

Strange Times in Illinois

The Importance of Advocacy

Tony Paulauski
The Arc of Illinois
The Third Annual Gathering
June 28, 2010

The Arc of Illinois

- 10,000 Members
- Volunteer Board
- 60 Local Chapters
- Public Policy
- The Family Support Network
- Illinois Life Span
- Family to Family Health & Ed Center
- Consumer Stipends- ICDD- \$100,000!

Overview

- The Arc of Illinois
- State of the State 2010
- Managed Care
- Health Care Reform
- Trends & Transitions
- Where Do We Fit In?
- How We Can Work Together

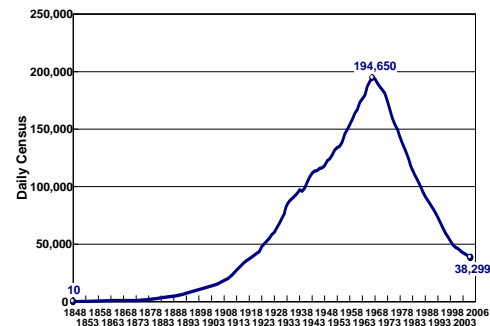
State of State 2010

- State Budget Deficit of \$13 billion!
- 20,000 on Waiting List
- Inefficient & Ineffective Spending
- 47th in Community Spending
- 51st in Small Living Options
- People are Losing Services
- We Need & Want Reform!

Illinois Asylum for Feeble Minded Children in Lincoln, IL, Estb. 1867



Daily Census of State Institutions in the US: 1848-2006



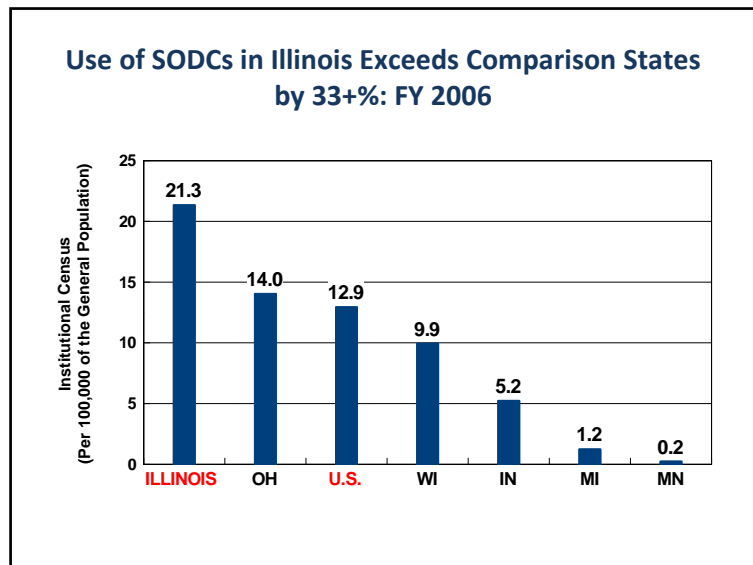
Source: State of the States, Coleman Institute and Department of Psychiatry, University of Colorado, 2008.

Dixon State Colony for Improvable Epileptics Who Are Not Insane

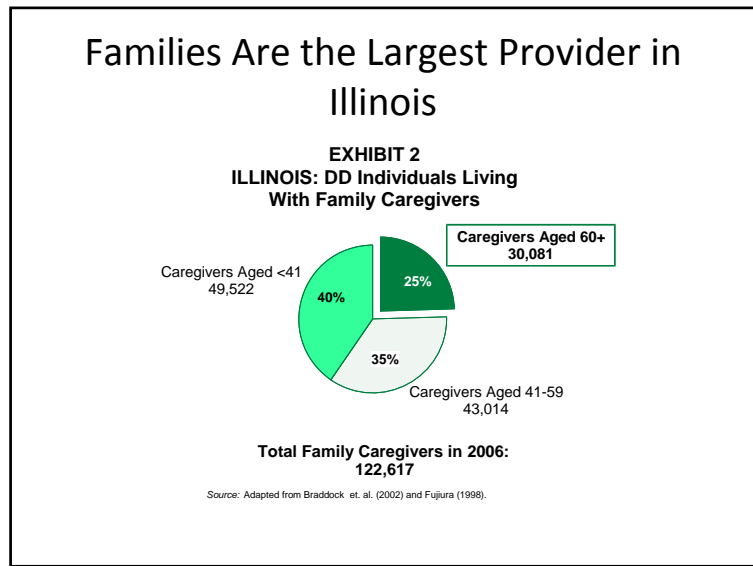


Average Daily Census in Illinois: FY 2008 & 2010

• Anna/Choate (Anna)	166	(244)
• Fox (Dwight)	153	(128)
• Kiley (Waukegan)	254	(219)
• Howe (Tinley Park)	409	()
• Jacksonville (Jacksonville)	259	(206)
• Ludeman (Park Forest)	414	(383)
• Mabley (Dixon)	99	(88)
• Murray (Centralia)	339	(296)
• Shapiro (Kankakee)	616	(536)
TOTAL AVERAGE DAILY	2,709	(2100)



- ### Largest Provider but Not At The Table!
- Support The Arc & Family Support Network
 - Share your stories with elected officials
 - Support your local network/support group
 - Vote for candidates that support our issues



- ### Legislative Forums
- Peoria: June 26, 10:00 to 11:30am – confirmed
 - Springfield: Aug. 3, 5:00pm (tentative)
 - Quad Cities: Aug. 30 (tentative)
 - Urbana: Aug. 11 – 7:00pm (tentative)
 - Rockford: July 14th or 15th (tentative)
 - Metro E. St. Louis – unknown
 - Candidates for Governor: Chicago (unknown)

