

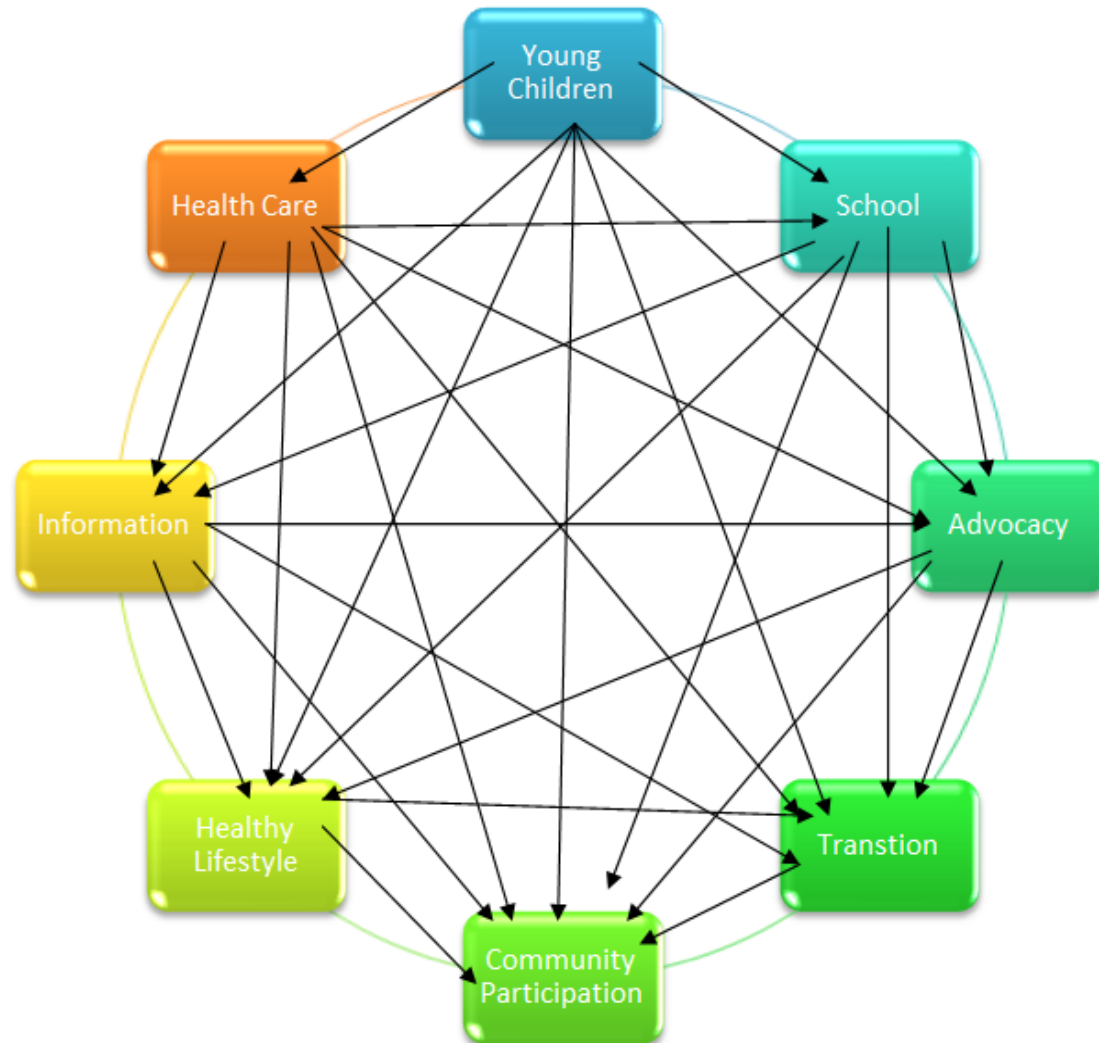
Health Advocacy Across the Lifespan

Funded by the NJ Council on Developmental Disabilities © 2014



*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

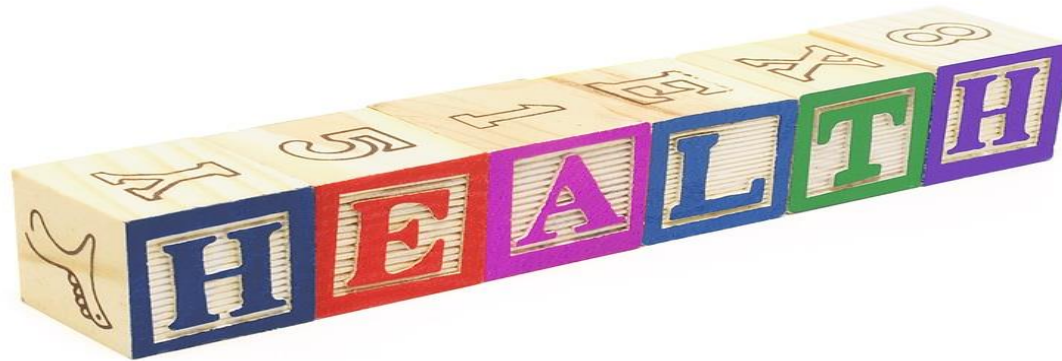
I wrote this manual to help other families of children with special needs and the professionals who work with them. My daughter now has 5 life-threatening conditions, and autism just to keep things interesting. We have been through everything from early intervention to currently going through transition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

Lauren Agoratus

NJ Coordinator-Family Voices @ SPAN



Health Insurance & Healthcare Financing



Health Insurance

- Affordable Care Act
- NJ Family Care
 - Medicaid
 - State Children’s Health Insurance Program
 - Medicare
- Other
 - Autism & Other DD Health Insurance Mandate
 - Mental Health Parity



Affordable Care Act (ACA)



Benefits for Women

Providing insurance options, covering preventive services, and lowering costs.

Young Adult Coverage

Coverage available to children up to age 26.

Strengthening Medicare

Yearly wellness visit and many free preventive services for some seniors with Medicare.

Holding Insurance Companies Accountable

Insurers must justify any premium increase of 10% or more before the rate takes effect.

TIMELINE



Starting in 2014, everyone must either:

1. Have Minimum Essential Coverage



They are already covered and don't need to do anything.

OR

2. Have a Coverage Exemption



They don't have to get coverage and won't have to pay a fee for not having coverage.

OR

3. Pay a fee (Shared Responsibility Payment)



They should consider getting coverage. If they don't, they will pay a fee.

What is Minimum Essential Coverage?

- If you have coverage from any of the following, you are covered and **don't have to do anything**
 - Employer-sponsored, including COBRA and retiree coverage
 - Medicare
 - Medicaid
 - Children's Health Insurance Program (CHIP)
 - Marketplace Coverage
 - Individual Coverage (outside the Marketplace)
 - TRICARE or certain types of VA coverage



About 85% of Americans already had Minimum Essential Coverage.

Marketplace and People With...

- Medicare
 - Medicare isn't part of the Marketplace so you don't need to do anything
- COBRA
 - You can drop COBRA and enroll in the Marketplace
 - During the Marketplace Open Enrollment Period
 - Within 60 days of COBRA expiring (Special Enrollment Period)
- Pre-existing Condition Insurance Plan (PCIP)
 - Ends December 31, 2013
 - Need to apply for Marketplace coverage by the deadline, to avoid a break in coverage (no automatic transition)

Who can get a coverage exemption and not have to pay a fee?

EXEMPT

- You may get a coverage exemption if you
 - Are conscientiously opposed (religious conscience)
 - Are a member of a recognized health care sharing ministry
 - Are a member of a Federally recognized Indian tribe
 - Don't make the minimum income required to file taxes
 - Have a short coverage gap (<3 consecutive months)
 - Suffered a hardship
 - Did not have access to affordable coverage (cost of available coverage >8% of household income)
 - Were incarcerated (unless pending disposition of charges)
 - Were not lawfully present

You May Pay a Fee

- You may pay a fee when you file your 2015 Federal tax return in 2016 (and thereafter)
 - If you don't have minimum essential coverage, and
 - You don't qualify for an exemption
- Paying the fee does not provide health coverage



Less than 2% of Americans are expected to have to pay the fee.

The fee you would pay

- You pay the greater of the flat dollar amount or the percentage of income

	2014	2015	2016 and beyond
Flat dollar amount (annual)	<ul style="list-style-type: none"> \$95 per adult 50% if under 18 	<ul style="list-style-type: none"> \$325 per adult 50% if under 18 	<ul style="list-style-type: none"> \$695 per adult* 50% if under 18
	Or	Or	Or
Percentage of income (annual)	<ul style="list-style-type: none"> 1% of household income 	<ul style="list-style-type: none"> 2% of household income 	<ul style="list-style-type: none"> 2.5% of household income

* After 2016 - Plus an increase based on cost of living

Not eligible for Medicaid?

