Session held on May 20, 2015 in Newark, NJ. For more information about the Medical Home Project, please contact Kunal Sanghavi at ksangha1@jhmi.edu.
SPAN MEDICAL HOME PARENT PARTNER TRAINING AGENDA

9:30 – 10:00  Introductions & Review of Agenda & Resources Overview of the Integrated Systems project Role of Family Resource Specialists
10:00-10:30  Expectations of the Medical Home Parent Partner Stories from Parent Partners
10:30-11:15  Components & Characteristics of a Medical home Relationship to other MCHB core outcomes
             -Adequate public & private insurance -Community-based services organized for easy access
             -Families are partners at all levels & satisfied with services -Early & continuous screening
             -Effective transition to adult systems of care
Care coordination & benefits of the medical home to families & practitioners
11:15-11:30  Small group activity re: What is a medical home? How can we tell if it exists?
11:30-11:45  Overview of the Monmouth County medical home project
11:45-12:15  Lunch
12:15-12:45  Helping families partner with health professionals
12:45 – 1:00  Small group activity re: parent partners & collaboration
1:00 – 1:30  Resources to share in the medical home
1:30 - 1:45  Small group activity re: resources
1:45 - 2:00  Questions from potential parent partners
2:00 - 2:15  How it works: Selection, notification, participation, reporting, payment
2:15 - 2:30  Questions & evaluation
Small Group Activity: *What is a medical home, and how can we tell if it exists?*

Divide the group into small groups of approximately 6 groups with 5-6 people in each group. Identify a facilitator and a note-taker for each group; assign a SPAN Health Projects staffer to coordinate each group.
5 minutes: Brainstorm what a “medical home” would look and feel like.
5 minutes: Brainstorm what a parent should look for to see if his/her child has a medical home.
5 minutes: Small groups come back together. Each group can report out 1 idea from each question. Collect notes from each group. Notes will be compiled and shared with all parent partners.

Small Group Activity: *Parent Partners Collaborating with Medical Home Practices*

Role-play a scenario of a parent partner’s medical home visit. The role play contains some positive aspects and some negative aspects. Debrief.
5 minutes: Role-play
5 minutes: Small group discussion about what was positive, what was negative, and how to improve
5 minutes: Report out 1 idea from each group. Notes from each group will be compiled and shared.

Small Group Activity: *Resources for Families in the Medical Home*

Provide a scenario to each of the small groups. Each scenario addresses one of the core outcomes. Ask them to consider possible resources.
5 minutes: Review the scenario.
5 minutes: Brainstorm possible resources for that scenario.
5 minutes: Report out core outcome and related resources for each group. Notes compiled and shared.
SPAN’s Integrated Community Systems of Care for CYSHCN & Families
Purpose

• To engage stakeholders in activities aimed at improving results on the MCHB six core outcomes for children and youth with special healthcare needs and their families
Core Outcomes

- Families are partners at all levels & satisfied with services
- Families have adequate public & private insurance
- There is early and continuous screening to identify needs
- Community-based services are organized so families can access them easily
- Services are provided within the context of a medical home
- YWD make effective transitions to adult life
Families are partners & satisfied with services

• Family Resource Specialists provide support at SCHS CMUs in each county
• Parent leadership development
• Parent partners in medical home visits
• Parents participate in all workgroups
Adequate insurance

- Ensuring families and health providers are aware of existing health coverage & other resources
- Advocacy to expand and enhance coverage
Early & continuous screening

- Assuring Better Child Development pilot with AAP
- Advocating for use of standard routine screening tools
- Informing families & providers of screening resources such as EI, EPSDT
Easy to access community services

- Primary care providers are aware of existing community services & how to connect families
- Family Resource Specialists help directly connect families
- Mini-grants to local communities to improve accessibility of services
- Expand use of community service tools
Medical home

- Expand Medical home pilots
  - Hospital
  - FQHC
  - pediatric practices
- Parents as partners on medical home teams
- Expand use of medical home tools
Transition to Adult Life

- Disseminate existing transition tools
- Develop & disseminate additional transition tools for families, youth, & health providers
- Pilot approaches to making health transition more effective
- Training & TA for families, providers, youth
- Statewide Youth Council
Integrated Systems Plan

- Develop accurate “map” of strengths & needs in systems of care for CYSHCN & families
- Know how others have addressed these issues
- Facilitate representative stakeholder workgroups to identify strategies to address barriers
- Implement solutions
- Evaluate impact
NJ Performance on Core Outcomes on CYSHCN Survey

- **Outcome 1:** Family participation & satisfaction: 55.4%
- **Outcome 2:** Medical home: 40.8%
- **Outcome 3:** Adequate insurance: 59.9%
- **Outcome 4:** Screening 71.7%
- **Outcome 5:** Easily accessible services: 88%
- **Outcome 6:** Effective transition: 37.9%
Core Team & Leadership Team

• Core Team
  - SPAN (PTI)
  - AAP-NJ/NJPCORE
  - NJDHSS, DHS, DCF
• Leadership Team/
  Advisory Committee:
  - Parents
  - Professionals
  - Advocacy organizations
  - HMOs
  - Others
Participation Opportunities

• Statewide Consortium of Care Summit and quarterly meetings
  - “White Papers” on each key issue with current status & recommendations
  - Feeds into workgroups

• Learning Collaboratives

• Workgroups
Parent Partners in the Medical Home

Presented by, Malia Corde, Medical Home Project Director

SPAN
Statewide Parent Advocacy Network
What is a Parent Partner?

The parent partner is an equal member of the team within a medical home.
Why Parent Partners?

The medical home team cannot appropriately review the quality of their service without the input of the individual families they are working with.
Why is the parent partner important?

- Ensures “family voice” is heard
- Provides input on systems change
- Shares personal experience and resources
- Helps to improve quality of service delivery
- Ensures that a family’s cultural background is recognized, valued and respected.
Who are Parent Partners?
Parents who...

