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

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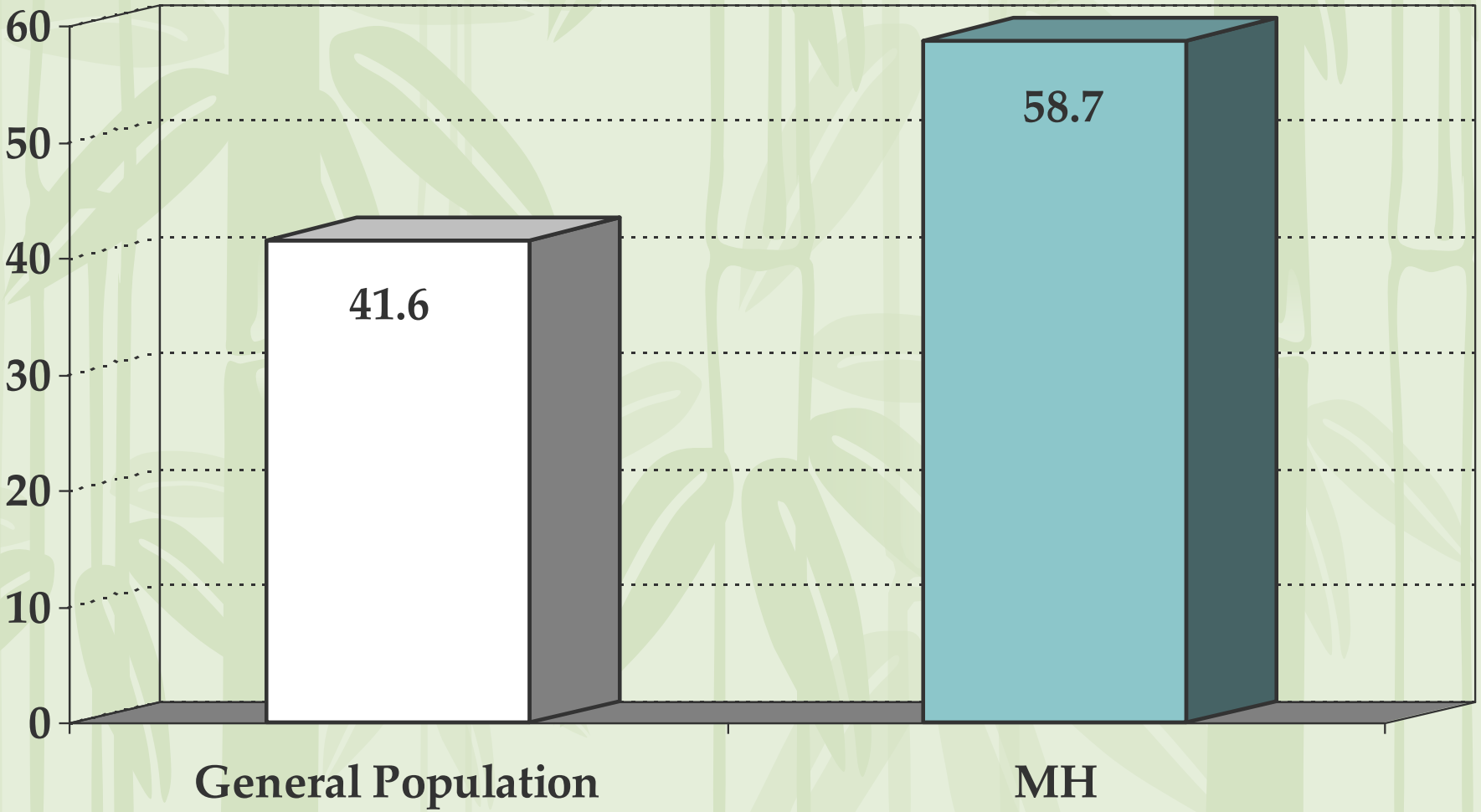
Youth with SED Struggle as Adults