SHOP the

Marketplace

Individuals or families
with an annual income
>138% up to 400%
of Federal poverty limit

Are eligible for financial assistance
to help with health insurance costs
Premiums will not exceed 9.5% of income

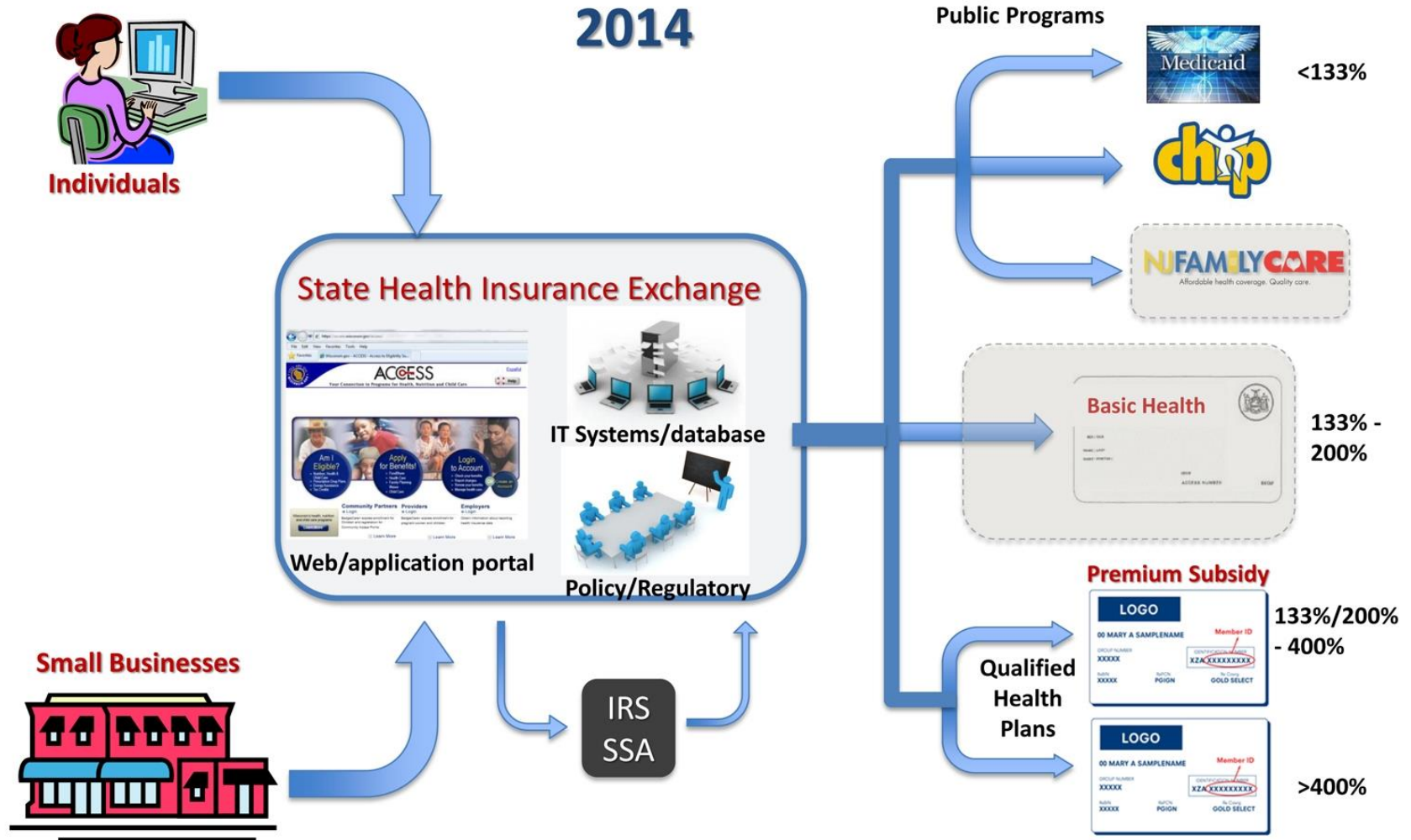
A New Way to Shop for Health Insurance

- 1-stop comparison shopping
- Provides information on Qualified Health Plan costs before you buy
(premiums/deductibles/out-of-pocket costs)
- Access to subsidies for consumers who qualify





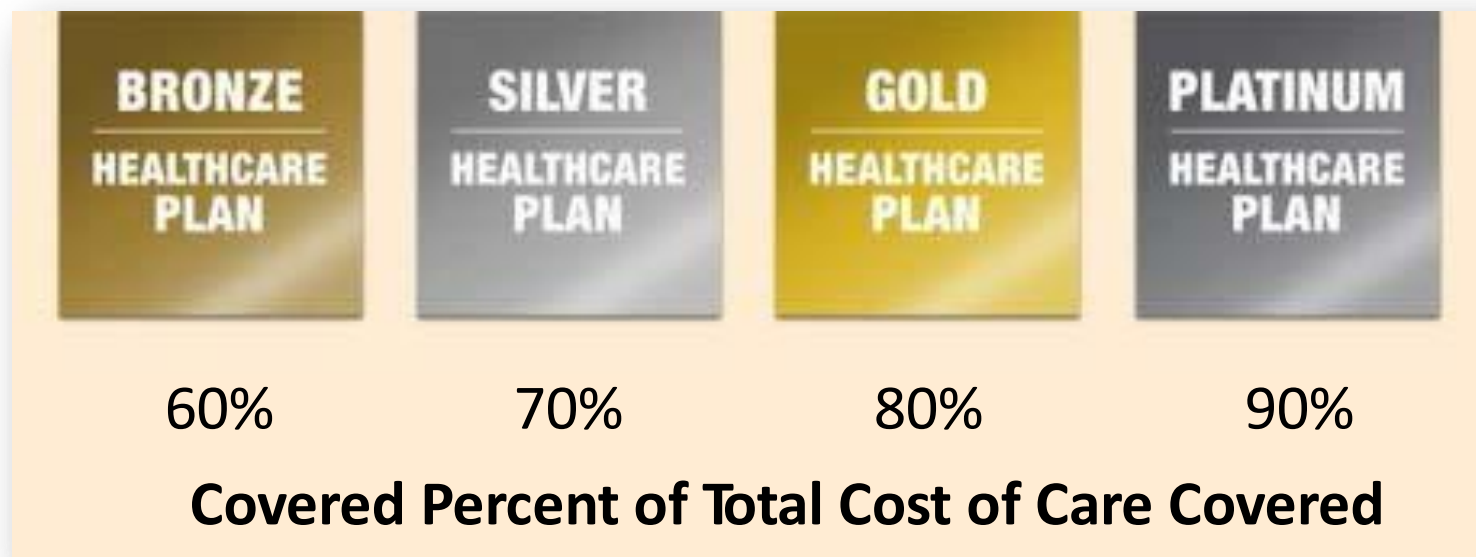
What is a Health Insurance Exchange?



Plan Levels of Coverage

**Lowest Premiums
Highest Out-of-Pocket Costs**

**Highest Premiums
Lowest Out-of-Pocket Costs**



Marketplace Subsidies

Premium Tax Credits

- WHAT: Tax credit applied to premium cost up front
- WHO: Available to individuals & families with income between 100 – 400% of the Federal Poverty Limit
- HOW MUCH: For those receiving subsidies premiums will range between 2 – 9.5% of income

Qualifying for Marketplace subsidies

- Meet income eligibility: Individuals/families with income 100 - 400% of Federal Poverty Level
- Must be ineligible for health benefits through another source – other than individual marketplace
- Individuals who can get insurance through an employer can get subsidized coverage through exchange if:
 - Employer premiums are unaffordable ($> 9.5\%$ of HH income)
 - Plan pays less than 60% of cost of covered benefits

Premium limits based on income

Income	Premium limit
Up to 133% of FPL	2% of income
133 – 150% of FPL	3 – 4% of income
150 – 200% of FPL	4 – 6.3% of income
200 – 250% of FPL	6.3 – 8.05% of income
250 – 300% of FPL	8.05 – 9.5% of income
350 – 400% of FPL	9.5% of income

Who is Eligible for a Cost-Sharing Reduction?

- Eligibility for reduced cost sharing is based on
 - Income at or below 250% of the FPL (\$59,625 annually for a family of four in 2013)
 - Receiving the Premium Tax Credit
 - Enrollment in a Marketplace Silver-level plan
- Members of Federally-recognized Indian Tribes
 - No cost sharing if income is <300% FPL

Out of Pocket Limits for Qualified Consumers on Marketplace

Income	Out of Pocket Limit *	Individual	Family
100 - 200% FPL	1/3 HSA limit	\$1983	\$3966
200 - 300% FPL	1/2 HSA limit	\$2975	\$5950
300 – 400% FPL	2/3 HSA limit	\$3966	\$7932
Above 400% FPL	100% HSA limit	\$5950	\$11,900

*HSA – Health Savings Account - Based on 2010 limits

Ways to Use a Premium Tax Credit

If you choose to...	Is your monthly premium lower?	Will you get a credit on Federal tax return?	Will you have to pay back money?*
Use all of your premium tax credit	Yes	Not likely	Maybe
Use part of your premium tax credit	Yes	Maybe	Not likely
Use none of your premium tax credit	No	Yes	No

*You should report changes in household size and income as soon as possible to ensure you are getting the right premium tax credit amount and avoid having to pay anything back.

Catastrophic Plans

- What is catastrophic coverage?
 - Plans with high deductibles and lower premiums
 - You pay all medical costs up to a certain amount
 - Includes coverage of 3 primary care visits per year and preventive services with no out-of-pocket costs
 - Protects consumers from high out-of-pocket costs
- Who is eligible?
 - Young adults under 30 years of age
 - Those who obtain a hardship exemption from the Marketplace



How the Marketplace Works?



Create an account

First provide some basic information. Then choose a user name, password, and security questions for added protection.



Apply

Next you'll enter information about you and your family, including your income, household size, other coverage you're eligible for, and more.

Visit HealthCare.gov to get a checklist to help you gather the information you'll need.



Pick a plan

Next you'll see all the plans and programs you're eligible for and compare them side-by-side.

You'll also find out if you can get lower costs on monthly premiums and out-of-pocket costs.



Enroll

Choose a plan that meets your needs and enroll!

Coverage starts as soon as January 1, 2014.



