National Academies Presentation

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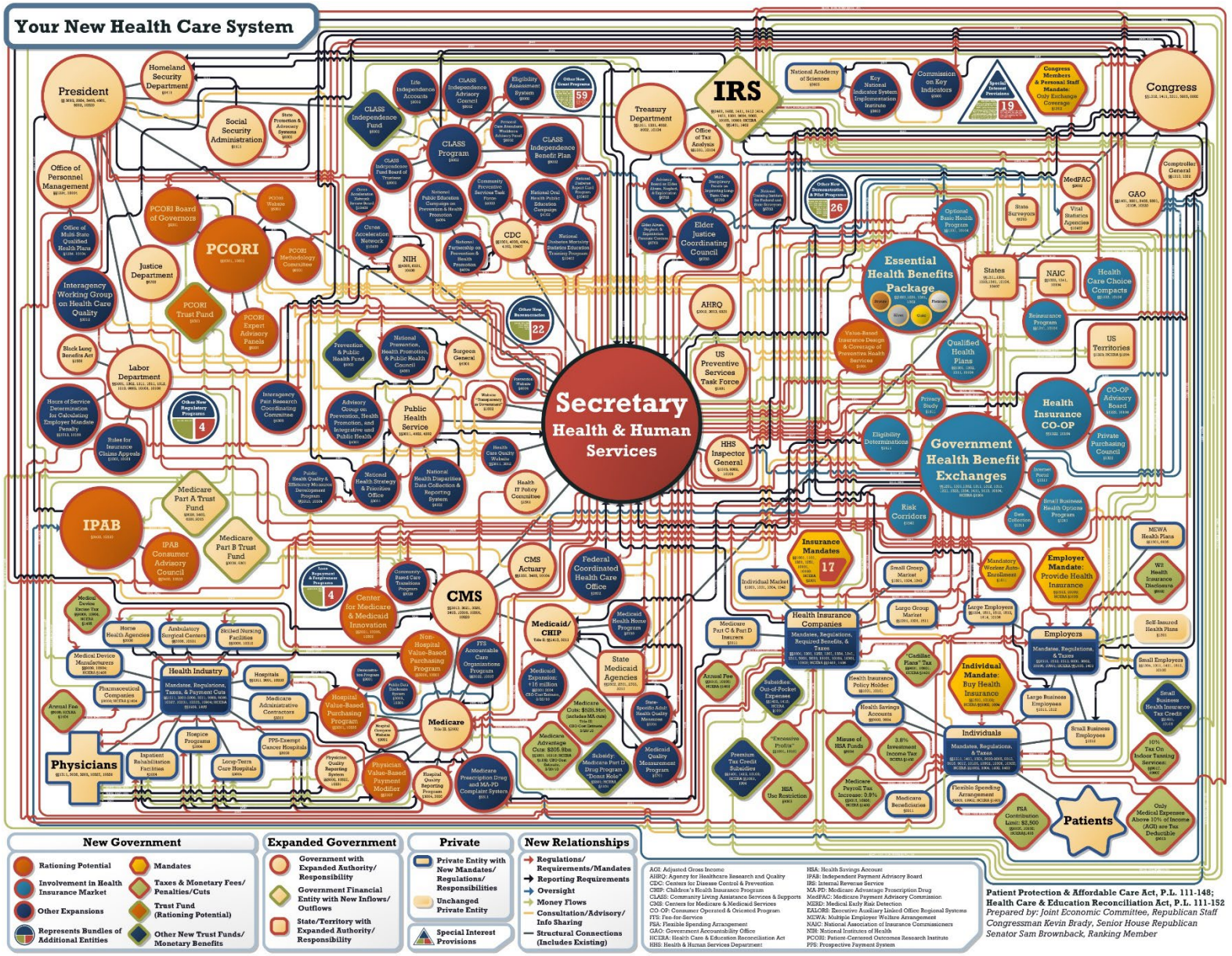
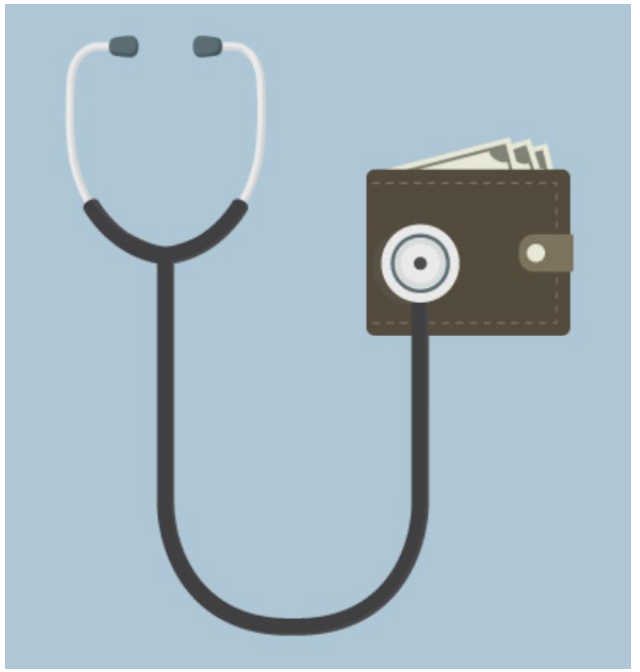
Presented by
Melanie Lendnal, Senior Vice President, The ALS Association

How do people living with ALS navigate the care & payment system?



Barriers to Access and Disparities



Top 5 Insurance Denials

1. Prescription medications or medication delivery supplies
2. Wheelchair accessories
3. Power wheelchairs
4. In-home physical, occupational, or speech therapist
5. Wheelchair-accessible vehicle or vehicle modifications

Results of Being Denied Prior Authorization or Claim for ALS Care

Note: Percentages do not add to 100% because question directed participants to "select all that apply."

How Much Does Living with ALS Cost?

	AVERAGE COST
Wheelchair Accessible Vehicle	$50,000
Basic Home Modifications	$15,000
Communications Device	$15,000
Complex Power Wheelchair	$30,000
Professional Home Care	$180,000
Assisted Living	$96,000
Prescription Drugs	$1,040
Supplies (i.e. supplements, specialty food, daily living assistance devices)	$5,000
Hospital Stays	$2,700
Non-invasive Ventilator (NIV)	$20,000

People Living with ALS Need…

- ✓ Immediate access to medically necessary and appropriate care as prescribed by their physician,
- ✓ research investments to dramatically expand treatments and cures, and
- ✓ support for family and paid caregivers who help to keep people with ALS out of expensive health care.

Recommendations

1. **Prior Authorization Reform** for People Living with Terminal, Progressive Diseases (such as ALS)

2. Legislation to Ensure **Home Care is Affordable and Accessible**

3. **Technology and Equipment Rule Reform**

4. **Reform Access to Ventilators**

5. **Patient Engagement:** Expand on the Biden Executive Order 13985 on health equity to include subpopulations that are disproportionately affected by health inequities, such as individuals with rare and rapidly progressing terminal diseases.