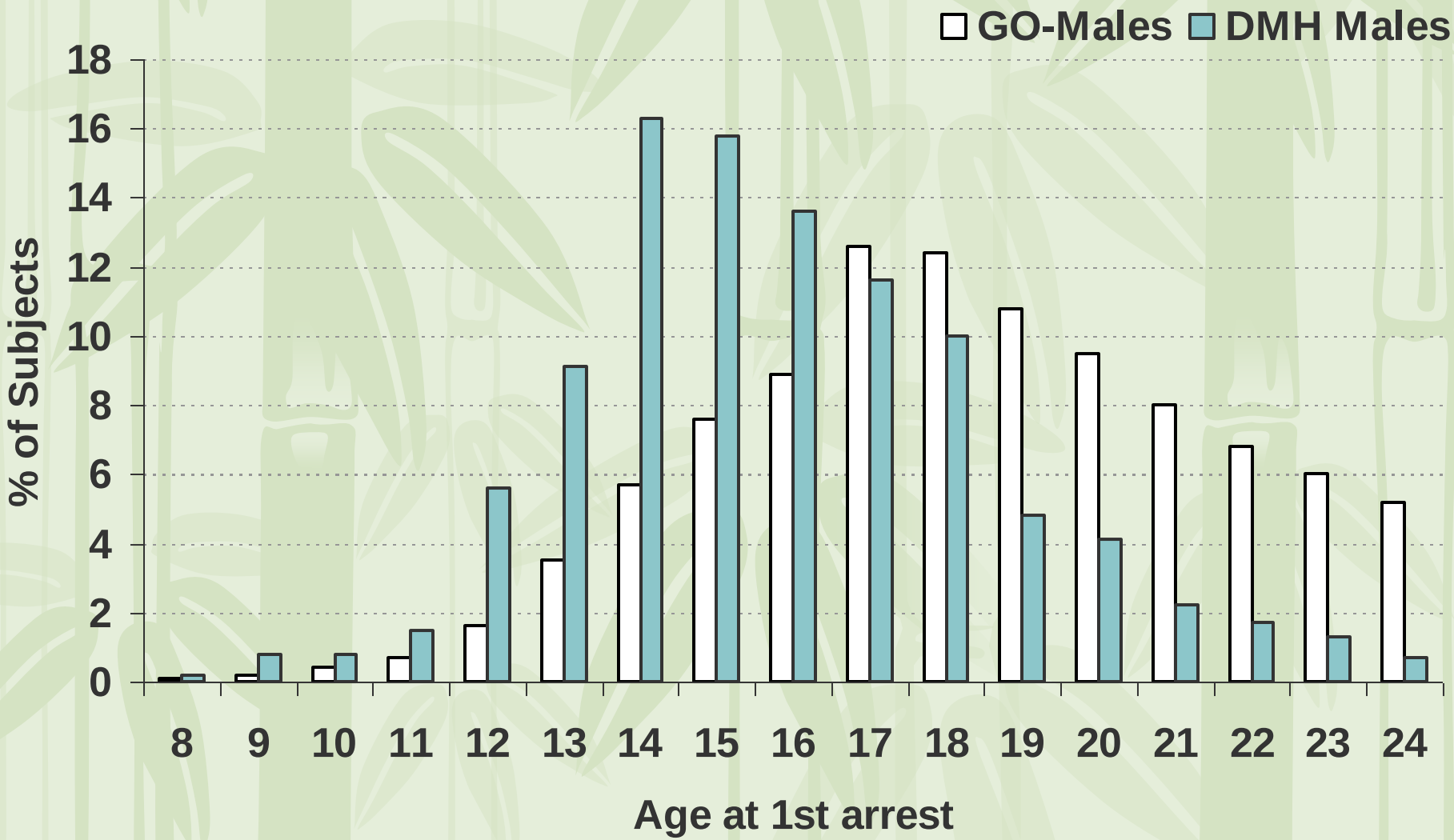
- **Few Graduate from High School**
  - **23-30% vs. 61% in community vs. 81-93% in general population**
- **Employment Rates are Low**
  - **46-51% vs. 59% vs. 78-80%**
- **Greater Risk of Homelessness**
  - **30% vs. 7% in general population**
- **Higher Pregnancy Rates in Women**
  - **38-50% vs. 38% vs. 14-17%**

(Valdes et al., 1990; Wagner et al., 1991; Wagner et al., 1992; Wagner et al., 1993; Kutash et al., 1995; Silver et al., 1992; Vander Stoep, 1992; Vander Stoep and Taub, 1994; Vander Stoep et al., 1994; Vander Stoep et al., in press; Davis & Vander Stoep, 1997)

