Policy & System Issues that Promote Recovery in Transition-Age Youth

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Youth with SED Struggle as Adults

- **Few Graduate from High School**
  - 23-30% vs. 61% in community vs. 81-93% in general population

- **Employment Rates are Low**
  - 46-51% vs. 59% vs. 78-80%

- **Greater Risk of Homelessness**
  - 30% vs. 7% in general population

- **Higher Pregnancy Rates in Women**
  - 38-50% vs. 38% vs. 14-17%

Proportion Arrested by age 25
Adolescent MH Clients vs. General Population

General Population: 41.6%
MH: 58.7%
Distribution of 1st Arrest Ages in Males
DMH Adolescent Clients vs. General Offenders

- GO-Males
- DMH Males

Age at 1st arrest vs. % of Subjects
Desistance After 2 years by 1st Arrest Age in Male General and DMH Offenders

Proportion Desisting After 2 Yrs

Age at 1st arrest

General Offenders
DMH Offenders
Functioning in Adults with Psychiatric Disorders:
Young Adults Fare Worse than Older Adults

*χ² (df=1)=31.4-105.4, p<.001
** χ² (df=1)=5.5, p<.02
Multiple Regression: Age in model (Adjusted $R^2= .128$, $F(1,1276)=188.3$, $p<.001$)
Psychosocial Development
Adolescence to Adulthood

Identity Formation
Cognitive
Sexual
Moral
Social

Developmental change on every front
With the exception of sexual development, as a group, youth with serious MH conditions are delayed in every area of biopsychosocial development.
Youth with SMH Conditions: System Implications

“Services as usual” not sufficient

Address Comprehensive Needs – Needs in all areas of functioning

Address Needs Continuously – Needs don’t end magically at 18 or 21, stable adulthood more likely by 30

Services for young adults need to be different from services for older adults
Transition has Changed

- Bachelor’s degree is the economic equivalent of high school degree in the 60’s
- Fewer opportunities to earn incomes that allow for independence (with college degree)
- Unaffordable housing
- More dependence on families for longer time

(Settersten, Furstenberg & Rumbaut, 2004)
# Stages of the Family Life Cycle

<table>
<thead>
<tr>
<th>Stage</th>
<th>Key Principles</th>
<th>Requirement to Proceed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families with Adolescents</td>
<td>Increasing flexibility of family boundaries for child’s independence and grandparent frailties</td>
<td>- Parent/child relationships shift to permit adolescents’ dependence to move in and out</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Refocus on midlife marital and career issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Shift toward caring for older generation</td>
</tr>
<tr>
<td>Launching children and moving on</td>
<td>Accepting a multitude of exits from and entries into the family system</td>
<td>- Renegotiation of marital system as dyad</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Children and parents develop adult to adult relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Inclusion of in-laws and grandchildren</td>
</tr>
</tbody>
</table>

From Carter & McGoldrick (1989)
Family Characteristics of Youth with SMHC

- History of separation from family
- Single parent families
- Families in poverty
- Youth and parents rate their families as more chaotic and lower in emotional bonding

*Families are the individuals who continue to be involved with youth after they leave school and child serving systems*
Families of Youth with SMHC: System Implications

- Involve Families as is developmentally appropriate
- Child systems shift away from parent lead/Adult systems bring parents in more
- Maximize potential family support through young adulthood (safety net and resource)
PART II.
the System
“Pour batter into a pan at a rate that will yield uncoated brownies, which when cut such as to meet the dimension requirements specified in regulations 3.4f. will weigh approximately 35 grams each. The dimensions of the coated brownie shall not exceed 3½ inches by 2½ inches by 5/8 inch. Shelled walnut pieces shall be of the small piece size classification, shall be of a light color, and shall be U.S. No. 1 of the U.S. Standards for Shelled English Walnuts. A minimum of 90 percent, by weight, of the pieces shall pass through a 4/16-inch-diameter round-hole screen and not more than 1 percent, by weight, shall pass through a 2/16-inch-diameter screen.

Source: Staged Government Tricky, John J. Kilcute; 1985 Plume/Penguin

DARL CAGLE

The Pentagon’s recipe for brownies (document MIL-C-44072 C) is 22 pages long and took six months and 175 work hours to prepare.

