A Brief History of the Future of IDD Services

By Steve Gieber, KCDD
In the beginning

It was the responsibly of each family

It was seen as God's will

In some cultures people were protected
In other cultures people were made fun of
or worse
Federal Government 1950-70

- Department of Health and Human Services
  Eisenhower Administration

- First federal money for research on causes of Mental Retardation

- Department of Mental Retardation
  Kennedy Administration
  birth of Special Olympics

- Great Society "end of poverty" Johnson Administration

- Expanded coverage SSI and SSDI
  Nixon Administration
Kansas in the early days

State Institutions Winfield, KNI, Norton, etc.

Starkey's

TARC

KETCH
Kansas Milestones (early days)

1963 Governor appoints a Council on Mental Retardation

1969 Kansas Association of Rehabilitation Facilities (KARF) 1996 Changed name to Interhab

1971 2,000 Clients in Institutions and 250 in community programs

1974 Legislation establishing Community Mental Retardation Centers (state grants and mill levy)
1970's in the USA

1970  181,404 people with IDD lived in 250 state run institutions

1971 Congress enacted legislation creating Intermediate Care Facilities (ICF's)

"Parents Movement" and a Self-Advocacy Movement

- Grassroots Legislation, Litigation, & Protection of Civil Rights

Creation of the DD Act and Amendments
Developmental Disabilities Councils

1970 DD act

- Insure that the most pressing needs of people with developmental disabilities are address
- Receive the services and supports they need
- Insure participation in development and design of services and supports

Systems Change, Capacity Building, Advocacy
DD Councils

- Charged by both Federal and State Law to promote:
  - Independence
  - Productivity
  - System Changes
  - Inclusion
  - Access to Quality of Life
The 1980's

State run institutions dropped to 132,690

Home and Community Based Waiver (HCBS)

Settings of fewer than 6 went from 13,535 in 1970 to 28,000 in 1980

1990's

State run institutions 84,818 vs. 101,776 in six or less homes

38,919 supported employment workers

Home of Your Own Demonstration Projects
<table>
<thead>
<tr>
<th>State Institutions 1994</th>
<th></th>
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<tbody>
<tr>
<td>Kansas Neurological Institute</td>
<td>285</td>
</tr>
<tr>
<td>Parsons State Hospital</td>
<td>225</td>
</tr>
<tr>
<td>Winfield State Hospital</td>
<td>296</td>
</tr>
<tr>
<td>0 Large ICFs/MR</td>
<td>650</td>
</tr>
<tr>
<td>34 Small ICFs/MR</td>
<td>300</td>
</tr>
<tr>
<td>28 CMRC’s</td>
<td>5600</td>
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Kansas Milestones

1975 State implements Title XX Program

1978 Licensing and Certification Standards

1984 First year HCBS funds were used in Kansas KARF establishes a taskforce on Supported Employment Program (SEP)

1990 ADA and HCBS expansion waiting list eliminated

1995 DD Reform Act establishing CDDO’s gatekeeper role and reasonable rates

1998 Winfield State Institution closed
2000's Nationally

In 2000 47,397 in state run institutions vs. 269,131 people in 6 or less homes

107,931 supported employment workers

By 2009 institutional census was 33,795 and 439,950 people in settings of 6 or less

142 institutions were closed leaving less than 200 and 12 jurisdictions had no institutions
Kansas Milestones

2006 CDDO Process Monitoring

2006 Money Follows the Person

2011 CMS guidelines on service funding

2012 SRS reorganization

2011, 2013 Employment First passes

2012 Managed Care Companies (Medicaid)
Federal Funding

1950s $5 Million
1970 $43 Million
1980 $1.5 Billion
1990 Medicaid $4.1 Billion HCBS $.5 Billion
2000 Medicaid $5.57 Billion HCBS $5.61 Billion
2010 Medicaid 7.7 Billion HCBS 15.4 Billion
Receipts vs. Spending

1970 $192 Billion vs. 43 Million .00022
1980 $517 Billion vs. 1.5 Billion .0029
1990 $1032 Billion vs. 4.6 Billion .0045
2000 $2025 Billion vs. 11 Billion .0054
2010 $2162 Billion vs. 23 Billion .0106
The Future Direction

MCO’s - efficiency and effectiveness

CMS - gives greater latitude to Managed Care

- phase out of Federal Habilitation

Self Directed Funding Allocation based on assessed need Support Intensity Scale (SIS)

Individual Rate/Budget

Self Sufficiency - subminimum wage not a path