Health Advocacy for Children with Special Health Care Needs

Helping NJ Families access health coverage and health services for their children

Family-to-Family Health Information & Resource Center
A Project of Family Voices-NJ @ the Statewide Parent Advocacy Network

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Health Insurance in NJ

- Medicaid (includes Early Periodic Screening, Diagnosis & Treatment (EPSDT) for families at or below poverty level, including those on Temporary Assistance to Needy Families)
- State Children’s Health Insurance Program (SCHIP) (in NJ, this is Family Care-Children’s Program) & Family Care Advantage
- Private insurance: Managed care/HMO (Health Maintenance Organization) or fee for service
EPSDT

- Medicaid’s comprehensive & preventive health program for children under 21
- Provides screening & services at medically-appropriate intervals
- Provides medically necessary health care services even if the service is not available under State’s Medicaid plan
- States must inform all Medicaid-eligible persons under 21 that EPSDT is available
EPSDT screening

- Health & developmental history, including mental health
- Comprehensive physical exam
- Appropriate immunizations
- Laboratory tests
- Health education
- Vision
- Dental
- Hearing
EPSDT

- **Diagnosis**: If screening indicates need for further evaluation, referral and follow-up

- **Treatment**: Health care must be made available to treat/correct/ameliorate physical, developmental, or mental health conditions discovered during screening
EPSDT - lead poisoning prevention

- Required component of screening
  - All children at age 12 and 24 months
  - Children over 24 months if no record of previous test
  - Medically-necessary diagnostic & treatment services must be provided to children with elevated blood lead levels
NJ Family Care

- What is it?
  - Federal & state-funded health insurance program that helps uninsured children receive affordable health coverage; availability & sliding fee scale based on family size and monthly income, not assets

- What’s covered?
  - Doctor visits, immunizations, dental care
  - Eyeglasses, prescriptions
  - X-rays, laboratory & other diagnostic tests
  - Hospitalizations
  - Mental health services
NJ Family Care: Who’s eligible

- Children 18 years old and under
- Family size & income eligibility (including working families): up to 350% of poverty for child eligibility
- No exclusion for pre-existing conditions
- Plan A Medicaid
NJ Family Care: Who’s eligible

- Plan B: No premium or co-pay
- Plans C & D: Premiums & co-pays up to 5% of family income
- Family Care Advantage: Families with incomes above 350% of FPL pay premium at rate negotiated by state so affordable
- Immigration status: legal permanent resident or other qualified immigrant status regardless of date of entry
Split Application Medicaid

- Children with disabilities not income-eligible for Medicaid through SSI or otherwise because their parents’ income has been “deemed to them” may be eligible if they have a sibling.

- If has a sibling, both children apply for Medicaid under Medically Needy program:
  - Parents’ income is deemed to child without disability.
  - Child with disability is now considered on his or her own and so will be income-eligible.
  - Child with disability must meet SSI disability requirements.
  - Resource limit of $6000.
Welfare, Supplemental Security Income & Medicaid

- If your family loses eligibility for welfare (Work First NJ Temporary Assistance for Needy Families) due to time limits or income changes, or
- If your child loses eligibility for SSI due to health improvement or income changes,

Your child may STILL be eligible for Medicaid!
Welfare, Supplemental Security Income & Medicaid

- For more information, consult the Medicaid Hotline at 1-800-356-1561
- Or your local county welfare agency/Board of Social Services in the blue pages of the telephone book
Medicaid Managed Care - Who must enroll?

- New Jersey Care 2000: Mandatory since 1995 for people receiving WFNJ/TANF Benefits
- New Jersey Care 2000+: ABD ("aged, blind or disabled") population: people with disabilities who receive Supplemental Security Income (SSI) and Medicaid; about 90,000 people
Exemptions to Medicaid Managed Care Enrollment

- People who are eligible for both Medicaid and Medicare do not have to enroll in Medicaid managed care at this time, although they may do so.
- Families of children with complex medical or mental health needs may be allowed to continue with fee-for-service providers and not enroll in an HMO. Apply through HBC.
- Denials of exemption requests may be appealed through Medicaid Fair Hearing Process.
Managed care: public or private

- a comprehensive approach to providing and paying for high-quality medically-necessary health care services -
- from routine to emergency -
- within a coordinated system -
- in a cost-effective manner
Health Maintenance Organizations (HMOs)