- Have a child with a disability and/or special health care need
- Are emotionally ready to support others
- Have time to commit
- Enjoy working in a group or as part of a team
- Are able to share community/state resources
- Are able to share ideas, concerns and their personal story in a meaningful way
- Are good listeners/communicators
Who are Parent Partners?

When practice teams were asked what they thought was an important trait in a parent partner. Almost all mentioned a “sense of humor” as being extremely helpful.

*The Center for Medical Home Improvement (CMHI) at The Hood Center for Children & Families*
Benefits to Families

- Provides a “voice” at the table for all the children & families in the practice
- Improves Communication between parents and other medical home staff
- Provides parents with resources & information on a variety of topics
- Ensures better health outcomes for children & families
Benefits to the Practice

- Provides input on the daily challenges parents experience
- Provides on-going support & meaningful family engagement
- Provides information on community/state resources (ex. P2P, FV, FSO’s, SCHS CMU’s/SPAN FRS’s, disability specific organizations, other)
- Improves communication-family/MH staff
- Improves partnership between family/MH staff
- Provides input into the development of tools used to assess the specific needs of children & families (ex. surveys, focus groups)
- Provides on-going feedback from families
Role of a Parent Partner

- Meet with medical home team on a regular basis (determined by individual practice)
- Clearly define your roles and responsibilities (specific to each practice) as a member of the medical home team
- Provide input on possible changes and decisions made that impact children & families
- Assist families in completing the Medical Home Family Index” to assess the “medical homeness” of a practice.
Role of a Parent Partner

- Provide materials to families that help support the vision of the medical home team
- Attend occasional learning sessions
- Attend full day Learning Collaborative (retreat)
- Speak and/or meet with PP’s from other medical home practices to share ideas, information and resources
Support for the Parent Partner

- Provide mentor
- Provide overview of current policies and procedures
- Provide a staff directory with roles and responsibilities
- Provide on-going opportunities for learning
  - Formal (lectures, workshops)
  - Informal (discussion over coffee and/or lunch)
- Ensure that the PP is given opportunities to provide input in a respectful and compassionate environment
- Connection to SPAN Family Resource Specialist housed at county-based Special Child Health Services Case Management Units
Parent Partner Selection Process

- Complete PP intake form
  - Geographic location you will travel (counties)
  - Languages you speak other than English
  - Special knowledge/skills (e.g. sign language interpreter)
  - Time availability (daytime vs. evenings)

- You will be contacted to see if you are available to participate on a medical home visit

- Complete PP “site visit” form and fax to Project Director

- Fill out PP timesheet for payment of stipend
Resources

- **Resource Binder & CD for Medical Home Practice**
  - Listing by categories (ex. health, education, family support, insurance...)
  - Disability specific organizations
  - Information on community & state resources

- **Care Notebook for Parents**
  - Includes all relevant medical information about your child
  - Child’s Care Plan
Medical Home Project

- Director, NJ Medical Home Initiatives for CYSHCN
  Malia Corde
  908-208-4040
  mcorde@spannj.org
  www.spannj.org/family2family/medical_home/index
“We need respect, we need to have our contributions valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best.”

A quote by parent Cory Moore
When speaking with a professional about her child

Taken from NICHCY News Digest, 3rd Edition, 2003
Welcome...
To our introduction to the medical home for children with special needs!
What is a Medical Home?

It is the **one 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)
A Medical Home is how you and your family receive services. It is not an actual building, house or hospital.
A Medical Home can be the doctor’s office, community clinic, or local health department where you take your children for all their health care needs.
The staff in your Medical Home knows your child and your child’s health history.
You can turn to your Medical Home staff for advice or help during office hours or after-hours rather than repeatedly using the emergency room for non-emergencies.
You and your Medical Home staff are partners in caring for your child(ren).
Why Is A Medical Home Important?
Why is a medical home important?

- Increased patient and family satisfaction
- Establishment of a forum for problem solving
- Improved coordination of care
- Enhanced efficiency for children, youth, and families
- Efficient use of limited resources
- Increased professional satisfaction
- Increased wellness resulting from comprehensive care
Why is a medical home important?

- 20% of all visits to the pediatrician’s office are developmental or behavioral in nature
- 70% of children diagnosed with cognitive disability are diagnosed by providers other than their pediatrician
- 80% of parental concerns are correct and accurate
Family-Centered Care = Best Practice

- Families involved in decision making are more satisfied with their primary care provider
- Families active in developing a CYSHCN care plan are more likely to follow and maintain the care plan
## Different Priorities

<table>
<thead>
<tr>
<th>Parents</th>
<th>Physicians</th>
<th>Rank of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>1</td>
<td>Respite Care</td>
</tr>
<tr>
<td>21</td>
<td>2</td>
<td>Day Care</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>Parent Support Groups</td>
</tr>
<tr>
<td>10</td>
<td>4</td>
<td>Help with Behavior Problems</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>Financial information or help</td>
</tr>
<tr>
<td>20</td>
<td>6</td>
<td>After-school child care</td>
</tr>
<tr>
<td>15</td>
<td>7</td>
<td>Assistance with physical household changes</td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>Vocational counseling</td>
</tr>
<tr>
<td>5</td>
<td>9</td>
<td>Psychological services</td>
</tr>
<tr>
<td>22</td>
<td>10</td>
<td>Homemaker services</td>
</tr>
<tr>
<td>4</td>
<td>13</td>
<td>Recreational opportunities</td>
</tr>
<tr>
<td>1</td>
<td>14</td>
<td>Information about community resources</td>
</tr>
</tbody>
</table>
What a Medical Home Means to Families

• I can get care for my child 24 hours a day, 7 days a week.
• I am a valued and respected member of my child’s medical team.
• I get the same doctor or office staff with every visit.
• My child’s doctor never gives up on meeting my child’s needs.
What a Medical Home Means to Families

• I can easily receive referrals to specialists or specialty care & other needed services when my child needs it.
• My child’s providers are familiar with who my child is and his/her health condition(s).
• My child and I are treated with genuine concern and compassion.

