

Disability Advocacy in a Post-Olmstead Environment  
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National Conference of State Legislatures

Presentation Goals

- \* Explain the roles of state legislators
- \* Underscore how important YOU are
- \* Summarize Current NCSL Olmstead Activities
- \* Offer some practical advice on how to work with legislators

Legislators: Why Should You Care?

- \* Control the purse strings: \$\$\$\$\$
- \* Establish programs
- \* Enact requirements
- \* Provide oversight

Variety in State Legislatures

- \* If you've seen one legislature-you've seen just one!
- \* Different cultures, powers, rules, procedures, etc.

o California

Full-time job

Members earn \$99,000/year

Large staff (non-partisan, partisan, personal)

o Wyoming

10 day general session, 20 day budget session

Members earn \$125/day

Approx. 20-25 full-time professional staff

Term Limits: Extra Challenges

- \* AZ, AR, CA, CO, FL, ID, LA, ME, MI, MO, MT, NE, NV, OH, OK, OR, SD, UT, WY
- \* Opposition and supporters leave
- \* Continuing education process
- \* Severe transitions in some states
- o Florida House 2000: 51 of 120 new (43%)
- o Ohio House 2000: 36 of 99 new (36%)

Legislators Are Generalists

- \* Agriculture
- \* Corrections
- \* Education
- \* Health
- \* Housing
- \* Human Services
- \* Labor
- \* Transportation
- \* Zoning . . .
- \* Dozens of topics: A to Z
- \* Hundreds of bills

\* Can't be experts in all

## Health Issues by the Dozens

- o Medicaid
- o Insurance/mg'd care
- o Pharmaceuticals
- o Long-term Care
- o Uninsured
- o Health professions
- o Health Facilities
- o Environmental
- o Public health
- o SCHIP
- o Prenatal Care
- o EMS
- o Nutrition
- o Oral health
- o Injury prevention
- o Mental Health
- o Disabilities
- o Substance Abuse . . .  
etc.

## Your Role

The "blip enlarger" !

- \* Expert
- \* Information resource
- \* Advocate

## Getting Their Attention: Barriers

- \* Magnitude of the issue
- Complex, multi-year commitment
- Systems: Medicaid, housing, transportation, etc.
- Workforce capacity
- Institution-based jobs & economic impact
- \* Funding concerns
- \* Competing needs and demands
- \* Lack of awareness
- \* Lack of thorough understanding

## State Challenges: Decision-Making

- \* Several departments
- \* Several committees & categorical bills
- \* Line-item budget
- \* Unanticipated consequences
- \* "Penny-wise and pound foolish"

## Getting Their Attention:

## Driving Forces

- \* Constituent needs
- \* The Olmstead case
- \* Local challenges
- \* The budget factors
- \* The "right" thing to do
- \* Lessons from other states

Where does the money go?

## Medicaid Perceptions

One view:

A black hole

Another view:

A cash cow

## Beneficiaries and Expenditures

(1998 -- U.S. average)

## How Do I Get Started?

- \* What are your goals?
- Be a key stakeholder and resource?
- Become involved in the planning process?
- Help develop a state plan?
- Develop the community infrastructure?
- Reduce the waiting list by X% a year?
- Empower consumers?
- \* What are the best methods to achieve them?
- \* What is your action plan?

## Other Things to Think About...

- \* What type of information do policymakers need?
- \* What's the best way to deliver the information?
- \* For legislators:
- Be brief, concise, thorough
- Be vigilant
- Follow-up if they need more

## NCSL Olmstead Activities

- \* Information clearinghouse
- \* Publications
- \* Web page
- <http://www.ncsl.org/programs/health/disabil.htm>
- \* Meeting sessions
- \* Phone conferences
- \* Advisory Group
- \* Track state activities

Sample Postcard - Front

## Sample Postcard - Back

### NCSL Olmstead Survey

March 2001

- \* Phone Survey in each state
- \* 37 states had task force or commission: AL, AK, AR, CA, CO, CT, DC, DE, GA, HI, ID, IL, IN, IA, KS, KY, ME, MD, MA, MI, MO, MT, NJ, NM, NY, NC, ND, OH, OK, PA, SC, TX, UT, WA, WV, VI, WI, WY
- \* Four comprehensive plans: MO, NC, OH, TX
- \* Significant documents: CA, IL, ND
- \* At least 21 states will issue plans in 2001: AL, AZ, AR, CO, CT, DE, GA, HI, IN, IA, KY, ME, MD, MI, MT, NJ, NC, SC, UT, WI, WY
- \* Bulk of activity is in the executive branch
- \* 2002 legislative sessions will be key

### NCSL Olmstead Survey

March 2001

- \* Commissions operating under diverse authorities, but very similar
- Broad-based membership (stakeholders coming together)
- Led by executive agency
- Focus on all disability groups
- \* Concern about fiscal implications on Medicaid
- \* Broad scope--focus on entire long-term care system  
([www.ncsl.org/programs/health/forum/olmsreport.htm](http://www.ncsl.org/programs/health/forum/olmsreport.htm))

### Role of State Legislators

- \* Planning and implementation is closely tied to the legislative process
- \* 5 states enacted legislation to form their commissions (CA, HI, IL, KY and MS)
- \* Legislators and legislative staff sit on some commissions (e.g., MO, UT and WI)
- \* Budget and program decisions

### Missouri

- \* Plan focuses on eight discrete activities
- Identify programs and services
- Measure service effectiveness
- Identify number of institutionalized people
- Identify waiting lists and pace of movement
- Examine whether consumers have adequate information
- Identify changes needed in community programs
- Identify means of expanding community programs
  - Develop a process to help people make the transition into the community

### Missouri

- Caregiver compensation: \$1 per hour increase for aides caring for people with MR/DD.
- Informed choice: ensure training for staff and individuals to transfer from a nursing
- Consumer and family directed care: personal care services an entitlement under Medicaid
- Transition to independence: one-time grant of up to \$1,500 to assist individuals in transition from an institution
- Challenges remain: housing, transportation, workforce

### State Challenges: Road Map

- \* Determine your goals
- \* You've got to start from where you are

Identify strengths

Identify barriers

Identify solutions

\* You can't get there if you don't know where you're going

State Challenges:

Effectiveness

\* Be vigilant

\* Are you meeting your goals?

\* If not, why not?

\* Are your goals reasonable?

\* Are you getting your money's worth?

\* Are people receiving appropriate services?

\* Is quality of life good?

\* Are you anticipating emerging challenges?

Dos and Don'ts

o DO:

o Get involved (year round)

o Be accurate, reliable, honest, concise, and vigilant

o Build relationships early

o Offer to be a resource

o Be inclusive of others

o Have written materials

o Personalize the issue/take a field trip

o Thank your audience

o Don't:

o Assume you don't count

o Mislead or give false information

o Make enemies

o Be too narrowly focused

o Refuse to compromise

o Go on and on . . .

o Give up

Your Role

o The power of one

o The added power of individuals working together