- The health plans that provide the Benefits Package for the Medicaid managed care system in New Jersey.
- HMOs provide coverage for enrollees in a geographical area for a prepaid, fixed premium (capitation).
- HMOs provide a larger menu of services than traditional fee-for-service Medicaid plans (for example, preventive).
Health Maintenance Organizations (HMOs)

- The health plans that provide the Benefits Package for the Medicaid managed care system in New Jersey
  - AmeriChoice
  - Amerigroup New Jersey
  - Horizon NJ Health
  - Health Net (was PHS)
  - University Health Plans

- Medicaid HMOs provide coverage for enrollees in a geographical area for a prepaid, fixed capitation rate. Fee is paid by Medicaid - no cost to the enrollee.
What managed care covers

- Plans differ in services provided
- Member handbooks list covered services
- Services are covered only if medically necessary for your specific health needs
- Emergency room care is covered only for a true emergency
- Specialty services usually require a referral from the Primary Care provider
Fee for Service: Unmanaged Care

Hospital
Dermatologist
Allergist
Neurologist
Medical Equipment
Speech Therapy
Physical Therapy
Primary Care Provider
X-ray
Lab
Emergency Room

...from The Boggs Center – University Affiliated Program
Managed Care: PCP and Referrals

Primary Care Provider

- Specialist
- Emergency
- Hospital
- Medical Equipment
- Lab
- Therapy

…from the Boggs Center – University Affiliated Program
 Covered Services

- **HMO benefits package**
  - See Fact Sheet 1, page 4
  - These services are provided for by the HMO
  - Include mental health & substance abuse services for DDD clients
  - Include some transportation
  - HMOs may offer participants additional services beyond those Medicaid entitles them to

- **HMO excluded services, or “carve out” services***
  - PT, OT, Speech
  - Some transportation
  - Mental health & substance abuse for non-DDD clients
  - Some meds
  - Some blood products

*Are still paid for by Medicaid fee-for-service
Care Management—Very Important Service!

- HMO assigns a care manager
- All children with special healthcare needs in NJ Medicaid Managed Care are entitled to a care manager!
  - Usually a nurse or social worker
  - Care manager helps coordinate care & is the 1st person to contact with a question or concern
  - Request a care manager if your child is not automatically assigned one!
Costs

- Medicaid entitles beneficiaries to free health care. Always bring your HMO ID card & Medicaid ID card to all visits.

- Enrollees who follow correct HMO procedures should never receive a bill.
  (If they don’t follow procedures they may be held liable for bills.)
Using Medicaid Managed Care

- Call the HBC to enroll in an HMO
- Read your HMO member handbook
- Select and work with your PCP
- Get referrals for other services
- Work with your care manager
- Use network providers
- Use emergency rooms only for emergencies (prudent layperson decision); if you think your child needs emergency care, go to ER!
Exemption from Medicaid Managed Care

- The exemption process is now hassle-free!
- If your child’s healthcare needs are being met from Medicaid fee-for-service, you can request an exemption.
- Call the Health Benefits Coordinator at 800-701-0710 to request an exemption.
- All requests are honored.
Choosing managed care plans

Which HMO/Plan is best for your child?

Which HMO provider network(s) are your child’s most important current providers in?

- Ask your providers or the HBC, or the plan’s consumer service. Some of your providers may be able to join the provider network for the HMO or plan that looks best to you. Ask the HMO’s or plan’s member services.

Which HMO/plan best meets most of your requirements?

- See Fact Sheet 2, page 3 for questions to ask. Compare the HMO member handbooks or see brochures available from HBC or ARC of New Jersey; or call the HMOs and ask to talk to a care manager about services and providers.

Choose the plan that includes your current providers or that meets most of your requirements.
Hospitals & Managed Care

- Keep in mind that the HMO network includes not only doctors but also hospitals, labs, durable medical equipment providers, etc.
Once you’ve chosen...