McCauley T. How to establish family professional partnerships. Presented at: Institute of Family Centered Care; September 5, 2003; Boston, MA
What families want depends on the difference between the support they already have and what they will need given their situation.
What Should You Look For In A Medical Home?

• Accessible
• Family-Centered
• Continuous
• Comprehensive
• Coordinated
• Compassionate
• Culturally Competent
What is “accessible?”

- **Personally**
  - Family/youth are able to speak directly to the physician when needed.
  - The practice is physically accessible and meets American with Disabilities Act requirements.

- **Geographically**
  - Care is provided in the CYSHCN’s community.
  - Practice is accessible by public transportation, where available.

- **Financially**
  - All insurance, including Medicaid & Family Care, is accepted. Changes in insurance are accommodated.
What is “family-centered?”

• The medical home physician is knowledgeable about the CYSHCN and family and their needs.

• Mutual responsibility and trust exists between the patient, family, and the medical home physician.

• Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.

• The family is recognized as the principal caregiver and center of strength and support for the child, as well as the expert, and families and youth are supported to play a central role in care coordination and share responsibility in decision making.
What is “continuous?”

- The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.

- Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the CYSHCN and family.

- The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.
What is “comprehensive?”

- Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.
- Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
- Extra time for an office visit is scheduled for CYSHCN, when indicated.
What is “comprehensive?”

- Preventive, primary, and tertiary care needs are addressed.
- The CYSHCN’s and family’s medical, educational, developmental, psychosocial, & other service needs are identified and addressed.
- The physician advocates for the child or youth and family in obtaining comprehensive care.
- Information is made available about private insurance and public resources.
What is “coordinated?”

• A plan of care is developed by the physician, CYSHCN, and family and is shared with other providers involved with the care of the patient.

• Care among multiple health & other providers is coordinated through the medical home.

• A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.
What is “coordinated?”

- The medical home physician shares information among the CYSHCN, family, and consultant; provides specific reason(s) for referral; and assists the family and CYSHCN in communicating clinical issues.

- Families are linked to support and advocacy groups, parent-to-parent groups, and other family resources.

- The medical home physician evaluates and interprets the consultant’s recommendations for the CYSHCN and family and, in consultation with them and sub-specialists, appropriate recommendations.
What is “compassionate?”

- Concern for the well-being of the CYSHCN and family is expressed and demonstrated in verbal and nonverbal interactions.

- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the CYSHCN.
What is “culturally appropriate?”

- The CYSHCN’s and family’s cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.

- All efforts are made to ensure that the CYSHCN and family understand the results of the medical encounter and the care plan, including the provision of professional translators or interpreters, as needed.

- Written materials are provided in the family’s primary language.
Care Coordination in the medical home

• Continuous care
  - 24 hours a day
  - 7 days a week
  - 365 days a year

• Requires competence by the physician & medical staff to care for CYSHCN

• Involves medical; developmental; educational; recreational; vocational; psychological and financial issues
How is care coordination part of comprehensive care?

Physicians can’t “do it all”
• Not much training
• Not much time

Families may have unmet needs
• Information, coordination of services
• Unvoiced needs
• Needs may be more than physician perceives
Care Coordination...

• Is a collaborative process
• Involves families, educational, social service and medical providers
• Ensures access to appropriate community-based services
• Advocates for the comprehensive community-based service systems
Goals of Care Coordination

To promote the well-being of families and CYSPCHN through:

- Information and referral
- Consultation
- Training
- Outreach
- Collaboration
- Service coordination
- Optimization of insurance and public benefits
Doctor’s Role in Care Coordination

- Gathering information, triage: medical; non-medical; “in-between”
- Interpret medical information; integrate it all into care plan
- Teach CYSHCN and families
- Learn from CYSHCN and families
- Mediate any potential conflicts
What does care coordination look like?

- A plan of care developed by doctor, CYSHCN, and family
- A central record with pertinent medical information kept in the primary care office
- When CYSHCN is referred for a consultation, the medical home assists the CYSHCN and family in communicating clinical issues
- The medical home evaluates and interprets the consultant’s recommendations for the CYSHCN and the family
- The written care plan is coordinated with other community agencies
Chronic Care Management: Making the decision

A primary care office staff should acknowledge the need for CCM strategies when a child/youth’s health condition meets the following criteria:

- significantly impacts daily living & family life
- impacts school performance
- impacts development
- involves on-going specialty care
- involves several providers and agencies
- causes new predicament/emergency
Chronic Care Management: Creating a plan

- Developed in concert with the PCP; family; CYSHCN (if developmentally appropriate); care coordinator (if appropriate)
- Addresses: goals; concerns; interventions; services; referral contacts for medical and non-medical needs
- Includes: medical information; visit schedules; communication strategies; other agencies services
- Continuously updated and assessed
- Family/CYSHCN are provided with copies of plan
Chronic Care Management:
The provider’s role with the family/CYSHCN

- Communicate office procedures to the family/CYSHCN
- Discuss & assess what family/CYSHCN support resources are available/needed
- Identify roles and expectations for all
- Discuss time lines and possible agendas for provision of care
Chronic Care Management: The Family's/CYSHCN's Role

- Act as a partner
- Communicate directly and honestly with providers
- Responsibly manage care notebooks to assist in communicating needs to provider(s)
- Bring notebook to provider appointments
- Continuously assess care plan and its integration into life-activities
Considerations for provision of comprehensive care: Medical Issues

- Is a recent and comprehensive medical history available?
- Has medical information been communicated in understandable terms?
- What procedures are in place for discharge planning?
- Has “medical necessity” been defined?
- How is family managing medical needs at home?
- Has care plan been reviewed by family? Medical contacts identified for family?
- What communication strategies are in place between the medical home and other providers?
Considerations for Provision of Comprehensive Care: Developmental Issues