In Person Assistance

- Marketplace in person help is available
 - Certified Assisters
 - Navigators
 - Non-Navigator assistance personnel
 - Certified Application Counselors
 - Agents and brokers
 - To find assistance in your area, go to Localhelp.HealthCare.gov



Visit Marketplace.cms.gov for information on your organization becoming a Champion for Coverage

Marketplace.cms.gov

Get the latest resources to help people apply, enroll, and get coverage in 2014

Click “Get Training” for helpful videos

Plan Compare (long version)



The screenshot shows the CMS.gov Health Insurance Marketplace homepage. At the top left is the CMS.gov logo and 'Health Insurance Marketplace' text. Below it is the text 'Centers for Medicare & Medicaid Services'. On the top right, there are links for 'About CMS', 'FAQs', 'Print', and 'Share', along with a search bar containing the text 'Type search term here' and a 'Search' button. Below the search bar is a 'Get email updates' link. The main content area features the 'Health Insurance Marketplace' logo and two paragraphs of text: 'If you're a professional learning about the Marketplace and helping people apply, get the latest resources here.' and 'If you're a consumer ready to learn about and buy health insurance through the Marketplace, visit HealthCare.gov, the official consumer site for the Marketplace.' At the bottom, there is a dark navigation bar with two buttons: 'Partner with us' and 'Get training', both with right-pointing arrows. The 'Get training' button is circled in red.

Join us to become a Champion >
for Coverage

Apply to be a certified
application counselor
organization >

Looking for consumer
information?

Visit HealthCare.gov, the official consumer
site for the Marketplace.

Get consumer information >

Have questions?

Find the right answers to your questions
about the Marketplace.

Get answers >

ACA Patient's Bill of Rights



The Affordable Care Act (ACA) has several patient protection measures that help children with special needs including:

- No lifetime caps and limited annual caps
- No rescinding policies due to getting sick
- Insurers cannot deny coverage due to pre-existing conditions
- Protects your choice of doctor
- Ends bureaucratic hurdles to emergency services
- Dependent coverage to age 26 (NJ is 31)
- Prevention services/preventative care with no cost share

Ensuring the right to choose your doctor



Choosing your doctor

- ❖ If you are enrolled in a health plan that requires you to designate a specific primary care provider, you are guaranteed the right to choose that doctor from within the plan's provider network, as long as s/he is accepting new patients like you. You must be informed of your right to pick your primary care provider. Until you do so, the plan may select one for you. You may designate a pediatrician as your child's primary care provider.



The ACA helps children with pre-existing conditions



The ACA helps children with pre-existing conditions

- Insurers cannot deny policies to children with pre-existing conditions
- Insurers will have to accept everyone who wants to purchase a plan, regardless of their health status. Health plans won't be able to exclude coverage of pre-existing conditions from their policies. This means that health plans can't refuse to cover your child's treatment solely because s/he already had a health condition when s/he joined the plan.

*Children with special health care needs
can get insurance to treat their illnesses*

Denial of specific treatments

The image shows a 'NEW YORK HEALTH INSURANCE CLAIM FORM'. A large, bold, red 'DENIED' stamp is superimposed diagonally across the entire form. The form contains various fields for patient and insurer information, including SSN, birth date, relationship to insured, address, and policy details. At the bottom, there are sections for medical history, diagnosis codes, and charges.

- Your insurance company can still deny coverage of a particular treatment if your plan does not offer coverage of that specific treatment to *anybody* enrolled in the plan.

ACA Essential Health Benefits



How Qualified Health Plans Can Vary

- Some plans may cover additional benefits
- You may have to see certain providers or use certain hospitals
- The premiums, copays, and coinsurance are different in different plans
- The quality of care can vary
- The coverage level can vary within each plan
- Some special types of plans are structured differently
 - Like high-deductible (catastrophic) plans



ACA Dependent Coverage



If your state has benefits such as dependent coverage (NJ is age 31), preexisting condition coverage, or mental health parity that's better than the federal law, state law will still apply.

The ACA helps people with chronic conditions or catastrophic illness



The ACA helps people with chronic conditions or catastrophic illness



- Health insurance companies can no longer place lifetime caps on coverage
- Limits annual coverage limits
- Creates a new, more affordable insurance option for people with chronic illnesses
- No unfair rescission of benefits because your child's care gets "too expensive"

Rescission of benefits

ADVANCE NOTICE

- Insurance companies will only be able to rescind policies if you commit fraud (you knowingly and willfully misrepresent or omit a piece of information relevant to your plan)
- You are protected if you stay in your current plan or if you buy or enroll in a new plan
- You are entitled to 30 days advance written notice if the plan wants to rescind coverage, and you have the right to appeal



Rescission of benefits

- Insurance companies will only be able to rescind policies if you commit fraud (you knowingly and willfully misrepresent or omit a piece of information relevant to your plan)
- You are protected if you stay in your current plan or if you buy or enroll in a new plan
- You are entitled to 30 days advance written notice if the plan wants to rescind coverage, and you have the right to appeal

Rescission of benefits

Insurers can cancel your policy if:

- *You stop paying premiums*
- *The insurer stops offering your insurance plan or leaves the insurance market in your area*
- *You move away, and the location of your new residence is not in the insurer's service area*
- *You get your coverage through an association, and you end your association membership*



ACA Annual & Lifetime Limits



- Annual limits apply on an individual basis
- If your child reaches their annual limit, the essential medical care that you and other members of your family get will still be covered by your health plan
- Some plans that have annual limits below \$750,000 now can apply for a waiver from the Secretary of Health & Human Services if they would have to significantly decrease benefits or raise premiums to comply

The ACA helps ensure
fair treatment for emergency care




The ACA helps ensure fair treatment for emergency care



- If you have an emergency medical condition (symptoms are severe enough that you would put your health in jeopardy or might be seriously harmed if you don't get immediate attention), you can get emergency medical screening and treatment at a hospital

The ACA helps ensure fair treatment for emergency care



- **Your health plan CANNOT:**
 - Require you to get preauthorization for emergency services
 - Make you go thru extra administration hurdles to get out-of-network emergency services covered
 - Charge you higher co-payments or co-insurance for out-of-network emergency services than it charges for in-network emergency services
 - Limit coverage for out-of-network emergency care more than it would limit care in-network

The ACA helps ensure fair treatment for emergency care



- Balance billing:
 - If a health care provider is not in the plan's network, that provider may not accept the plan's payment rates for a service, and may bill you the difference between what the plan pays for the service and what s/he charges
 - Your plan must pay emergency provides the greatest of the amount it pays in-network providers, a payment based on the same method it uses to pay for other out-of-network services (such as a % of usual and customary fees), or the amount Medicare would pay for that service

Your Right to Appeal



Photo: [Creative Commons UBC Library Graphics](#)

Ensuring the right to appeal health plan decisions



If you disagree with your plan's refusal to pay for care, the plan will have to review its decision

If you are not satisfied with that decision, you will have the right to appeal that decision to an independent reviewer who is outside of the health plan (consumers who appeal outside of their insurance companies win their cases about 45% of the time)

You can appeal a plan's decision not to pay for a benefit, or to reduce or end a covered service, which must be provided in writing through formal notice, when the plan says any of the following:

Ensuring the right to appeal health plan decisions



- The care is not medically necessary or appropriate
- You are not eligible for the health plan or benefit
- You have a pre-existing condition
- The care is experimental or investigational
- Your coverage is being rescinded

The Appeal Process



- (1) Ask for an internal review** by other people in the health plan not involved in the original decision. They must consult with appropriate medical experts, & give you the details of why the plan refused to pay for your care, and allow you to review your file, get the medical evidence used, and the plan's guidelines about when it does and doesn't pay for the type of care you requested, at no charge. You may present testimony and more evidence, and respond to any evidence the plan uses. You can ask a consumer assistance program or other advocate to help you, such as your state's F2F HIC. The plan must expedite its review if the matter is urgent & you request it. The plan must give you a final decision notice that explains how you can get external, independent review.

The Appeal Process



- (2) If you are not satisfied, request an external appeal.** You have a least 4 months to request an external review, to gather doctor statements, medical literature, and other evidence you might want to submit with your request for an appeal. After you submit your request, you will receive notice that you have 5 more business days to submit any additional information you want considered, and if the plan submits additional info, you may respond to it. The independent reviewer makes a decision within 45 days, or 72 hours (or sooner) if the matter is urgent. The plan must follow the reviewer's decision.

The ACA helps young adults



Photo: [Creative Commons UBC Library Graphics](#)

The ACA helps young adults



- Young adults up to age 26 can remain on their parents' health insurance (NJ already allows young adults up to age 30 to stay on their parents' health insurance), even if they are not students, don't live at home, and don't live in the same state as their parents!
- *It will help young adults stay healthy and protect them in the case of an accident*

Who is eligible?



- Their parent has coverage through their employer or buys family coverage in the individual market
- The plan provides “dependent coverage” (but the young adult does NOT have to be dependent on their parent(s), and does not have to live with their parent(s))
- The young adult doesn’t have a plan that offers health coverage

Getting back into the parents' plan



Young adults who have already lost coverage before the law goes into effect but who are not yet 26 will have a special one-time opportunity to re-enroll in their parents' plan. Their parents will receive notice of the opportunity at the beginning of the new plan year, and the young adults will have 30 days to enroll.

Avoiding breaks in coverage



It is especially important for young adults to avoid breaks in coverage of 63 days or more, because such gaps strip them of protections against pre-existing condition exclusions.

For more information, see *Your Guide to HIPAA Protections*, sections 7 and 8, online at <http://www.familiesusa.org/issues/private-insurance/legal-rights/guide-to-hipaa-protections.html>.