Bureaucratic Standards....
Point of Transition; Child and Adult Systems

AGE

Juvenile Justice
Special Education
Child Welfare
Child Mental Health

Housing
Vocational Rehabilitation
Substance Abuse
Criminal Justice

Adult Mental Health

Vocational Rehabilitation
Substance Abuse
Criminal Justice

住房
职业康复
毒品滥用
刑事司法

成人心理健康

AGE
Central Policy Tenets

I. Provision of continuity of care from ages 14 or 16 to ages 25 or 30.

II. Support of family role to ages 25-30.

III. Provision of continuity of care across the many systems that offer relevant services.

IV. Promotion of a density of developmentally-appropriate services from which individualized service and treatment plans can be constructed.

V. Support of expertise in this age group and disability population.
National Transition Survey of Child & Adult Mental Health Administrators

- Interviewed a state-level administrator from each state and DC (members of National Association of State Mental Health Program Directors)
- Either lead administrator for child/adult MH or their designee
- 42 States sufficiently centralized organizations - administrators considered sufficiently informed
- 8 states not included: CA, FL, NE, NY, PA, UT, WA, WV
- MI adult administrator declined to participate
Topics of Inquiry

1. Transition services provided by child/adult mental health
2. Interagency transition efforts in which mental health participates
3. Perceptions of system characteristics that work and hinder
4. Policies, regulations, & laws regarding transition
CENTRAL POLICY TENET

I. Provision of continuity of care from ages 14 or 16 to ages 25 or 30
Continuity Of Care

Based on written policies received from 45 states

From Davis & Koroloff, (in press)
# Child & Adult Mental Health Population Policy Differences

From Davis & Koroloff, (in press)

<table>
<thead>
<tr>
<th>Concept</th>
<th>Value</th>
<th>% State Policies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included diagnoses when diagnosis a qualifying condition (Child N=38, Adult N=44)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotic disorders</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Major affective disorders</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Borderline personality disorder</td>
<td>100.0</td>
<td>76.7</td>
</tr>
<tr>
<td>Post traumatic stress disorder</td>
<td>92.1</td>
<td>65.1</td>
</tr>
<tr>
<td>Attention deficit/disruptive behavior disorders</td>
<td>97.4</td>
<td>39.5</td>
</tr>
<tr>
<td>Requirement of functional impairment (n=46)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63.0</td>
<td>78.3</td>
</tr>
<tr>
<td>No</td>
<td>6.5</td>
<td>6.5</td>
</tr>
<tr>
<td>This or other conditions qualify*</td>
<td>30.4</td>
<td>15.2</td>
</tr>
<tr>
<td>Risk or history of out-of-home placement or other intensive services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence/risk psychosis/dangerous to self/others</td>
<td>28.3</td>
<td>13.0</td>
</tr>
<tr>
<td>Multiagency/interdisciplinary team involvement</td>
<td>19.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Special Education Student</td>
<td>8.7</td>
<td>0.0</td>
</tr>
<tr>
<td>Arrested/Convicted of Crime</td>
<td>0.0</td>
<td>8.7</td>
</tr>
<tr>
<td>Homeless and mentally ill</td>
<td>4.3</td>
<td>10.9</td>
</tr>
<tr>
<td>Other qualifying conditions (N=46); Other</td>
<td>34.8</td>
<td>23.9</td>
</tr>
</tbody>
</table>
Population Policy Differences

- No state had the same population policy for child and adult mental health
- Generally, child definitions/criteria are broader
- Produces arbitrary barrier of access to adult services based on a change in age, not on a change in need.
- “Grandfathering” corrects for those in the system, but not for “new” young adults
Some Remedies...

Change policies that define disability by age.

Example: CMHS definitions of SED/SMI are almost identical diagnostically but differ in functional impairment – make functional impairment developmentally appropriate across the entire age spectrum thus removing arbitrary age barrier...