Managed Care Pilot

- Integrated Care Program
- Older Adults & Adults (19) with Disabilities
- Eligible for Medicaid but
- Not Eligible for Medicare
- Lake, Kane, DuPage, Will, Kankakee & Suburban Cook County
- 40,000 to 60,000 Adults
- 3,000 with Developmental Disabilities

Phase 3 – DD Services

- Implemented in Three Phases
- 1st Phase - Delivery of Health Care Services, Mental Health & Substance Abuse – Oct, 2010
- 2nd Phase – Nursing Services & Home & Community Based-Services Non DD – Year Later
- 3rd Phase – DD Waiver Services, ICF/DD & State Institutions – Year Later

Integrated Care Program

- Implemented in Three Phases
- 1st Phase - Delivery of Health Care Services, Mental Health & Substance Abuse – Oct, 2010
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Two Prime Care Providers

- Aetna Better Health
- Centene Corp/IlliniCare Health Plan
- Harmony Health Plans/Wellcare
- Meridian Health Plan
- United Health Group

Arc Concerns on Managed Care

- We Do Not Support Managed Care for Disability Services
- We Support Self-Direction vs Medical Model
- “Blueprint” for System Redesign in Illinois is Our Model for Reform
- No Attention to 20,000 Children & Adults on Waiting List
- Lack of Specialty Care

Health Care Reform

- Significant benefits for infants, children, adults with disabilities and families
- Signed into law by President Obama
- Will be phased in over the next five years
- Is a work in progress that invests in all of our futures
- Giving people control over their health care

Arc Recommendations

- Work With Gov’s Office & Legislators to “Carve Out” Disability Services from Managed Care Pilot
- Utilize the “Blueprint” for System Redesign as our Model for Reform
- End The Waiting List for 20,000 Children & Adults with Developmental Disabilities
- Support Health Care Reform in Illinois

Five Components of Reform

- Pre-Existing Conditions Exclusions
- Rescissions
- Lifetime & Annual Caps
- Discrimination Based Upon Health Status
- Guaranteed Issue & Renewability

Affordability for Families

- Set up insurance exchanges through which individuals & families could receive subsidies to substantially reduce the cost of purchasing health insurance coverage
- Expand eligibility for Medicaid with substantial federal financial support
- Annual caps on cost sharing up to 400% of the federal poverty level (\$88,000)

The Community First Choice Option

- The Community First Choice Option would help to eliminate the institutional bias by encouraging states to cover personal attendant services under the state's optional service plan instead of through the waiver system by offering a 6% increase in the federal share of Medicaid for these services

The CLASS Act

- The Community Living Assistance Services & Supports (CLASS) Act would create a national long term services insurance program which assists eligible individuals and their families to meet long term needs with a cash benefit and without forcing them into poverty to receive Medicaid Benefits

Health Care Reform: The Beginning

- It will take years to implement
- We will work with the Dept of Insurance
- Our Family to Family Health & Education Center will continue to assist families to better understand and navigate the details of health care reform
- The Arc will continue to update our members
- This is a limited summary and a work in progress but the news for us is very good

Illinois Trends & Transitions

- Reform & Institutional Closing
- Increased Demand & Limited Resources
- Aging & Caregivers
- Workforce & Immigration

Increased Demand & Limited Resources

- The Waiting List is 20,000 and growing
- There are 121,000 infants, children & adults with intellectual disabilities in Illinois
- There are about 45,000 in the Developmental Disability System
- IL invests in inefficient, expensive services
- State & Federal resources are down
- We need to focus more on important policies that invest in families

Reform & Institutional Closings

- Every expert report calls for downsizing state institutions & provider dominated system
- Advocates want reforms that invest in the family and community supports
- State Institutions cost \$162,000
- Community Group Home cost \$40,000
- Home-Based cost \$16,000
- There is always opposition to any reform

Aging & Caregivers

- People with developmental disabilities are living longer
- Aging is having a profound impact on intellectual disabilities service system
- Requiring more individualized, specialized & appropriate services
- Caregivers Aged 60+ = 30,081 in IL

Workforce & Immigration

- Direct care turnover used to be our main concern
- Competition with elderly, other human services & health care – HIGH DEMAND
- Current system ill equipped for elderly individuals with intellectual disabilities
- Current workforce increasing with immigrant workers
- How do we compete for caregivers?
- How do we plan for a mixing of cultures to support our people?

Micro Boards & Cooperatives

- Provider responsibilities
- Unique position for the individual
- Priorities are focused on the individual
- Natural supports
- Flexible when change is necessary

Where Do We Fit In All of This?

- Stay Positive & Informed
- Promote Inclusive Options & Home-Based Supports
- Illinois Needs to Move Away from Institutional Settings
- LifeMyWay
- The “Blueprint” for System Redesign is Our Model for Reform

How We Can Work Together for Change

- Join The Arc – Tony’s List
- Legislative Forums – Know Your Rep’s
- Organize Locally
- Develop Relationships with Media
- Call The Arc
- Family Support Network
- Illinois Life Span
- Family to Family Health & Ed Center
- Support IAMC!

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References

- Sheila Romano, Ph.D., ICDD, Chicago
- Glenn Fujiura, Ph.D., UIC, Chicago
- State of the States 2008, UC, D. Braddock, Ph.D.
- US Dept of Health & Human Services, Video on Health Reform & People with Disabilities:
<http://www.youtube.com/watch?v=cckQNkIpCWg>