Tax implications



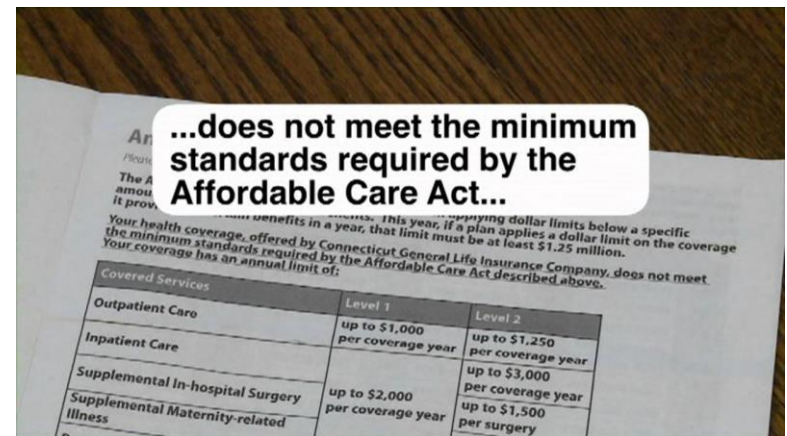
Job-based health benefits for young adults on their parents' health plans are **NOT** considered taxable income!

The ACA protects people from
“junk insurance”



The ACA protects people from “junk insurance”

- The ACA sets standards for policies, and eliminates co-pays for preventive care (Bright Futures standards for children’s preventive care)
- Insurers have to use more of your premium dollars to provide care, and limit what goes to salaries and administrative costs
- Insurance premium hikes are subject to scrutiny



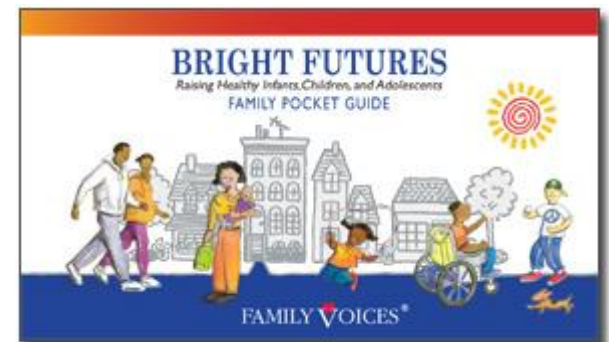
Preventive Care/Health Promotion

Preventive Health Care



ACA Preventive Services

- 27 Preventive children's services
 - Screening for children & adolescents
 - Immunizations
- 22 Preventive benefits for women
- 16 covered preventive services for all adults (men & women)
 - Screening services
 - Counseling services
 - Other services





- Families can apply for coverage during open enrollment (or special enrollment if there are life changes) at www.healthcare.gov
- Parents can see how healthcare reform has helped other families in the Family Healthcare Story Book at [http://www.spannj.org/Family2Family/NJ Family Healthcare Stories REVISED.pdf](http://www.spannj.org/Family2Family/NJ_Family_Healthcare_Stories_REVISED.pdf).
- Updated information is available from the Georgetown Center for Children and Families at <http://ccf.georgetown.edu/aca/>
- Check out our ongoing blog on the ACA at <http://www.fv-ncfpp.org/blog>



OTHER RESOURCES

Family Voices: www.familyvoices.org

Families USA: www.familiesusa.org or
www.standupforhealthcare.org

Catalyst Center: www.catalystctr.org

Community Catalyst: www.communitycatalyst.org

NJ Citizen Action: www.njcitizenaction.org

Kaiser Family Foundation:
<http://healthreform.kff.org>

Commonwealth Fund:
<http://www.commonwealthfund.org/Health-Reform/Health-Reform-Resource.aspx>



Photo blog.equifax.com

Insurance Plans/Appeals

Closely related to financial burden is getting the most out of insurance coverage.

- ✓ Families can use the “disabled dependent” provision to continue insurance as long as the parent stays employed by that company.
- ✓ Families can “appeal” if a claim is denied; usually a doctor’s note is all they need.

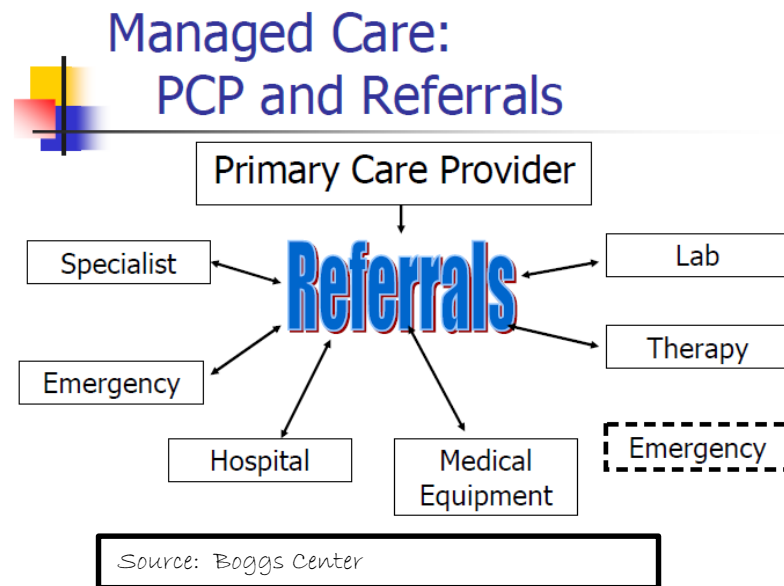
Insurance Plans/Coverage

Children may be eligible for Medicaid or Medicare.

- ✓ If the doctor doesn't take Medicaid they can still get reimbursed if it is secondary coverage by calling the HMO for the out-of-network billing process.
- ✓ If the doctor doesn't take Medicare, they can send their "opt-out" letter to the private insurance with the bill. Families can also file claims at <http://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/CMS-Forms-Items/CMS012949.html>
- ✓ See "When You Have Medicaid and Other Insurance"
http://www.state.nj.us/humanservices/dmahs/home/Medicaid_TPL_Coverage_Guide.pdf

Managed Care

Managed care is a system of health care delivery and financing which coordinates and provides timely access to high-quality, medically-necessary health care services for its members in a cost-effective manner.





Hallmarks of Managed Care:

- Using specific providers (in the insurance company network)
- Not relying on the emergency room for primary care services
- Authorizing of specialty care and referrals (a primary care physician such as a pediatrician or family practitioner would do this)

M A N A G E D
Care

Key Points:

- Any child with special needs in NJ Medicaid is entitled to a care manager.
- Parents can use the “prudent layperson” definition which means if they as a non-medical layperson think that the child needs emergency care, they can go to the E.R.

Medicaid



Photo www.yalescientific.org

Medicaid is a joint Federal-State program which pays for health care services for low income families with dependent children, senior citizens, and people with disabilities, as well as some people who are medically needy because their health expenses are high.



- See “Your Guide for Making Medicaid Managed Care Work for You”
<http://rwjms.rutgers.edu/boggscenter/products/documents/MedicaidManagedCareEnglishfinal2011.pdf>
- An important part of Medicaid for children is EPSDT (Early Periodic Screening Diagnosis & Treatment) providing access to all medically necessary care
<http://mchb.hrsa.gov/epsdt/overview.html>



Affordable health coverage. Quality care.

In NJ, Medicaid and SCHIP (State Children's Health Insurance Program) are together. Information on Medicaid/SCHIP can be found under the Family Care Program. Various resources for NJFC include:

- NJ FamilyCare factsheet
http://www.njfamilycare.org/docs/healthy_facts_english.pdf

- Healthy Facts at a Glance
http://www.njfamilycare.org/docs/healthy_facts_english.pdf

- Important News: Will Using Benefits Hurt my Chances of Getting a Green Card or Becoming a U.S. Citizen?
http://www.njfamilycare.org/docs/flyer_english.pdf

NJ Family Care-Eligibility

Child Eligibility

- 18 years or younger
- Income meets program guidelines (next slide)
- NJ resident
- US citizen or permanent resident
- Uninsured for at least 3 months prior to application (unless family income 133% of FPL or less; COBRA has expired; lost job through no fault; 200% of FPL or < can voluntarily drop COBRA or private insurance)

Adult Eligibility

- 133% or <of FPL
- NJ resident
- US citizen or permanent resident who has been in US at least 5 years
- Prior to Medicaid expansion, only parents of eligible children were eligible for NJ Family Care; now, even single adults are eligible

NJ Family Care-Income Limits

Children

- Up to 350% of FPL
 - 0-150% FPL: No premium or co-pay
 - 150-200% FPL: No premium, \$5-\$10 co-pay
 - 200-250 FPL: \$43 monthly premium, \$5-\$35 co-pay
 - 250-300% FPL: \$86 monthly premium, \$5-\$35 co-pay
 - 300-350% FPL: \$144.50 monthly premium, \$5-\$35 co-pay

Adults

- Childless adults: 133% FPL
- Adults with children: 133% of FPL based on family size
- Pregnant women: 200% FPL



Affordable health coverage. Quality care.

