



Patients? What patients?

Getting Medicaid to “get” consumer oversight



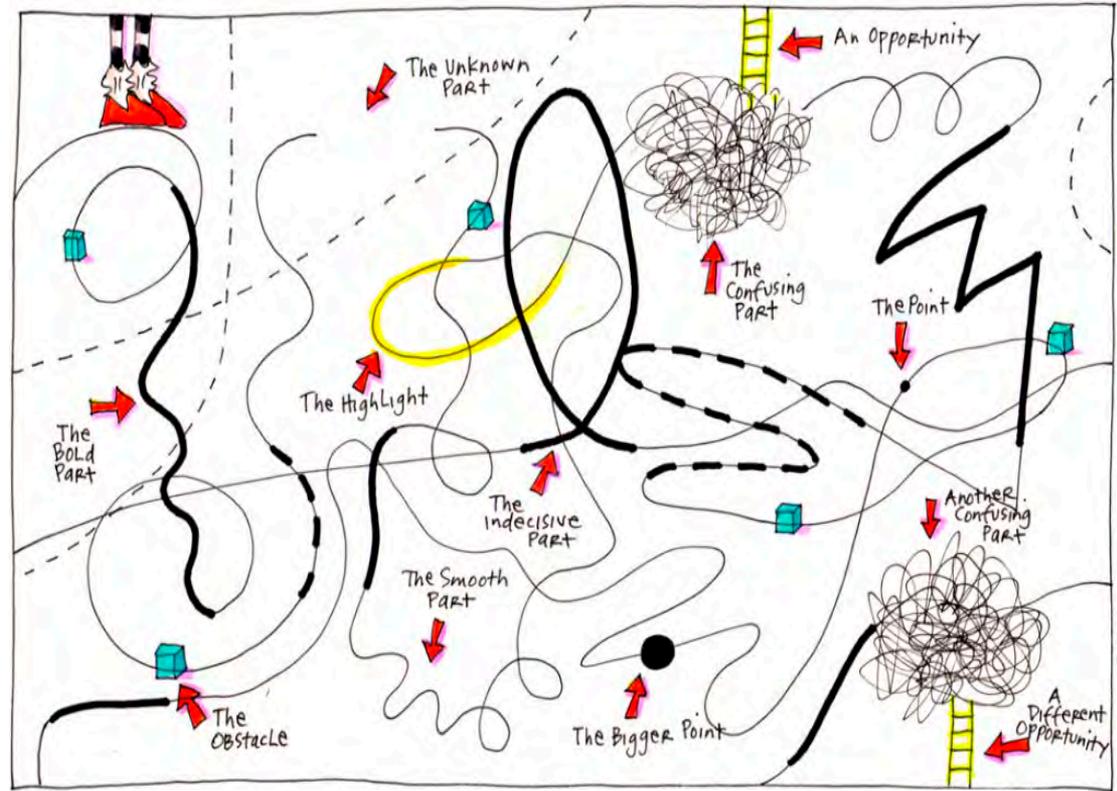
Jim Carnes
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Medicaid consumer representation



Medicaid consumer representation: 3 things we know

- Always hard
- Two-way street
- Wide state leeway



Roadmap to Medicaid consumer representation

Alabama context: 2012

- Governor after SCOTUS: Won't expand "broken" Medicaid!
- Appoints commission to "fix" (cost, quality, outcomes)
- 28 members include 1 consumer advocate



1/28 = Tokenism (barely)

- Get partners and group members to ask Gov. for more
- Gov. refuses
- 17 organizations form Medicaid Consumer Coalition
- Develop **principles** to build credibility, guide actions
- **Leverage** single commission seat to represent coalition





Patients First:

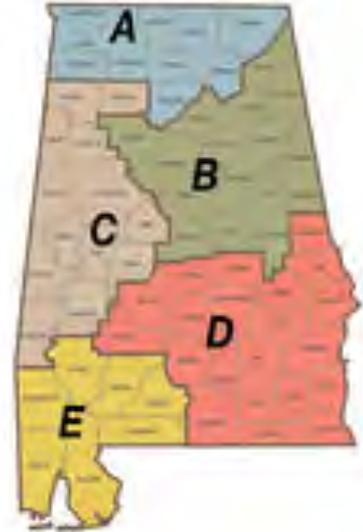
Principles of Consumer-Centered Medicaid Reform

1. Better health is the bottom line.
2. Consumer engagement is essential.
3. Effective consumer outreach includes education and assistance.
4. Successful managed care treats the whole person.
5. Special needs require special accommodation.
6. Expanding home- and community-based long-term care can improve outcomes and save money but takes time.
7. Accessible managed care requires a robust provider network.
8. Quality and accountability bring Medicaid reform full circle.