Functional impairment is defined as difficulties that substantially interfere with or limit an individual from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative, or adaptive skills, or functioning in social, family, and vocational/educational contexts. Adaptive skills include self care, home living, community use, self-direction, health and safety, functional academics, and work (Luckasson & Reeve, 2001).
Consequences of Population Policy Differences

- Systems are built around their target population, underlies many of the conflicts between child/adult systems
- Supports the false dichotomy of adulthood/adolescence
- Circular argument that you provide services to priority population, and you don’t others because others aren’t served well
- Denies ownership of the whole mental health population
Distribution of Programs by Age Groups Served (n=103)

“Youth Only”=up to 18 or 21, “Adult Only”=18 or 21 and older
Ages served by Various Systems

% of Programs

Service Sector
Segregated Child and Adult Systems

Block analysis of Clark County PYT; prior to grant implementation

From Davis et al., 2005
### Availability of Transition Support Services Offered by State Adult and Child MH Systems in 41 States and the District of Columbia

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>% with Any Type of Service</th>
<th>Type of Service</th>
<th>% with Any Type of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adult† Child</td>
<td></td>
<td>Adult† Child</td>
</tr>
<tr>
<td>Special Comprehensive Services**</td>
<td>19.0 38.1</td>
<td>MH Treatment</td>
<td>4.8 4.8</td>
</tr>
<tr>
<td>Supported/Supervised Housing/Group Homes</td>
<td>23.8 31.0</td>
<td>Psychosocial Rehabilitation</td>
<td>7.1 0.0</td>
</tr>
<tr>
<td>Vocational Support, Counseling or Preparation</td>
<td>11.9 19.0</td>
<td>Residential Treatment</td>
<td>7.1 --</td>
</tr>
<tr>
<td>Specialized Case Management††</td>
<td>11.9 7.1</td>
<td>Social Skills</td>
<td>4.8 2.4</td>
</tr>
<tr>
<td>Other</td>
<td>4.8 16.7</td>
<td>Dual Diagnosis Treatment</td>
<td>2.4 2.4</td>
</tr>
<tr>
<td>Educational Support</td>
<td>2.4 11.9</td>
<td>Homeless Mentally Ill</td>
<td>2.4 0.0</td>
</tr>
<tr>
<td>Independent Living Preparation</td>
<td>0.0 11.9</td>
<td><strong>Any Transition Services</strong></td>
<td>50.0 73.8</td>
</tr>
</tbody>
</table>

From Davis, Geller, & Hunt (submitted)
## Fragmentation

**Most Commonly Stated Themes From State Adult Mental Health Administrators (N=50)**

<table>
<thead>
<tr>
<th>Topic</th>
<th>States</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>System Fragmentation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interagency/Child/Adult MH Relationships</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>Interactions Across Child &amp; Adult MH</td>
<td>19</td>
<td>5</td>
</tr>
<tr>
<td>Eligibility Differences</td>
<td>19</td>
<td>5</td>
</tr>
<tr>
<td>Territoriality</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Separate Funding of Child/Adult MH</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>General Child/Adult Dichotomy</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Bureaucracy Bad/Small System Good</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Poor Handshaking</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>System Culture Differences</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Ignorance of Other Systems</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td><strong>Multi-Stakeholder Buy-In Important</strong></td>
<td>7</td>
<td>31</td>
</tr>
<tr>
<td>Different Funding Levels</td>
<td>6</td>
<td>37</td>
</tr>
<tr>
<td>Family vs. Individual Focus</td>
<td>5</td>
<td>42</td>
</tr>
<tr>
<td>Connection To Substance Abuse System</td>
<td>5</td>
<td>42</td>
</tr>
<tr>
<td>Child System Owns The Issue</td>
<td>5</td>
<td>42</td>
</tr>
</tbody>
</table>

From Davis & Hunt, (2005)
Factors State Adult Administrators Identified as Needed to Improve Transition

<table>
<thead>
<tr>
<th>Fundamental Change Prerequisites</th>
<th># states</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient Money or Resources</td>
<td>26</td>
<td>1</td>
</tr>
<tr>
<td>Leadership</td>
<td>23</td>
<td>2</td>
</tr>
<tr>
<td>Priority</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>Squeaky Wheels</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Fund YA Issue/Services/Population</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Federal Initiatives/Leadership</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Increased Awareness</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Requires Creativity</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Requires Service Guidelines Or Models</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Requires New Policies</td>
<td>7</td>
<td>23</td>
</tr>
</tbody>
</table>
Foster Leadership that Holds the Vision

- All 15-30 year olds with serious mental health conditions share the tasks of maturation and adult role fulfillment
- The service system needs to be continuous and on task throughout this developmental stage
- Youth voice required and foremost, family voice also needed
- Constant vigilance for recognizing and creating opportunities for change
Some Remedies...