• What early surveillance and screening procedures have been performed?
• What therapies are needed? Accessible?
• Has referral been made to Early Intervention? Has Release of Info been sent? Follow-up completed?
• What communication strategies between the medical home and other providers exist?
Considerations for provision of comprehensive care: Educational/Vocational Issues

- How will the CYSHCN access the educational system?
- Has an Individual Educational Plan or 504 been developed with guidance from medical home?
- How has the Individuals with Disabilities Education Act (IDEA) been incorporated into educational plans?
Considerations for provision of comprehensive care: Recreational Issues

- What are CYSHCN interests regarding exercise/recreation? Goals? Dreams?
- What are possible effects of medication on exercise/recreation?
- What is current level of fitness? How does that affect selection of which exercise/recreation to participate?
- Has medical home physician been aware/involved in selection of exercise/recreation activity?
Considerations for provision of comprehensive care: Psychosocial Issues

- Has a detailed psychosocial history been taken?
- What is the impact of CYSHCN’s condition on family?
- What is the impact of family’s dynamics on CYSHCN?
- Has an Individual Family Support Plan been developed?
- Was the medical home doctor involved in development?
- What current support groups are being used by family/CYSHCN?
- Have “Do Not Resuscitate”/comfort care issues been discussed?
- Has guardianship or other legal issues been discussed?
Considerations for provision of comprehensive care: Financial Issues

• What are current payment options offered by the primary care practice?
• If there are changes in the family's/CYSHCN's insurance, are they accommodated?
• Is the billing process flexible to meet needs of different health plans?
• Is there an office system established to continuously provide financial resource information?
• What is the medical home's understanding of different health plans & financial resources?
Considerations for provision of comprehensive care: Oral health Issues

- Has an oral health care provider been identified?
- Are oral health risk assessments available in the pediatric primary care setting?
- Are medical home providers familiar with billing codes for oral health assessments?
- What referral procedures are in place after conducting oral health assessment?
- What resources are available to discuss dietary practices, fluoride exposure, oral hygiene, and the establishment of a consistent oral health care provider with families?
Activity

Which Medical Home qualities are important to you?
My Ideas:
What’s important for your family?
Tips For Families:

• Bring a list of questions or concerns to discuss
• Share information on how your child is doing
• Ask about resources that may help your child
• Ask about how to get care after hours if needed
• Ask to meet the staff that will work most closely with you and your child
• Show your appreciation
Care Model for Child Health in a Medical Home

- Functional and Clinical Outcomes
  - Family-centered, timely, efficient
  - Evidence-based & safe
  - Coordinated & equitable

- Health System
  - Health Care Organization (Medical Home)
    - Care Partnership Support
    - Delivery System Design
    - Clinical Information Systems
    - Decision Support

- Community Resources & Policies

- Supportive, integrated community

- Prepared, proactive practice team

- Informed, activated patient/family

- Family-centered, timely, efficient

- Functional and Clinical Outcomes
Questions?
Helping families partner with Health Providers

© Statewide Parent Advocacy Network 2009
FV Principles of Partnership

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

- Trust is acknowledged as fundamental.
- Communication & information sharing are open & objective.
- Participants make decisions together.
- There is a willingness to negotiate.
Why build relationships?

• With strong, trusting relationships, health providers really stand behind families and their child(ren)
• Good relationships with committed providers relieve families of some of the stress of coordinating all the services their child needs, and provide support for problem resolution
Reciprocity

- It’s all about relationships!
- Families should expect quality care and responsibility from their providers, and show them they are responsible too.
Family-Professional Collaboration

- Promotes relationship in which family & professionals work together to ensure the best services for the child & family
- Recognizes & respects the knowledge, skills and experience that families and professionals bring to the relationship
- Acknowledges that the development of trust is an integral part of a collaborative relationship
Family-Professional Collaboration

- Facilitates open communication so families & professionals feel free to express themselves
- Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
- Recognizes that negotiation is essential
- Includes acknowledgment of mutual respect for each others’ culture, values, and traditions

Understand entitlements

- Parents should read their member handbook to learn
  - their rights and responsibilities
  - which services are available to their 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 parents...

- treat them with the same respect they expect them to give
- give them all the info they need to give their child the best care
- honestly express their concerns
- listen actively; take notes to help understand
- ask questions when they 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 their phone and record the date, name, position/title, and answer to their questions
• Use a care notebook
• Be persistent, but try to remain polite!
How to listen

• Parents can’t do two things at once if one of them is listening.
• Parents can’t listen if they are trying to figure out what to say.
• Parents can’t listen if they are assuming.
It helps providers when parents...

- use resources wisely (e.g. use 24 hour hotline for urgent, not routine, questions)
- keep or reschedule appointments
- thank them when they like what their providers do
Parents should expect the PCP to...

• See to their 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
Parents should expect themselves to...

Keep their PCP informed of contacts with other provider visits, including emergency room visits.
Expect the care manager to...

- have experience with people with special needs
- probably be one of the best troubleshooting resources
- coordinate all their child’s services & needs
- develop an IHCP with the parent(s) and child
- help with referrals & locating specialists
Getting a care manager

If children are enrolled in Medicaid Managed Care, parents should call the care manager to get a basic care plan started soon after HMO enrollment.
Effective Communication & Advocacy Skills

• Decide what they want to achieve
• Prioritize what they want
• Explain to others what they want and why: the reasons behind what they are asking for (their interests)
• Express themselves without being rude or aggressive
• Understand others’ perspectives & points of view
Explain their interests

Communicate and explain their interests.
Make their interests come alive.
Acknowledge the other party’s interests.
Share their interests and reasoning first and proposals later.