- Read your Member Handbook carefully!
- Identify important people and phone #s and post them by your phone
- Be sure you learn how to reach help after hours!
- Keep records of all provider contacts in case misunderstandings arise
Partnering with providers

- Work to build strong, trusting relationships so 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.
- Expect quality care and responsibility from your providers, and show them they can expect responsibility from you as well.
Pharmacy Services

- Fill your prescriptions **only** at a participating provider pharmacy
- Read your member handbook to understand how **and where** to get your child’s meds
- HMOs use Formularies of preferred medications
- **Medically-necessary** medications are paid for, though co-pays are not unusual. Your co-pay may be larger for a brand-name prescription than a generic prescription.
- For prescription changes, even if they require **prior authorization**, the pharmacy must give you a 72-hour supply.
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
If you have a problem with...

- **A provider**, talk to your care manager or PCP
- **Your care manager or your PCP**, call your HMO’s member services
- **With your HMO not meeting your child’s needs**, call
  - Medicaid Managed Care Hotline 800-356-1561
  - or Managed Care Consumer Assistance Program (MHCCAP) 888-838-3180
You can file a grievance or appeal:

- If you have complaints about quality of care; or
- If you or a family member has had a covered health benefit denied, reduced or terminated.
- See member handbook for process.
- Try to resolve the problem as close to its origin as possible.
Dispute Resolution...

- If you can’t prevent or immediately resolve a problem to your satisfaction, call HMO/plan member services and make a specific complaint.
- If member services can’t solve the problem in 24 hours, you may register a grievance with your HMO or plan by phone or letter.
- If you are not satisfied with the HMO’s solution, call the state Medicaid hotline or the MHCCAP helpline.
- Keep records of all contacts!
Appeals

- HMO must notify you in writing 10 days before it denies or limits covered services.
- You may file an appeal of the denial with your HMO. Contact SPAN's F2F 800—654-SPAN.
- Sometimes appeals are resolved easily, but the process can become complicated, so you may want to turn to your care manager or to the Community Health Law Project or Legal Services of New Jersey for advice.
Medicaid Fair Hearing

- Within 90 days of service denial, you can file for a fair hearing.

- Call the Medicaid Hotline at the NJ Department of Human Services 800-356-1561

- At a fair hearing, an impartial judge listens to your position. You can bring witnesses and cross-examine the HMO’s witnesses.

- It’s a good idea to take legal representation to the fair hearing. Call Community Health Law Project or Legal Services of New Jersey.
Top Resources for Questions about Medicaid Managed Care

- Your HMO Care manager
- Medicaid managed care hotline: 1-800-356-1561
- Managed Health Care consumer Helpline: 1-888-838-3180
- Health Benefits Coordinator (HBC): 1-800-701-0720
Other Medical Assistance

- **The Catastrophic Illness in Children Relief Fund** provides eligible families with financial assistance to help them cover medical expenses that were previously incurred because their child became catastrophically ill or injured. Covered expenses include, but are not limited to, special ambulatory care, acute or specialized in- or out-patient hospital care, medical equipment, medically-related home modifications, home health care and medical transportation.
How does a family apply?

- Call the toll free Family Information Line: 1-800-335-FUND (3863) for information and an application.
- The completed application is forwarded to the State Office of the Commission for screening and review. All applications to the Fund are confidential.
- The Commission will review the application and make the final determination on eligibility and the amount of assistance.
- Approved grant awards are disbursed directly to the providers to offset outstanding balances.
- Families may be reimbursed for their out-of-pocket expenses.
Health Consumer Rights & Related Laws

- COBRA (Consolidated Omnibus Budget Reconciliation Act of 1986)
- HIPAA (Health Insurance Portability & Accountability Act of 1996)
- ERISA (Employee Retirement Income Security Act)
- FMLA (Family Medical Leave Act of 1993)
Other Medicaid Issues: Medicaid Waivers

- Medicaid system has an “institutional bias;” to avoid this bias, which reimburses states for expenses associated with institutional placement, states must develop and submit to CMS for approval “Medicaid waivers”

- Most NJ Medicaid waivers apply to adults (ages 18 and older)
Resources for Support and Information

- Family Voices Resource List: important literature and phone numbers to help you with Medicaid managed care questions.
- Family Voices Fact Sheets
- Top resources:
  - Your care manager
  - Medicaid managed care hotline 1-800-356-1561
  - Managed Health Care Consumer Helpline 1-888-838-3180
  - HBC 1-800-701-0720
Case Management Services

- In each NJ county, case management units work with families to:
  - Promote family-centered, community based care
  - Coordinate service delivery (Service Coordination for infants and toddlers with developmental delays & disabilities, birth to 3, and Case Managers for children and youth 3 to 21)
- For information about county-based Special Child Health Services Case Management Units, contact the NJ Special Child Health Services Program, NJ Department of Health & Senior Services, at 609-777-7778
- SCHS is funded by US DHHS - Maternal & Child Health Block Grant
The Individual Health Plan

- Essential to achieve educational equality for students with health management needs
- Ensures access to an education for students with special health care needs, whether or not the student is classified as eligible for special education
Why an IHP?