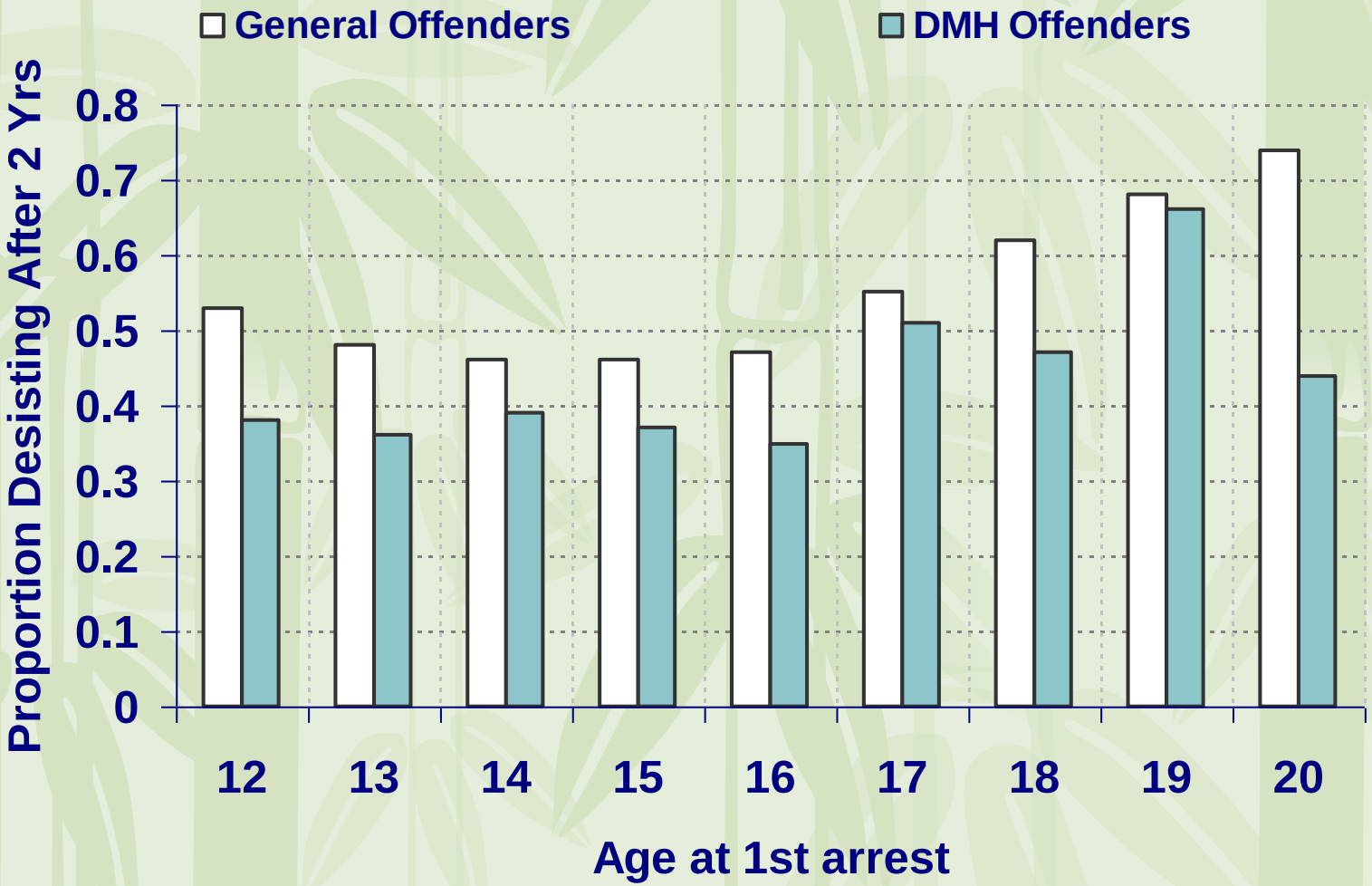
Proportion Arrested by age 25
Adolescent MH Clients vs. General Population



Distribution of 1st Arrest Ages in Males
DMH Adolescent Clients vs. General Offenders