Adapted from Roger Fisher and William Ury (1981), *Getting to Yes, Negotiation Agreement without Giving In*.
When they Disagree

- Maintain respect
- Find out the policy & procedures to resolve disagreements
- Use discretion about when and where disagreements - or the people disagreed with - are discussed.
Resolving Problems

• Talk directly with those involved about the problem
• Check the facts before drawing conclusions or allocating blame
• Avoid criticizing professionals in front of children:
  - It may cause confusion and conflict
  - It may foster arrogance, defiance and rudeness toward adults
When they disagree

• If they have a problem with:
  - A provider, talk to the care manager or PCP
  - The care manager or PCP, call the plan’s member services
Resolving Disputes

• If the parent can’t prevent or immediately resolve a problem to their satisfaction, call member services and make a complaint. Be specific.

• If member services can’t solve the problem in 24 hours, they may register a grievance their plan by phone or letter (procedure in member handbook)
Advocacy

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

Other families of children with special needs can share their experiences and what has helped them; ask them.

• Their child’s providers can be powerful advocates for their child; build good relationships with them.

• An attorney or other advocate can go with parents for any formal hearings; take them!
Enlist Allies in Advocacy

• **Ask their child’s providers**
  PCP, specialist, or care manager to advocate with them or for them for needed or denied services

• **Volunteer for**
  - HMO consumer advisory boards
  - State agency consumer advisory groups

• **Ask elected officials to**
  support policies that will help children with special health care needs
CYSHCN and advocacy

• Help CYSHCN 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 the CYSHCN, the parent knows their child best and are their best advocate; don’t be afraid to speak up for him/her.
Benefits of advocacy

• When parents advocate effectively for their child’s needs, they may change a whole system to better meet other children’s needs.

• When parents advocate effectively for all children with special needs, they may help make systems work better for their child and family.
Remember: Keep the end in mind!
Getting CYSHCN what they need today to lead to a successful transition to adulthood tomorrow!
New Jersey Medical Home Initiative
for Children and Youth with Special Health Care Needs

Barriers to Effective Identification & Collaboration
with a Parent Partner

- Lack of a provider champion in the office
- Staffing changes
- Cultural competency of staff to work with diverse communities
- Time Restraints
- No consistent meeting time (inflexible)
- Lack of communication
- Lack of understanding of the goal by the professionals &/or the parent partner(s)
- Lack of clear direction for project
- Lack of specific tasks for families to engage
- Lack of funding for parents to support their participation
- (childcare, travel, etc.)

Taken from Family Voices Colorado
New Jersey Medical Home Initiative for
Children and Youth with Special Health Care Needs

Parent Partner Characteristics

- Has a child with special health care needs
- Is able to look beyond their own issues and concerns to be able to address perspectives of other families with CYSHCN
- Has accessed a wide variety of services and supports
- Have accessed many different providers (specialist, therapist)
- Has a knowledge of statewide and local family and disability organizations
- Is ready to put energy into changing the health care system, at the practice level
- Has a strong desire to make a difference
- Can make a commitment to the time necessary for meetings, assignments and have some flexibility.
- Can work within a team environment
- Is a self-starter
- Can communicate effectively. Not feel intimidated and be able to voice ideas and concerns comfortably

Parent Partner Job Description

- Assist with completing the Medical Home Index to assess “medical homeness” of the practice periodically
- Assist with completing the Medical Home Family Index to assess parents’ perceptions of the “medical homeness” of the practice initially and periodically
- Attend Learning Sessions with the Practice Team
- Meet regularly with the Practice Team (schedule determined by the Practice Team)
- Attend parent partner training on medical home
- Assist in identifying and selecting office and care processes, related to caring for CYSHCN, to be improved
- Provide input to the Practice Team on changes and decisions for the practice
- Communicate regularly with the MH Project Staff
- Participate in monthly calls with other Parent Partners and in a listserv to share knowledge with other practices regarding family advocacy and Medical Home issues
- Participate in Parent Partner Leadership development
- Participate in record keeping activities to receive stipends for medical home events
New Jersey Medical Home Initiative for Children and Youth with Special Health Care Needs

Choosing a Parent Partner for the Medical Home

1. All practice team members need to understand and embrace the idea of having a parent of a child with special health care needs (CYSHCN) as equal partners.
2. Discuss the parental traits, qualities, and characteristics that would compliment the practice team.
3. Discuss potential parent partners and determine if they would be a good match for the practice team.

Ideas about selecting a parent partner:
- Have a child with special health care needs
- Be able to look beyond their own issues and concerns to be able to address perspectives of other families with CYSHCN
- Have accessed a wide variety of services and supports
- Have accessed many different providers (specialist, therapist)
- Has a knowledge of statewide and local family and disability organizations
- Ready to put energy into changing the health care system
- Have a strong desire to make a difference
- Can make a commitment to the time necessary for meetings, assignments and have some flexibility.
- Can work within a team environment
- Is a self-starter
- Can communicate effectively. Not feel intimidated and be able to voice their ideas and concerns comfortably

Look for a parent partner who values the input of every team member and enjoys working with a team where trust and respect are reciprocal. You want someone who can work at this level of partnership and also is an expert in family issues. This may take time.

Some Expectations:
- Assist with completing the Medical Home Index to assess “medical homeness” of the practice periodically
- Assist with completing the Medical Home Family Index to assess parents’ perceptions of the “medical homeness” of the practice initially and periodically
- Attend Learning Sessions with the Practice Team
- Meet regularly with the Practice Team (schedule determined by the Practice Team)
- Attend training on medical home
- Assist in identifying and selecting office and care processes, related to caring for CYSHCN, to be improved
- Provide input to the Practice Team on changes and decisions for the practice
- Communicate regularly with the Project Staff
- Participate in monthly calls with other Parent Partners and in a listserv to share knowledge with other practices regarding family advocacy and Medical Home issues
- Participate in Parent Partner Leadership development
- Participate in record keeping activities to receive stipends for medical home events
New Jersey’s Medical Home Initiative for Children and Youth with Special Health Care Needs

10 Ways to Engage Parent Partners Within a Medical Home

Low Level

#1 Ask parents if they would be interested in creating a patient suggestion box
#2 Ask parents to create a bulletin board for community resources, and to share information about community events on the bulletin board