- Ensures that the school has needed information and authorization
- Addresses family & school concerns
- Clarifies roles & responsibilities
- Establishes a basis for ongoing teamwork, communication, & evaluation
“Hallmarks” of a Good IHP

- Contains information, guidelines & standards that promote a student’s health & educational goals
- Avoids unnecessary risk, restriction, stigma, illness, & absence
Basis for an IHP

IDEA
Sec. 504
ADA
14th Amend.
State nursing Practice acts
State laws
Equity
Common sense
Public health
Inclusion
Safety
Benefits of IHP to Schools

- Protect individual and district liability of school boards & administrators
- Documents compliance with federal and state laws and regulations
- Data from IHPs about individual and aggregate needs facilitates planning for staffing, budgeting, professional development, policies, & cost-effective use of school and community resources
IHP needs to address:

Collaboration!!

- Access to medication
- Environment
- Staff & peers
- Medical Equipment
- Personal fitness goals
- Therapy
- Crisis & Emergency
...
Who might need an IHP?

- Students with:
  - Asthma
  - Serious allergies
  - Chronic conditions
  - Physical disabilities
  - ADD/ADHD
  - Medication needs
  - Need for catheterization
  - Need for toileting assistance
What are the consequences of not having an IHP?

- Students can’t reliably access medication as needed
- Staff do not understand the precautions necessary to avoid hazardous or life-threatening situations
- Staff can’t assist students to overcome obstacles to participation & achievement
Other negative consequences

- Student absences may increase
- Student absences & poor performance may be blamed on the child or family
- Student health deteriorates
- Student lives may be threatened
- Other students may also suffer
Developing the IHP

- Speak with your child’s health care provider(s) about your child’s school experiences and the potential threats to their health in the school environment.
- Seek information from your child’s health care provider(s) about your child’s specialized needs in the school environment.
Developing the IHP, continued

- Develop the IHP containing:
  - Description of your child’s needs
  - Description of the specific services
  - Identification of parties responsible
  - Description of training needed
  - Specify ongoing services as well as protocols for emergencies
  - How will the family be informed
  - Starting date and plan review dates
Once the IHP is developed:

- Sign and date the IHP document
- Copy the IHP document
- Disseminate the document to all relevant school and district staff, family members, student if appropriate
- Meet as needed with staff who have responsibilities under the IHP to explain their responsibilities & set training
Provide follow-up

- Ensure that training is provided
- Ensure the IHP is being implemented
- *Contact appropriate staff periodically to ensure plan is working*
- Check with your child frequently
- Keep your child’s health care provider(s) informed
- Inform your school of any changes
- Update the IHP at least annually
Health Help for “Non-Parents” Raising Children

- NJ children are often eligible for state & federal benefits even if their caregivers do not have legal guardianship or custody, including health insurance.
- “Non-parents” may apply for free or low-cost health insurance for the children they are raising through Medicaid & NJ Family Care.
- For more information or to apply, contact 800-701-0710 or www.njfamilycare.org.
Cultural Competence & Equity

- NJ DHSS regulations make the New Jersey Law Against Discrimination in “public accommodations” applicable to all HMOs
- HMO’s must:
  - Accept any individual for enrollment without regard to race, ethnicity, color, national origin, or ancestry
  - Provide equal access, i.e., equal opportunity and consideration for needed services without exclusionary practices of providers or system design because of race, etc.
Cultural Competence & Equity

- NJ is one of the few states that has an express prohibition against collecting race or ethnic data on health insurance application forms.
- NJ is one of the few states that expressly prohibits the use of ANY policy of health that indirectly or directly limits coverage based on discriminatory categories.
- NJ requires HMOs participating in Medicaid managed care to examine the correlation between culture, language & health outcomes.
Thank You for joining us for this presentation.

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