Gross Income Guidelines as of July 1, 2014

1-800-701-0710

1-800-701-0720(TTY)

www.njfamilycare.org

Federal Poverty Level Range	Family Size One person	Family Size 2 people	Family Size 3 people	Family Size 4 people	Family Size 5 people	Family Size 6 people	Family Size 7 people		
	Maximum Annual/ Monthly Income	Maximum Annual/ Monthly Income	Maximum Annual/ Monthly Income	Maximum Annual/ Monthly Income	Maximum Annual/ Monthly Income	Maximum Annual/ Monthly Income	Maximum Annual/ Monthly Income	Premiums	Copayments
0 - 133%	\$15,522	\$20,921	\$26,321	\$31,721	\$37,121	\$42,521	\$47,920	No premium	No copay
	\$1,294	\$1,744	\$2,194	\$2,644	\$3,094	\$3,544	\$3,994		
0 - 142%	\$16,572	\$22,337	\$28,102	\$33,867	\$39,633	\$45,398	\$51,163	No premium	No copay
	\$1,381	\$1,862	\$2,342	\$2,823	\$3,303	\$3,784	\$4,264		
> 142 - 150%	\$17,505	\$23,595	\$29,685	\$35,755	\$41,865	\$47,955	\$54,045	No premium	No copay
	\$1,459	\$1,967	\$2,474	\$2,982	\$3,489	\$3,997	\$4,504		
> 150 - 200%	\$23,340	\$31,460	\$39,580	\$47,700	\$55,820	\$63,940	\$72,060	No premium	\$5 - \$10
	\$1,945	\$2,622	\$3,299	\$3,975	\$4,652	\$5,329	\$6,005		
> 200 - 250%	\$29,175	\$39,325	\$49,475	\$59,625	\$69,775	\$79,925	\$90,075	\$43.00 monthly per family	\$5 - \$35
	\$2,432	\$3,278	\$4,123	\$4,969	\$5,815	\$6,661	\$7,507		
> 250 - 300%	\$35,010	\$47,190	\$59,370	\$71,550	\$83,730	\$95,910	\$108,090	\$86.00 monthly per family	\$5 - \$35
	\$2,918	\$3,933	\$4,948	\$5,963	\$6,978	\$7,993	\$9,008		
> 300 - 350%	\$40,845	\$55,055	\$69,265	\$83,475	\$97,685	\$111,895	\$126,105	\$144.50 monthly per family	\$5 - \$35
	\$3,404	\$4,588	\$5,773	\$6,957	\$8,141	\$9,325	\$10,509		

Family size larger than 7 people call 1-800-701-0710 for guidelines.

- Children
- Adults

NJ Family Care

- Apply online at www.njfamilycare.org or www.njhelps.org
- Download application from www.njfamilycare.org or call 1-800-701-0710 to request an application be mailed to you
- Apply at your local County Welfare Agency.

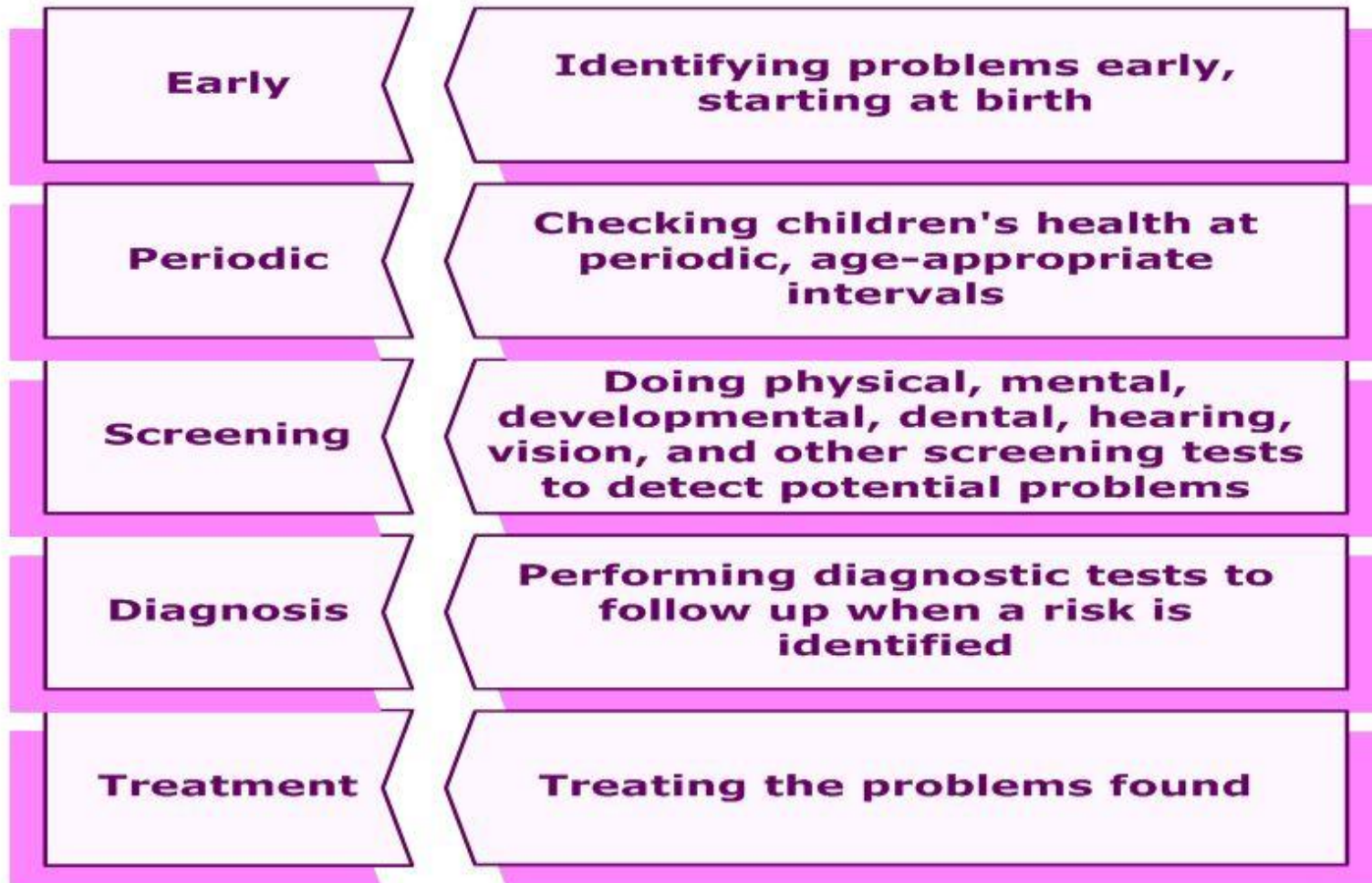




Medicaid & EPSDT

- 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

Early and Periodic Screening, Diagnosis, and Treatment



EPSDT screening

- Health & developmental history, including mental health
- Comprehensive physical exam
- Vision: Diagnosis/treatment for vision defects, including eyeglasses
- Dental: Maintenance of dental health, relief of pain/infections, restoration of teeth
- Hearing: Diagnosis/treatment for defects in hearing, including hearing aids
- Lead poisoning
- Appropriate immunizations
- Laboratory tests
- Health education





- *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

What's covered in NJ Family Care

- Doctor visits
- Eyeglasses
- Hospitalization
- Lab tests
- X-rays
- Prescriptions
- Regular check-ups
- Mental health
- Dental
- Preventive screenings



Dental Care under Medicaid

- The New Jersey Medicaid contract requires specific policies for the provision of services to enrollees with developmental disabilities including
 - Consultation with patient caregivers
 - Reimbursement for initial & follow-up visits to provide comprehensive exam & services
 - Up to 4 visits annually without prior authorization
 - Home visits when medically necessary
 - Adequate support staff to meet patient needs
 - Use & replacement of fixed or removable prosthetic devices
 - Pre-post operative evaluations
 - Oral hygiene instructions to caregivers to maintain a patient's oral health between visits including designing and implementing a “dental management” plan, coordinated by the care manager
 - Care manager must coordinate authorizations for dentally required hospitalizations by consulting with the plan's dental and medical consultants in an efficient and time-sensitive manner



Other Medical Programs for Children Under 21

- *Medicaid Special:* Children under the age of 21 who do not qualify for other NJ FamilyCare/ Medicaid programs may be eligible for the Medicaid Special program. Family income for all family members living in the same household is used to determine financial eligibility. For instance, children 19 or 20 years old who have “aged out” of NJ FamilyCare/Medicaid may be eligible if their family has earned income at or below 133% of the federal poverty level.
- *Medically Needy:* This program provides limited health coverage to children under 21 who do not qualify for regular NJ Medicaid because their family income or financial resources are too high. It includes a “spend down” provision that allows documented medical expenses to be used to reduce monthly income to meet eligibility limits. Children who qualify for this program receive most Medicaid services except in-patient hospital care. Find more information at www.state.nj.us/humanservices/dmahs/clients/medicaid/medically_needy_fact_sheet.pdf and www.state.nj.us/humanservices.dmahs/clients/medicaid/medically_needy_checklist.pdf.



Some families have had difficulties with the “Disabled Adult Child (DAC)” provision affecting Medicaid eligibility. This means that if the child had SSI before but the parent becomes disabled, retires, or dies; the child is a DAC and should maintain Medicaid eligibility.