Mid Level

#3 Create listserv of parents to send information about community events and/or practice-specific information.
#4 Create a practice-specific survey that would help to identify areas in “Need of Improvement”
#5 Invite families to attend medical home conferences, Family Voices or Family to Family Health Information Center workshops, or other opportunities that develop the families’ skills to become leaders
#6 Have parents help support other parents in the practice by reaching out via telephone or face to face meeting
#7 Ask parents to share their personal experiences with practice staff to help staff become more sensitive to the daily challenges parents of children and youth with special healthcare needs (CYSHCN) face

High Level

#8 Participate as a representative of the practice in a community coalition
#9 Ask parents to participate in panel discussions with healthcare providers and community providers to help everyone understand the challenges families face on a daily basis and how to support families as they deal with those challenges
#10 Ask parent(s) to help create a parent advisory council for the practice
Quality Indicators of an Effective Physician

Please indicate whether your child’s health care provider exhibits these behaviors:
1 = Almost Always 2 = Sometimes 3 = Hardly Ever 4 = Almost Never

<table>
<thead>
<tr>
<th>Medical Practice</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Child’s/Youth’s Physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has a convenient phone system</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has extended evening and/or weekend hours</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has staff that uses appropriate procedures with children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has staff that is courteous and compassionate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Attitude</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Child’s/Youth’s Physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responds to my child’s needs first</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is nonjudgmental</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involves me in finding solutions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invites and responds positively to my ideas and suggestions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Child’s/Youth’s Physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is knowledgeable about my child’s diagnosis/disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gives options for solving problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides information about additional resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follows up on outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication Skills</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Child’s/Youth’s Physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is a good listener</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encourages questions and answers all questions asked</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Checks to ensure I understand their instructions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Makes sensitive and appropriate statements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interpersonal Style</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Child’s/Youth’s Physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Takes time and does not seem rushed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides me with open minded feedback</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is respectful of my experience &amp; knowledge of my child</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shows personal involvement and interest in my child and family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cultural Competence</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Child’s/Youth’s Physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides information in my native language</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respects my family’s cultural differences</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not judge my decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides language access, ie., translator or diversity of staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Based on a survey reported by Liptak and Revell, both parents and physicians were asked what services families most needed. The following table displays the comparative differences in priorities between physicians and parents.

**Survey Results:**
**Physicians’ and Parents’ Ranking of Needed Services**

<table>
<thead>
<tr>
<th>Services</th>
<th>Physicians</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite care</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Day care</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>Parent support groups</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Help with behavior problems</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Financial information or help</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>After-school child care</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Assistance with physical household changes</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Vocational counseling</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Psychological services</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Homemaker services</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Recreational opportunities</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Information about community resources</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>Dental treatment</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Summer camp</td>
<td>19</td>
<td>7</td>
</tr>
</tbody>
</table>

Families who participated in the survey listed "information about community resources" as the number one need whereas physicians listed "respite care". Families focused on information and the physicians on services. **The important point to remember is that without family involvement, a practice may focus on changes that represent different priorities than those of the parents they serve.**

Why is family involvement the cornerstone of the Medical Home in your practice? **Because each partner - the family, the primary care provider and other office staff - brings their unique perspective to the process.**

Each partner has important viewpoints to contribute to the process, so each has uniquely meaningful ways to enhance the delivery of quality health care.
Elements of a Medical Home

All children should have a Medical Home where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. (This definition is from the U.S. Department of Health and Human Services’ Maternal and Child Health Bureau, as described by the American Academy of Pediatrics, which houses the National Center of Medical Home Initiatives for Children with Special Needs, funded by the US DHHS MCHB. For more information, go to www.medicalhomeinfo.org).

Examples of these elements include:

**Accessible:**
- Care is provided in the child’s community
- All insurance, including Medicaid, is accepted and changes in insurance are accommodated.

**Family-Centered:**
- Recognition that the family is the principal caregiver and the center of strength and support for children.
- Unbiased and complete information is shared on an ongoing basis.
- Family-professional partnerships

**Continuous:**
- Same primary pediatric health care professionals are available from infancy through adolescence
- Assistance with transitions (to school, home, adult services) is provided

**Comprehensive:**
- Health care is available 24 hours a day, 7 days a week
- Preventive, primary, and tertiary care needs are addressed

**Coordinated:**
- Families are linked to support, educational, and community-based services
- Information is centralized

**Compassionate:**
- Concern for well-being of child and family is expressed and demonstrated

**Culturally Competent**
- Family’s cultural background is recognized, valued, and respected
US DHHS MCHB Core Outcomes for CYSHCN

All children and youth with special healthcare needs (CYSHCN) and their families should be provided with services and supports that achieve the six core outcomes: families are partners at all levels and satisfied with services; adequate public and private insurance to pay for all needed services; community-based services that are organized for easy access; early and continuous screening to identify needs; access to a medical home where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective; and effective transition to adult life. (These outcomes are part of the Healthy People 2020 outcomes developed by the U.S. Department of Health and Human Services’ Maternal and Child Health Bureau). Every outcome has a National Center to assist families and professionals achieve that outcome.

These National Centers include:

**National Center for Family-Professional Partnerships (National Family Voices, [www.familyvoices.org/info/ncfpp/](http://www.familyvoices.org/info/ncfpp/))**: Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive.

**National Center for Medical Home Implementation for Children with Special Needs (American Academy of Pediatrics, [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org))**: Children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.

**Catalyst Center: Improving Financing of Care for CYSHCN (Health & Disability Working Group, Boston University School of Public Health, [www.hdwg.org/catalyst/](http://www.hdwg.org/catalyst/))**: Families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.