Commission recommends . . .

- Nonprofit managed care
- Regional Care Organizations (RCOs) – provider-based, community-led
- Five Medicaid regions – each with one or more RCOs
- No “hub” to connect regions
- **Advocacy win: Give consumers a strong formal role in RCO governance!**

Regional Care Organization Districts
Effective October 1, 2013



Putting recommendations into law

Strong legislative buy-in strengthens consumer provisions:

- Arise and disabilities coalition to nominate consumer reps
- Advisory committees + two consumer seats on each regional governing board





Building something new

- First statutory consumer role in Medicaid governance
- Acknowledgment that community engagement is crucial to success
- ACA offers new incentives
- Consumer reps are key players in historic transformation
- *Flaw: Narrow interpretation of “beneficiaries” in consumer representation leaves 600,000 children without a voice.*





Alabama Community Health Partners

- Team approach to consumer representation
- Arise and disability coalition reps, plus regional advocacy partners
- Reps connect regions, in lieu of official “hub”
- Training and ongoing support



Reality check

- Unrealistic expectations: faster savings, magic bullet for budget
- Vicious cycle for legislators and investors: “You go first!”
- **Commercial investors neglect consumer oversight.**
- Delays reduce confidence and political will.
- New governor uses budgetary “escape clause” to circumvent law.
- Salvage mode . . .
- **Huge blow to rep engagement/retention**



A do-over – but not from scratch

Commissioner aims to keep key RCO provisions and “lessons learned”

- Health home model of care coordination – expand to most beneficiaries
- Quality measures as incentives to better care and outcomes
- *Advocacy win: Allow parents & caregivers to represent beneficiaries*

Coalition is calling for:

- Strong consumer engagement, protections and oversight
(We’ve shared our original principles as a starting point.)



Hurry up and wait . . .

- As RCOs floundered and died, ACHP lost enthusiasm, focus
- “Down time” far exceeded two-year term of service
- Attendance at calls and meetings flagged
- Medicaid defense (“repeal and replace,” “work requirement”) gave a boost
- Likely shift to new recruits, new supporting role for original reps





New advocacy setback

Under new plan, each region will have:

- 1 consumer representative on governing board, instead of 2
- Consumer Advisory Committee (CAC), reporting semiannually to board

Medicaid's message: "Adding consumer seats would have domino effect. Health centers, etc., would want another seat."

Backward step reflects deeper problem: Medicaid's failure to embrace its own claims of "patient-centered care delivery."



Our response (Part 1)

Core challenge: Getting Medicaid to take patients/consumers as seriously as they take providers.

Core argument: Consumer representatives are not merely a stakeholder *type* (comparable to community mental health centers or FQHCs) but rather a stakeholder *class*, parallel to risk-bearing & non-risk-bearing providers

Core advocacy:

- Public requests, direct appeals to commissioner, governor
- Comment on 1915(b) waiver proposal (*comment period not mandatory*)
- Negotiate – e.g., LTSS CAC handbook reflects consumer principles
- Member education → member advocacy

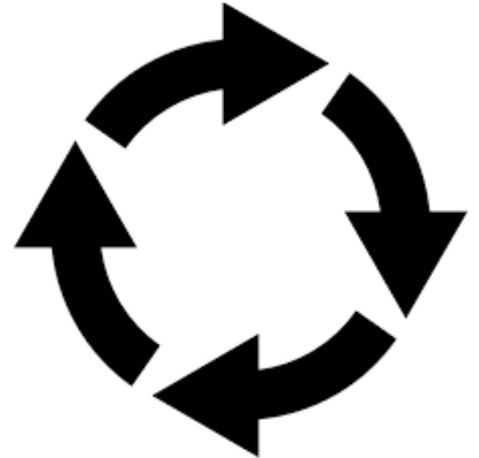




Our response (Part 2)

Extend feedback loop to support formal consumer reps:

- Use outreach meetings to identify “community contacts”
- Partner with specific Medicaid constituencies (e.g., People First, Family Voices, AIDS Alabama, peer support organizations) to grow community contact network and outreach partners
- Equip community contacts for feedback loop role
- Stipends – modeled on Deep South Network
- Keep Medicaid informed!



Our response (Part 3)

Keep raising public awareness of Medicaid:

- #IamMedicaid campaign
- Expand partnerships for Medicaid expansion
- Inform voters and legislators on Medicaid's role in their districts





Thank you!



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