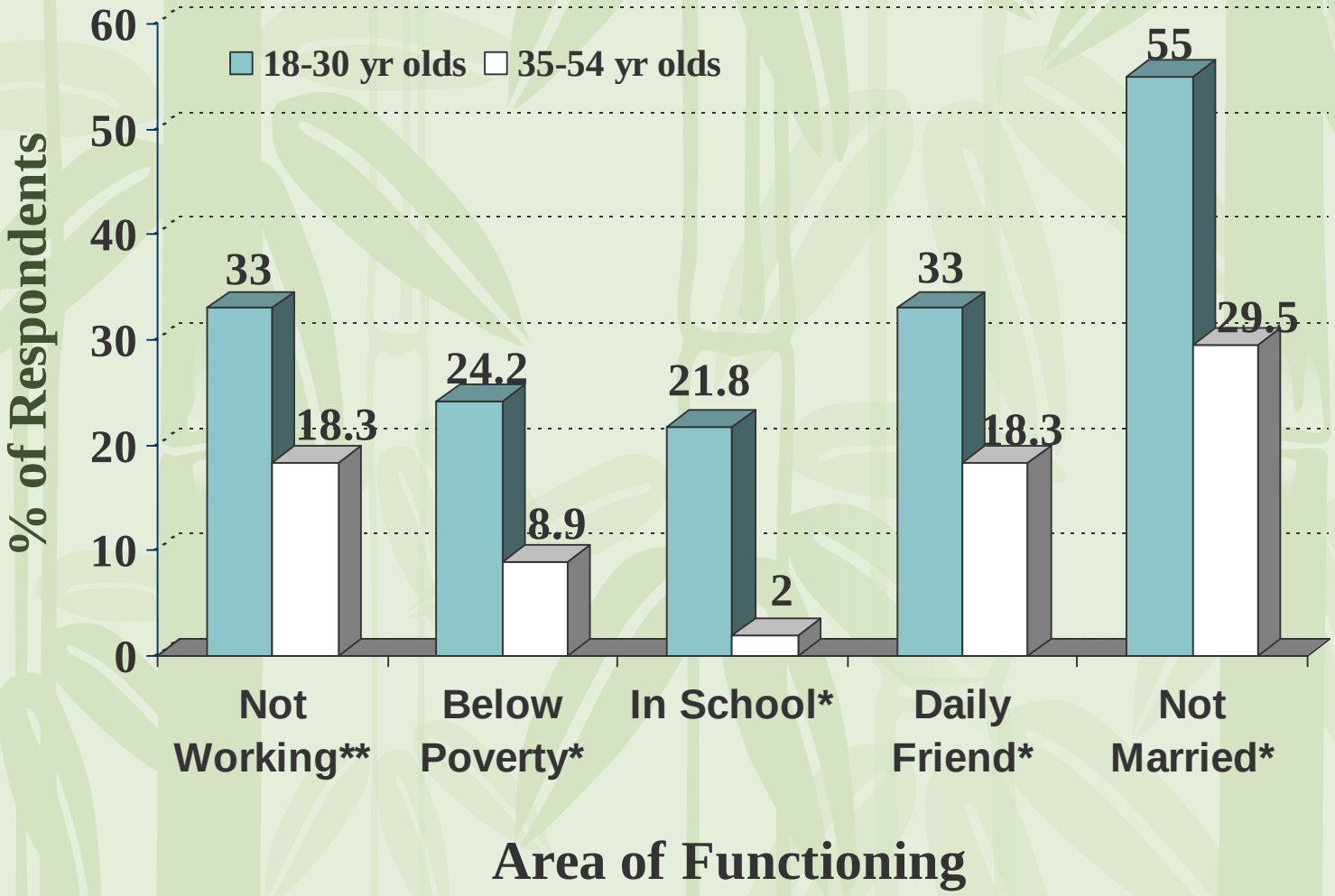


Desistance After 2 years by 1st Arrest Age in Male General and DMH Offenders