**National Coordinating Center for the Regional Genetic Service Collaborative (American College of Medical Genetics, [www.nccrscg.org](http://www.nccrscg.org))**: Children will be screened early and continuously for special health care needs. (The NY Mid-Atlantic Consortium for Genetics & Newborn Screening, NYMAC, [www.wadsworth.org/newborn/nymac/](http://www.wadsworth.org/newborn/nymac/), is our regional center).

**National Center for Ease of Use of Community-Based Services (Institute for Community Inclusion, [www.communitybasedservices.org](http://www.communitybasedservices.org))**: Community-based service systems will be organized so families can use them easily.

**Got Transition National Healthcare Transition Center (National Alliance to Advance Adolescent Health, [www.gottransition.org](http://www.gottransition.org))**: Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
# INDIVIDUALIZED HEALTH CARE PLAN

<table>
<thead>
<tr>
<th>NAME: ___________________</th>
<th>DOB: ______</th>
<th>SEX: ____</th>
<th>ALLERGIES: _______________________</th>
<th>PHYSICIAN ________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>RELEVANT DIAGNOSIS (ES):</td>
<td>_____________________</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DIET: ___________________</td>
<td>MOBILITY: ___________________</td>
<td>EQUIPMENT: ___________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEDICAL HISTORY:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEDICATION/TREATMENT:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SIGNATURE: ___________________</td>
<td>SIGNATURE: ___________________</td>
<td>SIGNATURE: ___________________</td>
<td>(parent)</td>
<td>(student)</td>
</tr>
</tbody>
</table>

## HEALTH CARE GOAL

<table>
<thead>
<tr>
<th>DATE</th>
<th>HEALTH PROBLEM/ NURSING DIAGNOSIS</th>
<th>STUDENT OBJECTIVES</th>
<th>INTERVENTION AND RESPONSIBLE PERSON</th>
<th>EVALUATION AND TIMELINE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
NAME: ________________________________

<table>
<thead>
<tr>
<th>DATE</th>
<th>HEALTH PROBLEM/ NURSING DIAGNOSIS</th>
<th>STUDENT OBJECTIVES</th>
<th>INTERVENTION AND RESPONSIBLE PERSON</th>
<th>EVALUATION AND TIMELINE</th>
</tr>
</thead>
</table>

Adapted from Hartford Public Schools for use in Connecticut Department of Education Guidelines for Students with Special Health Care Needs.
# Getting to Know Me

<table>
<thead>
<tr>
<th>My Name:</th>
<th>Nickname:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Today’s Date:</td>
</tr>
</tbody>
</table>

**A Little About Me:**

**My Strengths:** (things that are easy for me)

**My Challenges:** (communication, feeding, learning, mobility, social, energy, behavior)

**My Life in the Community:** (school, childcare, place of worship, my favorite places)

**My Home and Family Information:**

**My Diagnosis (Diagnoses):**

**My Overall Health:**

**My Prior Surgeries, Procedures, Lab/Diagnostic Studies:**
### Getting to Know Me

<table>
<thead>
<tr>
<th>My Name:</th>
<th>Nickname:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date of Birth:</th>
<th>Today’s Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My Current Medicines/Doses:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My Allergies:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Things to Avoid: (food, activities, and procedures)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My Equipment/Assistive Technology: (braces/orthotics, walker, wheelchair, communication device, home O₂, insulin pump, nebulizer, suction)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other Things I’d Like You to Know About Me:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ways You Can be Helpful to Me:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

Copies of this form are available at [http://www.cshcn.org](http://www.cshcn.org)
## What’s the Plan?

<table>
<thead>
<tr>
<th>Child’s Name:</th>
<th>Date of Birth:</th>
<th>Provider:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s Name:</td>
<td>Today’s Date:</td>
<td></td>
</tr>
</tbody>
</table>

### Questions/Concerns:
What do I want to talk about today?

What do I hope to have happen?

Next steps? What needs to be done?

Who will do this?

By when? (time frame)

How will we follow-up?

Copies of this form are available at [http://www.cshcn.org](http://www.cshcn.org)
Surviving a Hospital Stay with your Child with Special Needs…and After!

Night Shift… & general child stress

- Once your child is recovering, the nurses may only check on the child once an hour. Each time your child is moved to a new room, find out who will be with the child at all times if you’re not there. There are different staff people that can help the child depending on their needs. Remember, if your child has special needs, they may require extra care, especially overnight.
- You may need to set up night nursing at home depending on the needs of your child. Even if it’s in the discharge plan, set up the actual schedule with the agency before going home. Also, you should appeal if insurance says it’s not covered, so you need to get the denial in writing, not just over the phone.
- Another thing to keep in mind is the fear any child would feel if they are in an unfamiliar setting and don’t understand what is happening to them. Hospitals also usually have “Child Life” departments which will help your child if they’re scared about a procedure, especially if they have special needs. They’ll come in with puppets or dolls and show the child what to expect.

Discharge—Going Home

- Make sure you have as much in place as possible and a written “discharge plan” (what your child needs at home) with instructions on how to best care for your child. Review the plan with the nurse and/or doctor and be sure to clarify anything you don’t understand. Don’t be afraid to ask as many questions as you need to ask to feel confident about going home!
- There are practical things you can do. If your child will be on many medications or it’s difficult to get to the drugstore, set up pharmacy home delivery. Make sure before you leave the hospital that you know how to give the medications and if there are any side effects. If your child was already on medication before, ask if you should still give it to him/her. Ask if there is anything like food that would affect medications. You can also use an online tool to create a medicine chart (and also bring a copy for doctor visits), a pill organizer, and a checklist to fill it.
- Other practical ideas are things like whether or not your child can have a bath or shower, and if not, what to do (no rinse soap or shampoo), and if so how to do it (how to wash around stitches or staples).
- Make sure your child has no problems with the usual bodily functions such as going to the bathroom, eating, etc., before leaving the hospital.
- Ask if your child’s diet needs to change.
- Find out if there’s anything they’d like you to keep track of at home such as blood pressure, weight, temperature, measuring intake/output, etc. and that you know how to do this and have the equipment at home. For example, you can get a digital scale and ask the pharmacy for help with a blood pressure cuff, quick thermometer like the one the nurses use, etc., and actually get everything before leaving the hospital.
Insurance
You may need to figure out which insurance (private, Medicaid, Medicare) covers what.