There are two good publications are:

- ❑ “Disabled Adult Children” at [http://www.state.nj.us/humanservices/ddd/documents/Document%20for%20Web/DisabledAdultChildren\(DAC\).pdf](http://www.state.nj.us/humanservices/ddd/documents/Document%20for%20Web/DisabledAdultChildren(DAC).pdf)
- ❑ “Continued Eligibility for Disabled Adult Children” at http://www.state.nj.us/humanservices/dmahs/info/resources/medicaid/2013/13-03_Continued_Eligibility_For_Disabled_Adult_Children_DAC.pdf

Medicaid Concerns

Families can ask questions about their Medicaid benefits from their HMO member services or care manager. If families still have concerns they can try:

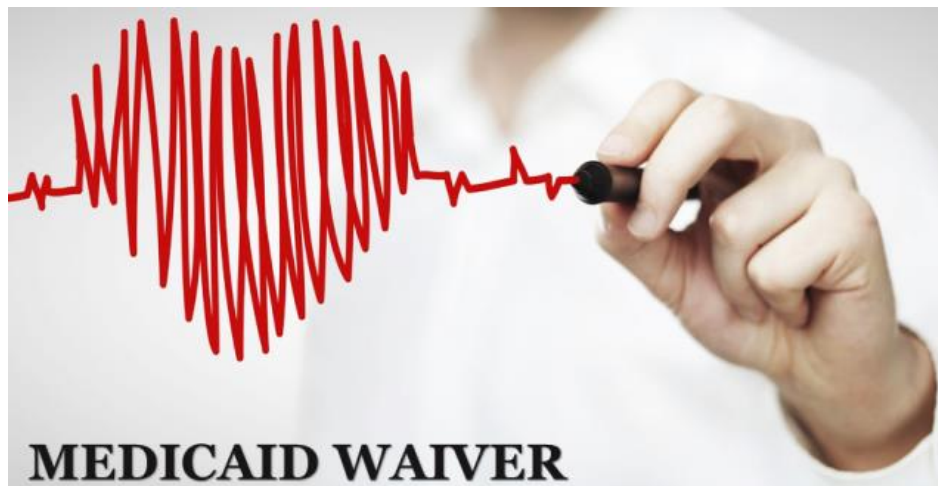
- ❑ NJ Medicaid hotline at (800)356-1561
- ❑ Medical Assistance Customer Centers at <http://www.state.nj.us/humanservices/dmahs/info/resources/macc/>

Families can also look at “A Guide to the Medicaid Appeals Process” at <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8287.pdf>.

Forthcoming changes using the NJ Comprehensive Medicaid Waiver can be found at <http://www.state.nj.us/humanservices/dmahs/home/waiver.html>.

If families haven't been able to resolve the issue, they can fill out the Medicaid problem reporting form found at <http://www.spannj.org/medicalproblemreportingform.htm>.

The last resort is a Medicaid fair hearing and there is a guide with tips on how to prepare at <http://pandasc.org/wp-content/uploads/2012/01/Medicaid-Fair-Hearing.pdf>



MEDICAID WAIVER

- Please note that effective 7/1/14, 4 Medicaid waivers transitioned to Medicaid Managed Long Term Services and Supports found at <http://www.state.nj.us/humanservices/dmahs/home/mltss.html>.
- Also see SPAN's update with resources at <http://www.spanadvocacy.org/content/nj-medicaid-waivers-transition-managed-care-effective-7114>

Medicare



Photo www.Medicare.gov

Some children with special health care needs may also be eligible for Medicare (e.g. kidney transplant) or if their parent retires, becomes disabled, or passes away.

As adults, some children with disabilities may become dually eligible for both Medicaid and Medicare.

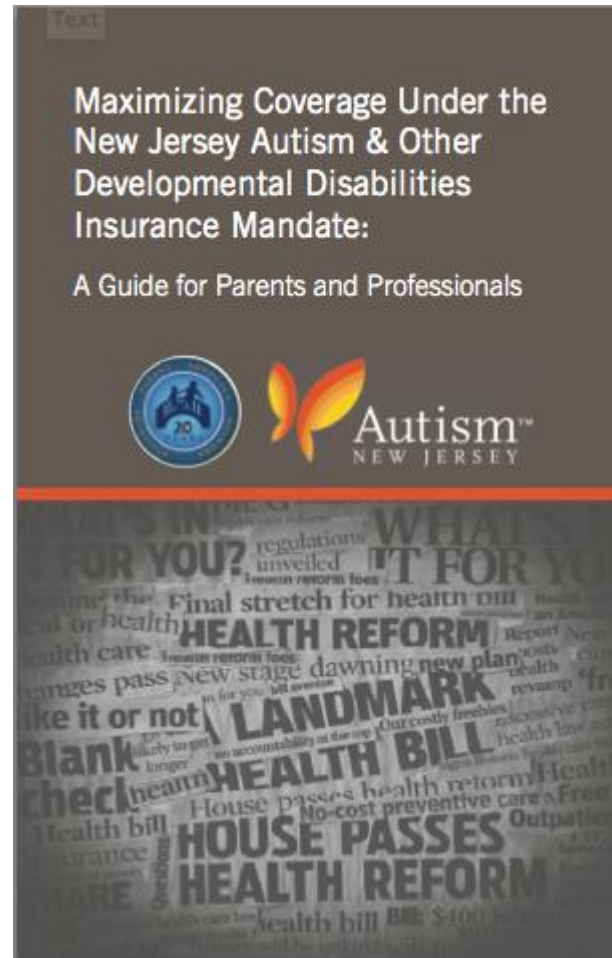
Other Health Insurance Issues

- Autism & Other DD Health Insurance Mandate
- Mental Health Parity



Autism & Other DD Insurance Mandate

www.spanadvocacy.org/content/maximizing-coverage-under-nj's-autism-other-developmental-disabilities-insurance-mandate



Mental Health



Photo www.nami.org

Mental Health is just as important as physical health. The Affordable Care Act strengthened access to mental health services.



Federal Laws

- Wellstone-Domenici Mental Health Parity and Addiction Equity Act
 - Employers with 50 or more employees whose group health plan chooses to offer mental health or substance abuse disorders
 - Requires mental health parity; can't limit benefits or require higher costs, set higher deductibles or co-pays, stricter limits on treatment
 - Includes depression, autism, schizophrenia, eating disorders, and alcohol and drug abuse
- State Children's Health Insurance Program
 - Qualifying financial requirements and treatment limitations for mental health or substance use disorder benefits can't be more restrictive than those applied to medical surgical benefits. No separate qualifying criteria may be applied to mental health/substance use disorder benefits. When out-of-network coverage is available for medical surgical benefits, it must also be available for mental health or substance use disorder benefits

New  Jersey

Mental Health Cares

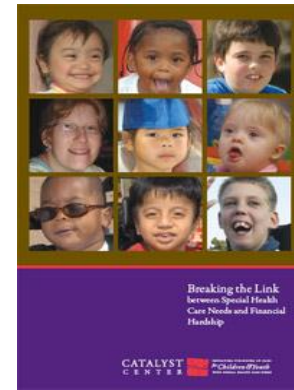
- *NJ Biologically Based Mental Illness Mandate (1999)*: This requires all health insurers in the state who are covered by the NJ Department of Banking and Insurance to cover treatment of “biologically-based mental illness” according to the same conditions for other illnesses and diseases. This also covers small employers. Biologically-based mental illness means a mental or nervous condition that is caused by a biological disorder of the brain and results in a clinically significant or psychological syndrome or pattern that substantially limits the functioning of the person with the illness, including but not limited to schizophrenia, schizoaffective disorder, major depressive disorder, bipolar disorder, paranoia and other psychotic disorders, obsessive-compulsive disorder, panic disorder, and pervasive developmental disorder or autism. Copayments, deductibles, and benefit limits for behavioral health services must be the same as for medical and surgical benefits. For more information, go to www.njleg.state.nj.us/9899/Bills/s2500/2277_i1.pdf or www.state.nj.us/dobi/division_insurance/ihcseh/bulletins/seh9906.htm.

Healthcare Financing Resources

- Catastrophic Illness in Children Relief Fund
- Economic & Health Resources for Families
- Family Leave Insurance
- NJ Helps
- Supplemental Security Income
- SSDI



Financial Issues



Parents of children with special healthcare need have financial burdens. General resources, including free medical care, are:

❑ Healthcare financing factsheet

http://www.spannj.org/ISG_HealthcareFinancingFactSheetSeries.pdf

❑ “Economic & Health Resources for Families” (including housing and utilities)

http://www.spanadvocacy.org/sites/g/files/g524681/f/files/Economic%20%26%20Health%20resources_2012_0.pdf



- Families can get reimbursed for extraordinary medical expenses or home modification at <http://www.state.nj.us/humanservices/cicrf/home/index.html>
- Parents can call 2-1-1 or check out resources at <http://www.nj211.org/>
- Families can apply online for benefits at <http://www.njhelps.org>

Catastrophic Illness in Children Relief Fund

MISSION

- Assist all NJ families cope with uncovered medical expenses for their children.
- Eligibility requirements:
 1. Child was 21 years of age or younger when expenses were incurred.
 2. Uncovered expenses incurred exceeded 10% of family's annual income, plus 15% of any excess income over \$100,000.
 3. Child's parents or legal guardian have been residents of NJ for at least three months prior to submitting an application.



www.njcatastrophicfund.org
800-335-FUND (3863)



Services Covered

- Specialized pediatric ambulatory care
- Addictions/mental health services
- Acute or specialized hospital care, both in and outpatient
- Physician care in all settings
- Medical equipment or disposable medical supplies
- Pharmaceuticals
- Medically related home modifications and medical transportation
- Home health care
- Medical transportation
- Experimental medical treatment or pharmaceuticals following special review
- Other medical expenses.

Financial Issues

- ❑ National family leave benefits are found at <http://www.dol.gov/whd/fmla/index.htm>
- ❑ NJ family leave information is at <http://lwd.state.nj.us/labor/fli/fliindex.html>
- ❑ Parents can help maximize their child's independence at transition age, see <http://www.njsilc.org/>



Supplemental Security Income (SSI)

According to the Social Security Administration (SSA), “Supplemental Security Income (SSI) program pays benefits to disabled adults and children who have limited income and resources.



