RDLA Policy Primer:
Types of Insurance Regulation and Advocacy Strategies

Background:

Rare disease advocacy often intersects with the complex world of health insurance. With some health benefit plans regulated by the federal government and others regulated by states, or by both, novice and experienced advocates are left wondering where to begin. This primer provides an overview of each type of insurance and offers practical guidance on advocating for improvements within each system. By gaining a clear understanding of these systems, advocates will be better prepared to help rare disease patients receive the comprehensive care they deserve.

INSURANCE TYPE	EXAMPLES	WHAT IS IT?	TYPE	HOW DO I ADVOCATE FOR POLICY CHANGE?
MEDICARE	Medicare	Federal health insurance plan for those 65 or older and some people younger than 65 with certain disabilities or conditions.	Public	**Federal Advocacy** The Centers for Medicare and Medicaid is federally run by the Department for Health and Human Services. Medicare cost and coverage standards are determined federally and will be the same no matter what state you live in.
MEDICARE	Medicare Advantage	Plans that include Medicare A, B, and D together through a private company, but are still regulated by the federal government/CMS.	Private	**Federal Advocacy** Advantage plans must follow rules set up by Medicare/Centers for Medicare and Medicaid Services (CMS).
MEDICARE SUPPLEMENTAL PROGRAMS	Medigap	Health insurance plans sold by private insurance companies to fill the "gaps" in Traditional Medicare Plan coverage. These plans are regulated by the federal government/CMS. However, state governments also have a role. States can require Medigap plans to be guaranteed in the state because federal rules	Private	**Federal and State Advocacy** The federal government standardizes the Medicare Supplemental Programs and mandates consumer protections. State governments provide oversight and additional protections like guaranteed issues.

		only require Medigap to be guaranteed issue within the first six months of someone enrolling in Medicare. This means someone with preexisting conditions may not be able to get a plan outside of that six-month period unless the state government acts to require more.		
MEDICARE PRESCRIPTION DRUG PLANS	Medicare Part D (Also provided through Medicare Advantage Plans)	Prescription drug benefit for people with Medicare provided through private plans that contract with the federal government.	Private	**Federal Advocacy** Medicare prescription drug plans are administered by insurance companies and other private companies approved by Medicare. Each plan can vary in cost and drugs covered but must adhere to federal standards.
MEDICAID	Medicaid	Joint federal and state program for children and families with low income, seniors with low income, some people with disabilities, and children in foster care. States can also choose to expand eligibility to other groups.	Public	**Federal and State Advocacy** Federal rules set a baseline for Medicaid eligibility and coverage requirements. States administer Medicaid programs and have some flexibility to determine which populations and services to cover above the federal baseline, which utilization management policies apply to drug coverage, how to deliver care, and how much to reimburse providers.
DUAL ELIGIBLE	Medicare Part A and B plus a Medicaid program	Coverage for those who qualify for both Medicare and Medicaid Programs.	Public	**Federal and State Advocacy** Dual-eligible individuals may choose to receive their Medicare benefits through traditional Medicare or Medicare Advantage. This decision may have implications for how their care is regulated.
CHILDRENS HEALTH INSURANCE PLANS	CHIP	The Children's Health Insurance Program (CHIP) provides low-cost health coverage to children in families that do not qualify for Medicaid. In some states, CHIP covers pregnant women. In some states, CHIP is called	Public	**Federal and State Advocacy** The Children's Health Insurance Program (CHIP) is regulated similarly to Medicaid. Plans are administered by states according to federal requirements.

		something else such as AllKids, KidsCare, and Cub Care.		
TRICARE	Prime, Prime Remote, Overseas, Select	Program that combines coverage for military health system and civilian health care professionals.	Public	**Federal Advocacy** The Defense Health Agency, under the Department of Defense runs Tricare. These plans are regulated by federal standards and state and local laws generally do not apply
FEDERAL EMPLOYEE HEALTH BENEFIT PLANS	Private health insurance companies	The Federal Employee Health Benefits (FEHB) Program offers coverage to federal employees, retirees, and their families. It offers a variety of health services including PPO plans, HMOs, consumer-driven plans, and high deductible health plans. Premiums for enrollment are generally shared by the enrollee and the Federal agency.	Public	**Federal Advocacy** The Federal Employees Health Benefits Act (FEHBA) regulates federal governmental health plans. The U.S. Office of Personnel Management is responsible for contracting with private insurers to administer FEHB plans.
STATE EMPLOYEE HEALTH PLANS	Private health insurance companies	All 50 states provide health insurance coverage for their state employees; however, the extent of coverage, enrollment eligibility, and employer versus employee premium contributions vary from state to state.	Public	**State Advocacy** States have significant control over how they choose to finance and operate their state employee health plans.
INDIVIDUAL PLANS	Private health insurance companies	Plans bought individually or as a family rather than through an employer or the government. This can include private and public plans. The Health Insurance Marketplace, commonly referred to as the ACA Marketplace is a shopping and enrollment service created by the Affordable Care Act in 2010.	Depends on plan selection	**Federal and State Advocacy** For private plans, coverage and cost determinations are ultimately made by the private insurer while adhering to federal and state laws. The federal government, primarily through the Affordable Care Act, determines what individual plans must cover and how much an individual or family is allowed to be charged per year for out-of-pocket expenses. States also have a major role in regulating private individual plans sold in their states. States can

				require plans to cover certain healthcare services and treatments. Some states also run their own Health Insurance Marketplace, while others defer to the federally run Marketplace.
SMALL GROUP PLANS/FULLY INSURED EMPLOYER PLANS	Private health insurance companies	Plans offered by companies who, in most cases, pay part of their employees' premiums. In most states, a small group health plan is a group insurance product covering 50 or fewer enrollees. In four states (California, Colorado, New York, and Vermont), small group plans are defined as group insurance arrangements covering 100 or fewer enrollees.	Private	**Federal and State Advocacy** Coverage and cost determinations are ultimately made by the private insurer while adhering to federal and state laws, including the federal Affordable Care Act. This legislation sets some requirements for what individual plans must cover and how much an individual or family is allowed to be charged per year for out-of-pocket expenses. Fully Insured health benefit plans are also regulated by state law, so state governments can establish baseline benefits in these plan types.
SELF INSURED EMPLOYER PLANS (ERISA PLANS)	Administered by private health insurance companies	The employer takes on most or all of the cost of benefit claims. Typically, employers contract with a private insurance company to administer the health coverage they offer so employees may not know if their coverage is provided through a self-insured plan without further questions.	Private	**Federal Advocacy** Coverage and cost determinations are ultimately made by the private insurer while adhering to federal laws including the Employee Retirement Income Security Act (ERISA) and in some cases, the Affordable Care Act. ERISA often preempts coverage requirements passed by state and federal laws so self-insured plans may be exempt from many consumer protections.
RETIREMENT COVERAGE	Private health insurance companies	Some employers offer health insurance to retiring employees and their spouses that is typically like the plan for active employees. In many cases, people with retiree coverage will also have Medicare. In these cases, retiree coverage acts as secondary coverage for the costs not covered by Medicare.	Private	**Federal Advocacy** Coverage and cost determinations are ultimately made by the private insurer while adhering to federal laws including the Employee Retirement Income Security Act.

STOP LOSS COVERAGE	Aetna, United Healthcare, Anthem BlueCross BlueShield	Plans sold to self-insured employers in order to cover excessive unexpected claims	Private	**Federal Advocacy** Most stop loss plans are subject to ERISA regulations.

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers. Please contact Shannon von Felden at svonfelden@everylifefoundation.org to learn more about RDLA.

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