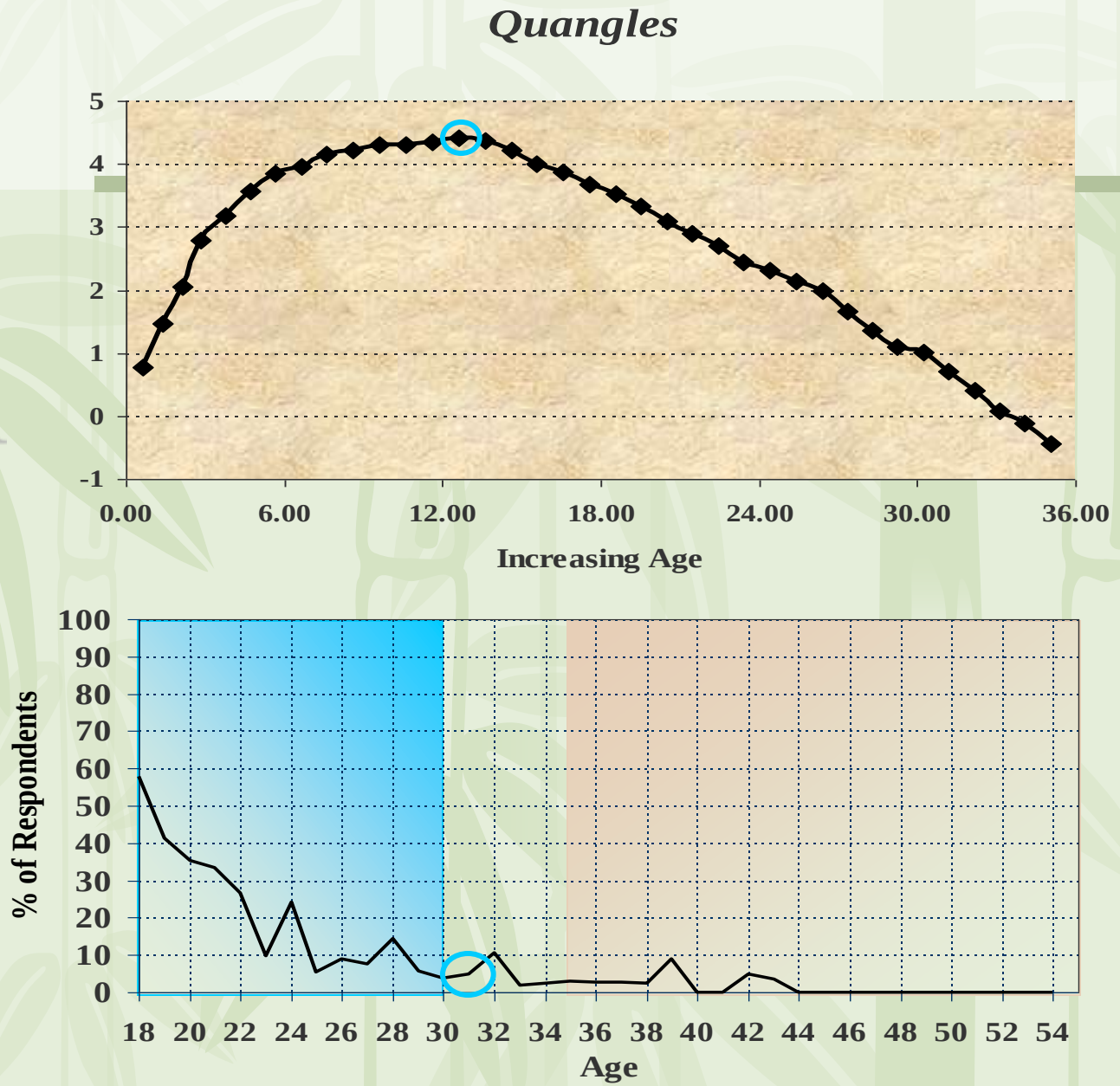
Functioning in Adults with Psychiatric Disorders