Identify this age group as a priority population in policy and funding

- Require reporting the numbers of those aged 15-30 receiving services
- Require reporting of services that target transition to adulthood tasks
- Provide incentives to be creative in addressing this need
- Provide trainings to raise awareness of the population and needs
Some Remedies...

Engage ownership of this developmental stage within the adult system

- This is not an “aging out” issue, it is an issue of providing developmentally appropriate services to all clients
- Build on strengths of each system
- Collect outcome data
Engage ownership of this developmental stage within the adult system

- Provide trainings to raise awareness of the population and needs
- Call on CMHS to provide leadership in engaging adult services
- Be sure to include adult systems at the table
- Talk to sites that have had success with this (MD, CT)
Judge David L. Bazelon
Center for Mental Health Law

Analyzed 55 Federal Programs
as of Spring ’05

http://www.bazelon.org/publications/movingon/index.htm
# Number of Relevant Federal Programs in Each Life Domain

<table>
<thead>
<tr>
<th>Life Domain</th>
<th># programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Health Treatment (includes Mental Health)</td>
<td>6</td>
</tr>
<tr>
<td>Behavioral Health Specific Programs</td>
<td>7</td>
</tr>
<tr>
<td>Basic Supports (e.g. food stamps)</td>
<td>4</td>
</tr>
<tr>
<td>School-Based Transition Programs</td>
<td>5</td>
</tr>
<tr>
<td>Higher Education</td>
<td>7</td>
</tr>
<tr>
<td>Independent Living for Persons with Disabilities and Other Special Populations</td>
<td>7</td>
</tr>
<tr>
<td>Generic Independent Living (Skills training, employment-related services, etc.)</td>
<td>6</td>
</tr>
<tr>
<td>Housing</td>
<td>7</td>
</tr>
<tr>
<td>Family Planning and Parenting Assistance</td>
<td>2</td>
</tr>
<tr>
<td>Social Services</td>
<td>3</td>
</tr>
<tr>
<td>Youth In or At Risk of Juvenile Justice</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>55</strong></td>
</tr>
</tbody>
</table>
The sheer number of programs makes it difficult for providers and policymakers to be aware of, much less fully understand, all programs.

No specific attempt has been made by the federal government to align programs with each other.

Typically, there are rules unique to each program.

Eligibility differences result in an individual youth being eligible for some programs but not others, or being eligible at one age but not consistently eligible through age 25.
Differing Age Criteria

- Ten programs limit services to those under age 21.
- Five programs limit services to those under 18/19.
- One program limits services to those under age 23.
- Seven programs accept youth up to age 25.
Funding may go directly to states, local nonprofit entities or some combination of public and private entities.

Even among programs that have similar funding mechanisms, the eligibility criteria for grant applicants can be quite different.

Thus, there is no one kind of entity serving transition-aged youth with SMHC that is eligible to apply for all federal programs.
Recommendations For SAMHSA

1. New Program for Transition-Aged Youth with Serious MH Conditions – to encourage statewide change. Modeled after much of the language in PART C of IDEA (requirements/incentives/waivers/TA)

2. Develop policy that encourages coordination and cooperation of all branches of the Division of Service and Systems Improvement within CMHS with the Centers for Substance Abuse Treatment and Substance Abuse Prevention regarding this population.

3. CMHS spearhead development of an interagency technical assistance center for youth in transition to adulthood with SMHC; develop a uniform training curriculum for child and adult agencies.

4. Align CMHS definitions of SED/SMI to remove arbitrary age barrier at 18 and emphasize age appropriate functioning in adulthood and attach to block grants.

5. CMHS take responsibility for providing a single source describing federal government programs that impact this population.

6. Mandate grantees under the system of care program to organize Youth Councils.
http://www.umassmed.edu/cmhsr/working_papers