Photo www.ssa.gov



- ❖ The Social Security Administration has a booklet on this and other benefits at <http://www.ssa.gov/pubs/index.html> (see Benefits for Children with Disabilities.)
- ❖ It is important to note that if the child isn't eligible for SSI due to family income, at age 18 h/she can reapply as a "family of one."

Supplemental Security Income

- Supplemental Security Income (SSI) makes monthly payments to people with low income and limited resources who are blind or disabled, or 65 or older. A child under age 18 (or 22 if regularly attending school) may qualify for SSI if s/he meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. A young adult age 18 and over may also qualify based on blindness or disability
- Child/young adult must not be working & earning more than \$860/ month, & must have countable resources of not more than \$2000; must have a physical or mental condition (or combination) that seriously limit life activity; conditions must have lasted or be expected to last at least 12 months
- Benefit Eligibility Screening Tool is at <https://s044a90.ssa.gov/apps12/best/benefits>
- There are two ways to contact Social Security. The first way is to visit www.socialsecurity.gov, their website, where you can receive information on all of Social Security's programs. The second way to contact Social Security is to call them at their toll-free number, 800-772-1213, or the local Social Security Office. For more information on SSI, you can access the Understanding SSI guide at www.ssa.gov/notices/supplemental-security-income/text-understanding-ssi.htm
- Apply in person with needed documents; may need to have medical appointment; Disability Determination Services decision takes 3-5 months except for certain severe conditions
- How much the child/young adult will receive in SSI benefits depends on their income, resources, and expenses, up to a maximum federal payment of \$603/month which New Jersey supplements with an additional \$27/month. Generally, the more income and resources, the less the SSI benefit.



SSDI



- SSDI is a federal program that pays benefits to people who *cannot* work because of a medical condition expected to last at least one year or result in death. It is not for people with partial or short-term disability. Certain family members of disabled workers can receive “family benefits.”
- To get disability benefits, an individual must meet two earnings tests: a “recent work test” based on age at the time of disability, and a “duration of work” test to a long enough work record under Social Security. The charts with the rules for these two tests are at www.ssa.gov/pubs/10029.html#part
- *What are family benefits and who is eligible?* Members of the family of an individual who qualifies for SSDI may qualify for benefits based on that individual’s work. Eligible family members include a spouse who is 62 or older; a spouse who is caring for a child younger than age 16 and disabled; an unmarried child, including an adopted child and in some cases a stepchild or grandchild, if the child is under age 18 or under age 19 if in school full time; and an unmarried child, age 18 or older, with a disability that started before age 22



SSDI

- *What are “child’s benefits” and who is eligible?* An adult who was disabled before age 22 may be eligible for “child’s benefits” if a parent is deceased or starts receiving retirement or disability benefits. A “child’s” benefit is paid on a parent’s Social Security earnings record. The disability decision is based on the disability rules for adults. The “adult child” must be unmarried, age 18 or older, and have a disability that started before age 22
- *What if the adult child is currently working?* The adult child can’t have earnings above \$900 a month, excluding certain work-related expenses. For more information about work and disability, refer to Working While Disabled-How We Can Help, www.ssa.gov/pubs/10095.pdf
- *What if the adult child is already receiving SSI benefits?* An adult child already receiving SSI benefits should check to see if benefits may be payable on a parent’s earnings record. Higher benefits and/or entitlement to Medicare might be possible.
- *What if the adult child is already receiving disability benefits on his or her own record?* An adult child already receiving disability benefits should still check to see if benefits may be payable on a parent’s earnings record. It is possible for an individual disabled since childhood to attain insured status on his/her own record and be entitled to higher benefits on a parent’s record.

Other Healthcare Financing Resources

- FQHCs/Community Health Centers
- NJ Charity Care
- Children's System of Care for Children with Mental Health challenges
 - County Care Management Organizations & County Family Support Organizations; Mobile response
- Children's System of Care for Children with I/DD

Federally Qualified Health Centers

- FQHCs are community-based organizations that provide comprehensive [primary care](#) and [preventive care](#), including [health](#), [oral](#), and [mental health/substance abuse](#) services to persons of all ages. Federally Qualified Health Centers (FQHCs) provide care specifically to medically underserved areas where healthcare access is otherwise limited or non-existent, especially for those who are uninsured and underserved
- FQHCs provide comprehensive primary care that includes physical, behavioral, and oral health, on-site or by referral, including obstetrics/ gynecology, prenatal care, pediatrics, well-child visits, vaccines, adolescent health, family practice, internal medicine, and geriatrics
- FQHCs offer nutrition care, pregnancy testing, social services, pharmacy discounts, and family dental services
- FQHCs accept payment for services through the following: • Medicaid • Medicare • Some commercial / private insurances • Self-pay • Sliding fee scale and discounts for those who demonstrate the ability to qualify.
- Most FQHCs offer bilingual services in English and Spanish. Visit or call one of the county based locations with clinic hours that include nights and weekends. Visit the website to find a FQHC near you at www.njpc.org/FQHC/directory.aspx.



NJ Charity Care

- The New Jersey Hospital Care Payment Assistance Program (Charity Care Assistance) is free or reduced charge care provided to patients who receive inpatient and outpatient services at acute care hospitals throughout NJ
- Hospital care payment assistance is available to New Jersey residents who:
 - Have no health coverage or have coverage that pays only for part of the bill: **and**
 - Are ineligible for any private or governmental sponsored coverage (such as Medicaid); **and**
 - Meet **both** the income and assets eligibility criteria
 - Hospital assistance is also available to non-New Jersey residents, subject to specific provisions
- The patient or prospective patient must apply for hospital care payment assistance at the hospital from which he/she plans to obtain or has obtained services at the business office or admissions office of the hospital
- The patient or responsible party must answer questions related to income and assets, and provide documentation of the income and assets.
- The hospital will make a determination of whether the applicant is eligible as soon as possible, but no more than ten working days from the time a complete application is completed
- Call the Health Care for the Uninsured Program during business hours at 1-866-588-5696 or email Charity.Care@doh.state.nj.us



Charity
Care

Mental Health

Family Support Organizations have information and support for parents at <http://njfamilyalliance.org/>.

NJ has the Children's System of Care and an overview of services, including emergency mobile response for crisis stabilization, is available at <http://www.nj.gov/dcf/about/divisions/dcsc/>.

Performcare's "Youth & Family Guide" is found at <http://www.performcarenj.org/pdf/provider/youth-family-guide-eng.pdf>.

NJ Children's System of Care-MH



- Care Management Organizations (CMOs)
- Family Support Organizations (FSOs)
- Mobile Response
- Perform Care (Contracted System Administration) (CSA)
 - 877-652-7624 or www.state.nj.us/dcf/families/csc

NJ Children's System of Care-I/DD

- The NJ DCF CSOC determines eligibility of individuals under age 18 for DD services, and provides support and services, deemed “clinically and functionally appropriate,” for individuals under the age of 21 with DD
- Services include:
 - Group home placements
 - In-Home supports
 - Assistive technology devices
 - Respite
 - Camp
 - Home and vehicle modifications
- Families are asked to provide insurance information to PerformCare; families that are not already Medicaid or NJ Family Care eligible are required to complete a NJ Family Care Application. Families requesting services for DD-eligible youth must apply for all benefits to which their youth may be entitled, including but not limited to Supplemental Security Income (see SSI fact sheet in this series). While all families are required to apply for Medicaid and/or Family Care, if families are not eligible for this health insurance, CSOC services may still be available. Eligibility for Medicaid is not a prerequisite to obtaining most services
- Call 877-652-7624 or go to www.performcarenj.org/families/disability/index.aspx



Hospitalization

Families of children with disabilities may need to be prepared for hospital stays, either through planned procedures or through the emergency room. Some tips:

- First aid/CPR training
- Emergency medication administration
- Know when to call the doctor or 911
- Monitor at night if needed
- Preparing for a hospital stay:
www.spanadvocacy.org/content/preparing-hospital-stay
- Surviving a hospital stay:
www.spanadvocacy.org/content/surviving-hospital-stay-your-child-special-healthcare-needsand-after

Photo www.boston.com





Life Threatening Illness

Parents of children with life-threatening illness need even more support.

- Classes are available from the American Heart Association or Red Cross
- Chai Lifeline provides housing & food for families during hospitalization www.chailifeline.org
- Hospice care information can be found at <http://www.webmd.com/balance/tc/hospice-care-topic-overview> or <http://www.nhpco.org/about/hospice-care>

Prescriptions

One of the main causes of treatment failure resulting in hospitalization for both physical and mental health is medication errors.

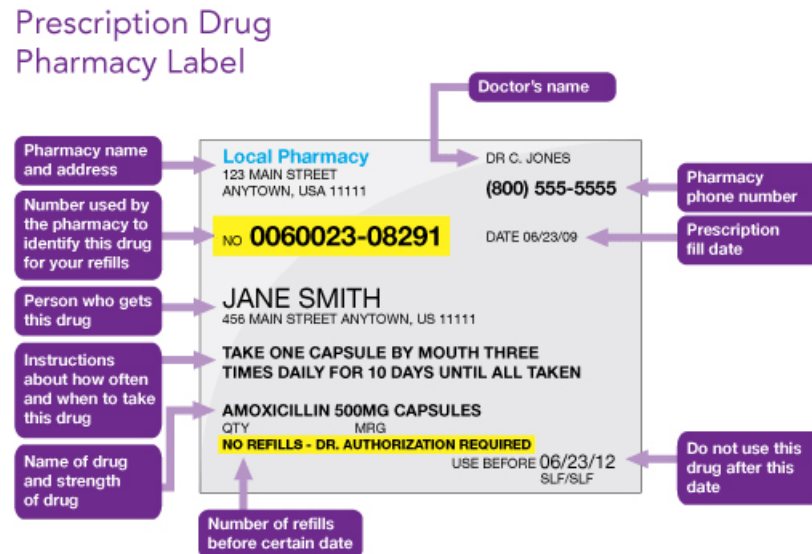


Photo www.merckengage.com

Prescription Resources

MyMedSchedule at www.mymedschedule.com has

- ✓ a medication schedule
- ✓ what each one looks like and its use
- ✓ checklist for filling the pill box

“My Medicine Record” form is available at <http://www.fda.gov/downloads/AboutFDA/ReportsManualsForms/Forms/UCM095018.pdf>.