Young Adults Fare Worse than Older Adults



*χ^2 (df=1)=31.4-105.4, p<.001 ** χ2 (df=1)=5.5, p<.02

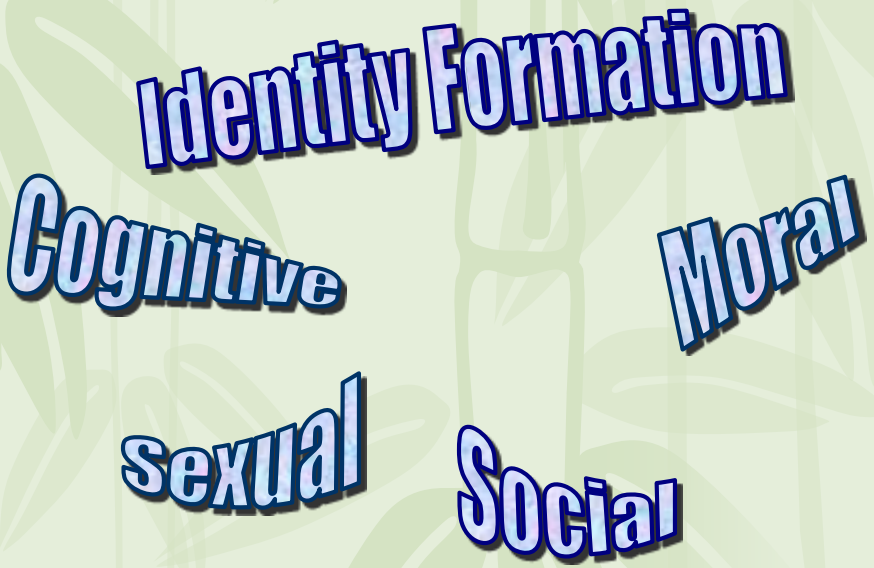
In School



Multiple Regression: Age in model (Adjusted R^2=.128, F(1,1276)=188.3, p<.001)

Psychosocial Development

Adolescence to Adulthood



Developmental change on every front

Biopsychosocial Development in Youth with Serious Mental Health Conditions

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

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

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

Bureaucratic Standards….

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.

"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 walnuts shall be… of the U.S. Standards for Shelled English Walnuts……"