- Your private insurance is usually first.
- Medicare is usually second. Part A covers hospital stays; Part B covers clinic visits and immunosuppressive drugs. Part D is the prescription plan. If your child is a “dual eligible” (Medicaid/Medicare), Medicare automatically enrolls the child in the prescription plan. Be careful to check with the Human Resources Department at work because Part D could cancel private prescription and health insurance. Also, if you have Part D, Medicaid will put your child into a “limited benefit pharmacy wraparound program” which only covers certain medications. Parents must call both Medicare to opt out of Part D and also disenroll by calling the actual prescription plan.
- Be prepared to prove you legally can make decisions for your child if s/e is 18 or over, which is important because otherwise they won’t give you information or let you speak on your child’s behalf. You may have to send them documentation such as guardianship or power of attorney. NOTE: Medicare, SSI, Medicare Part D plan, Medicare Coordination of Benefits all need this separately because the systems don’t link. The Medicare national number (open 24 hrs.) and SHIP (State Health Insurance Program) Medicare counselors are very helpful.
- Medicaid is always the “payor of last resort” which means they are billed after either private and/or Medicare. Helpful Hints on Medicaid: If your state is switching from traditional “fee for service” Medicaid to managed care, make sure you get to choose and don’t get “autoassigned” to an HMO. You need to check if each doctor, not just office or hospital, is listed as a participating provider in the HMO. If your child gets care outside of your state, you may also need to get a Medicaid “out of state authorization”. Also, pharmacies aren’t included in the out of state authorization so stay local for medications. Be aware that even pharmacies that do take Medicaid fee-for-service, may not accept Medicaid HMOs.
- Don’t pay bills until you’ve checked that all insurance was billed first.

Home Instruction
Besides a doctor’s note, you may need your doctor to fill out additional paperwork. Parents may also be asked to sign a HIPAA (health information privacy) release form so you need to decide if you want the school to have access to all of your child’s medical records or just some, if any, and for what time period. Also it may take some time for the school to set up home instruction so give them as much notice as possible beforehand in writing, especially if the surgery is planned and you know the dates you’ll need. If you have concerns setting up home instruction, contact your Parent Training and Information Center.

Resources:
Medication tools
www.mymedschedule.com

National Medicare Office
www.medicare.gov or 24 hr. hotline (800)633-4227

SHIP (State Health Insurance Assistance Program) Counselors for Medicare
www.medicare.gov/contacts/search-results.aspx?customresult=AllSHIP

Centers for Medicaid/Medicare “Who Pays First” guide on insurance (private/Medicaid/Medicare)
www.medicare.gov/Publications/Pubs/pdf/02179.pdf

Parent Training and Information Centers (special education)
www.parentcenternetwork.org/parentcenterlisting.html

Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.
Preparing for a Hospital Stay Fact Sheet

Preparation for a Hospital Stay
Some families have children who started their lives in NICU (neonatal intensive care unit), others have dealt with surgery, while still others have had ongoing hospital visits. Whether it’s an emergency or scheduled procedure, there are things that families can do to prepare. These tips are based on the National Family Caregivers Spring 2011 newsletter article, “Be Prepared for a Hospital Stay,” and their flyer, “When Your Loved One is Hospitalized.”

Paperwork—what you really need (make copies if possible)
- Insurance cards (private, Medicaid/Medicare, prescription)
- Guardianship/advance directives
- List of medications
- Most recent testing results if blood work, etc., is being monitored
- List of important phone numbers (e.g., doctors) and address book (family/friends and anything you’ll need to cancel like school, bus, therapies, etc.) and calendar/schedule
- Family Leave (some states have family leave insurance, all are covered by Family Medical Leave Act).

Be like a scout—be prepared
- Draft work/personal emails so you can just hit send
- Do NOT post on Facebook or on your email message that you’ll be away from home
- Give a family/friend a housekey and arrange for pet sitting or plant watering
- Stop mail, newspapers, packages unless someone will pick up daily

What to Pack
Make a list for each person’s suitcase which includes clothes, personal care, medications, and maybe some paperbacks. Pack ahead of time if possible. Your child may need security items like a blanket or stuffed animal, but check if this is allowed. Don’t forget if your child is bringing an iPod or handheld videogame to bring the charger; ditto for your cellphone. Also make sure you have doubles of everything like toothbrushes or enough clothes so you’re not constantly unpacking and repacking. Think about what’s really needed (soap) vs. nice to have (lotion) and bring only what is essential. Keep each person’s list in their suitcase so it’s also a checklist so you don’t forget anything when you’re returning home.

Helpful Hints
It’s helpful to ask the hospital social worker what you should or shouldn’t bring. Check if the hospital has a Child Life Department which explains procedures to children before the actual hospital stay. Go on the hospital website which will have a map of departments and where to get food, gift store, etc. Find out where you can stay like nearby hotels, Ronald McDonald Houses, and there’s also Chai Lifeline which is an organization that helps with lodging, food delivery for both patient and family, and other support. (Priority is given to families of Jewish faith since food is kosher but all are welcome). Getting ready ahead of time will reduce stress for your family.

Resources:
- National Family Caregivers Association
  “When your loved one is hospitalized” www.nfcacares.org/pdfs/WhenHospitalized.pdf
- Take Care newsletter www.thefamilycaregiver.org/caregiving_resources/takecare_newsletter.cfm
- National Transition of Care Coalition—Guidelines for a Hospital Stay www.ntocc.org/portals/0/hospital_guide.pdf
- Support for Families of children with life-threatening illness www.chailifeline.org
- Ronald McDonald Houses http://rmhc.org/what-we-do/ronald-mcdonald-house