“Medical Prescription Tips” is found at http://www.fv-ncfpp.org/files/5813/0593/6859/Prescip_Tips.pdf.

Prescription Concerns



The challenge of paying for medications sometimes causes families to either skip doses or even take a medicine from another family member which can cause even more health problems.

Parents should make sure the insurance paid what it should and also have the pharmacy bill the secondary insurance if any.

For families without prescription coverage:

- ✓ The Partnership for Prescription Assistance (free or low cost medicine)
http://www.pparx.org/en/prescription_assistance_programs
- ✓ Pfizer Helpful Answers has a similar program and will also refer to non Pfizer prescriptions at
<https://www.phahelps.com/pages/Find/FindAll.aspx>

Records

- Health Records
- Health Information Technology
- HIPAA



Medical Records

Medical records are critical to keep track of care. Besides records kept by medical professionals, families can also keep track of the most important information regarding their child.



Records

A good starting point would be to look at the Universal Child Health Record at <http://www.state.nj.us/health/forms/ch-14.pdf> as well as the Care Plan for Children with Special Health Care Needs at <http://www.state.nj.us/health/forms/ch-15.pdf>.

“Build Your Own Care Notebook” for families at http://www.medicalhomeinfo.org/for_families/care_notebook/care_notebook.aspx has information on providers, insurance, appointments, hospitalization, immunizations, medical bills, etc.

Health Information Technology

The use of Health Information Technology (HIT) has many benefits such as

- avoiding duplicative forms/tests
- sharing information between providers
- making appointments online
- e-prescribing
- preventing medical errors



Health Information Privacy



- Families can “opt out” of information sharing but this may have consequences such as not being able to access information in an emergency.
- Protections are in place to prevent unauthorized access to the private health information.

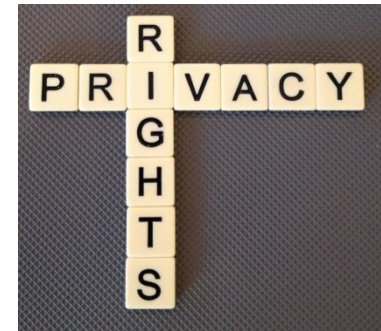
HIPAA Scope: What is Covered?

- Protected health information (PHI) is:
 - Individually identifiable health information
 - Transmitted or maintained in any form or medium
- Held by covered entities or their business associates
- De-identified information is not covered



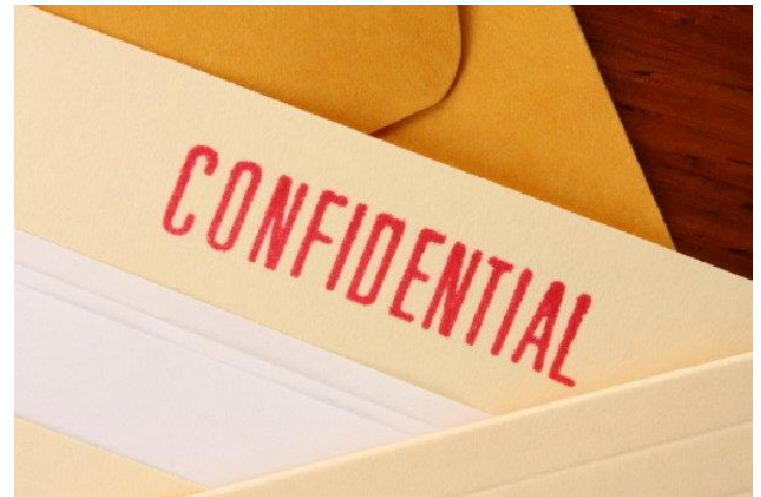
Individual's Rights

- Individuals have the right to:
 - A written notice of information practices from health plans and providers
 - Inspect and copy their PHI
 - Obtain a record of disclosures
 - Amend their medical record
 - Have reasonable requests for confidential communications accommodated
 - Request restrictions on uses and disclosures
 - Complain about violations to the covered entity and to HHS



Consents for TPO

- Direct health care providers must obtain consent from an individual before using or disclosing PHI for treatment, payment, or health care operations (TPO)
- Other covered entities may, but are not required to, obtain consents from individuals for these purposes
- Generally, the covered entity may condition treatment or enrollment on the provision of an individual's consent
- Exceptions for emergency treatment and certain other circumstances



Administrative Requirements

- Flexible & scalable
- Covered entities required to:
 - Designate a privacy official
 - Develop policies and procedures (including receiving complaints)
 - Provide privacy training to its workforce
 - Develop a system of sanctions for violations of policies
 - Meet documentation requirements

HIPAA 45 CFR 164

§ 164.308

(2) Standard: Assigned security responsibility. Identify the security official who is responsible for the development and implementation of the policies and procedures required by this subpart for the entity.

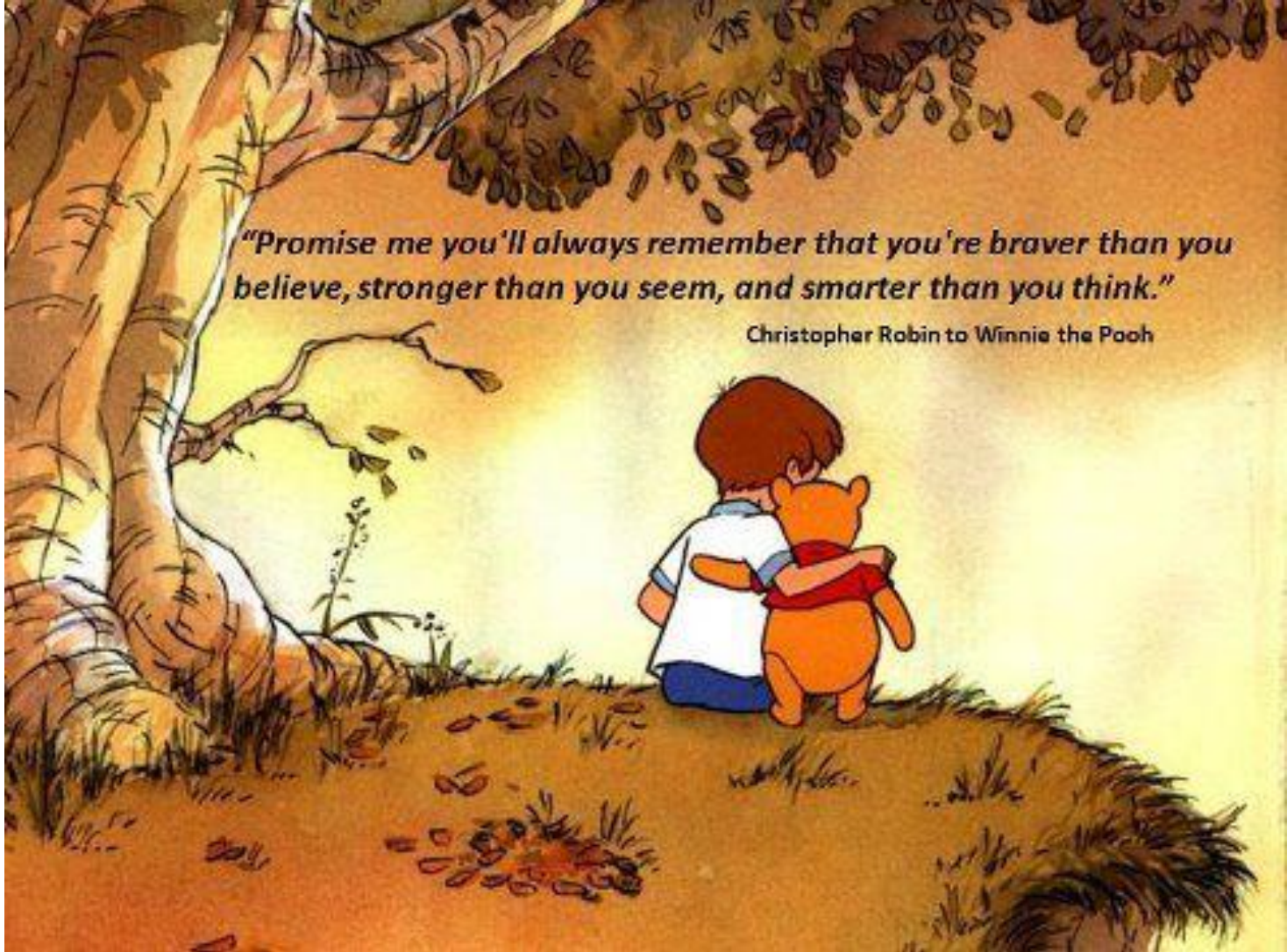
§ 164.530 Administrative requirements.

(a)(1) Standard: Personnel designations.
(i) A covered entity must designate a privacy official who is responsible for the development and implementation of the policies and procedures of the entity.

Forms

In our manual we have forms for:

- appealing denied insurance claims
- logs for communication with providers
- healthcare transition forms
- consent to release information(including schools)
- Advance Directive, Power of Attorney, Living Will

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