Point of Transition; Child and Adult Systems

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

National Transition Survey of Child & Adult Mental Health Administrators

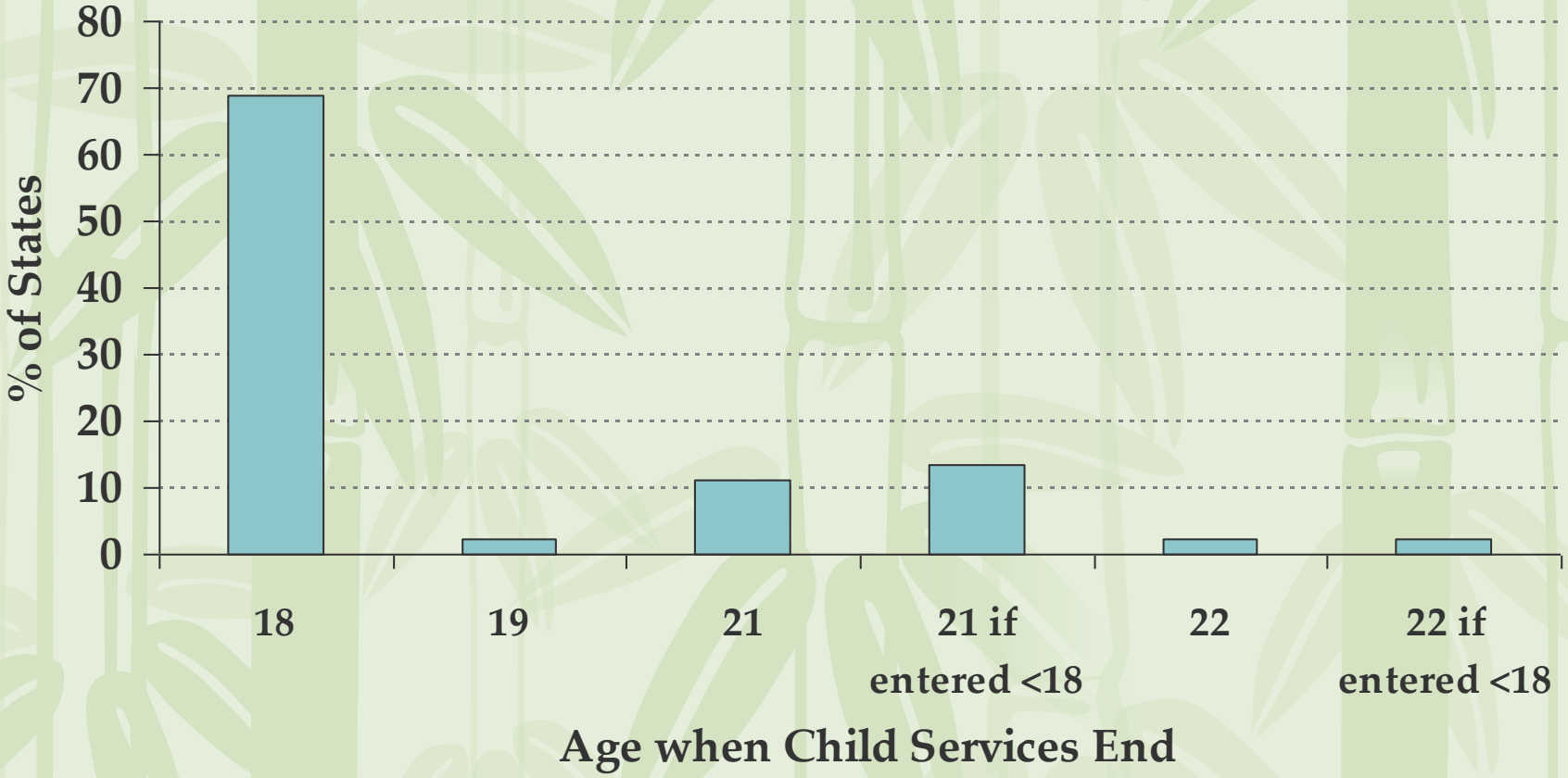
Topics of Inquiry

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)

Concept	Value	% State Policies	
		Child	Adult
Included diagnoses when diagnosis a qualifying condition (Child N=38, Adult N=44)	Psychotic disorders	100.0	100.0
	Major affective disorders	100.0	100.0
	Borderline personality disorder	100.0	76.7
	Post traumatic stress disorder	92.1	65.1
	Attention deficit/disruptive behavior disorders	97.4	39.5

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.

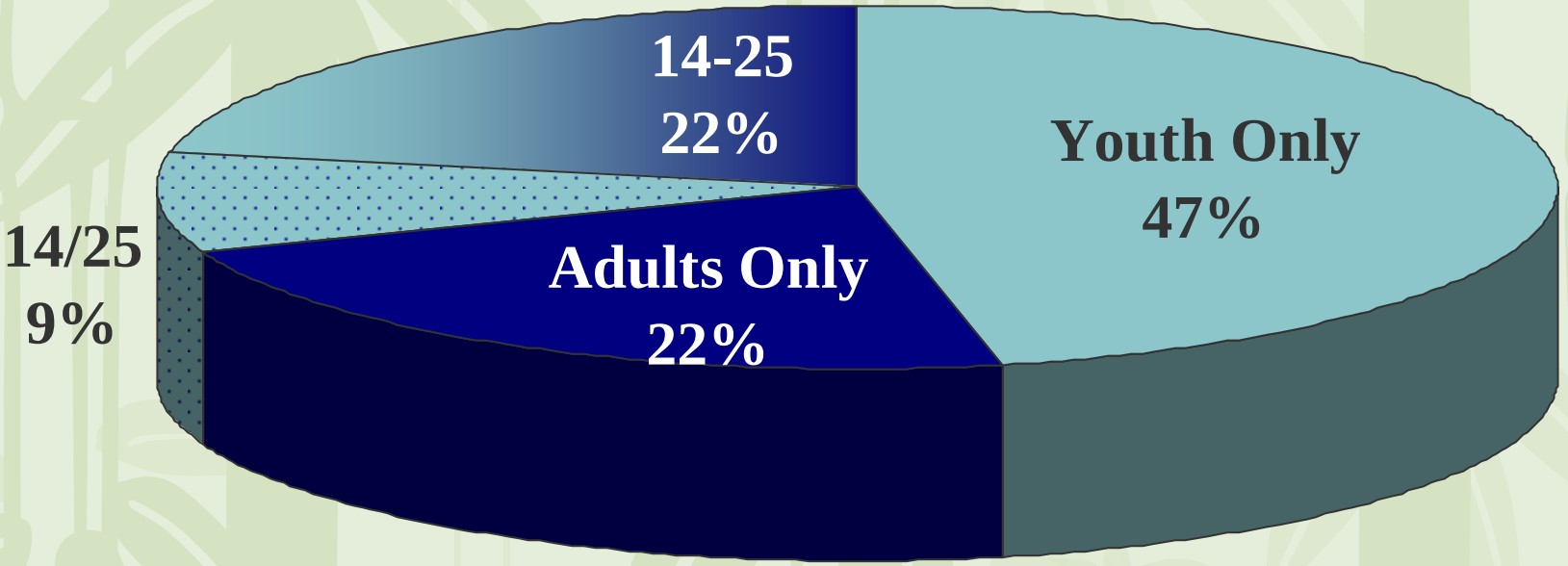
Example: CMHS definitions of SED/SMI are almost identical diagnostically but differ in functional impairment – make functional impairment developmentally appropriate across the entire age spectrum thus removing arbitrary age barrier…

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

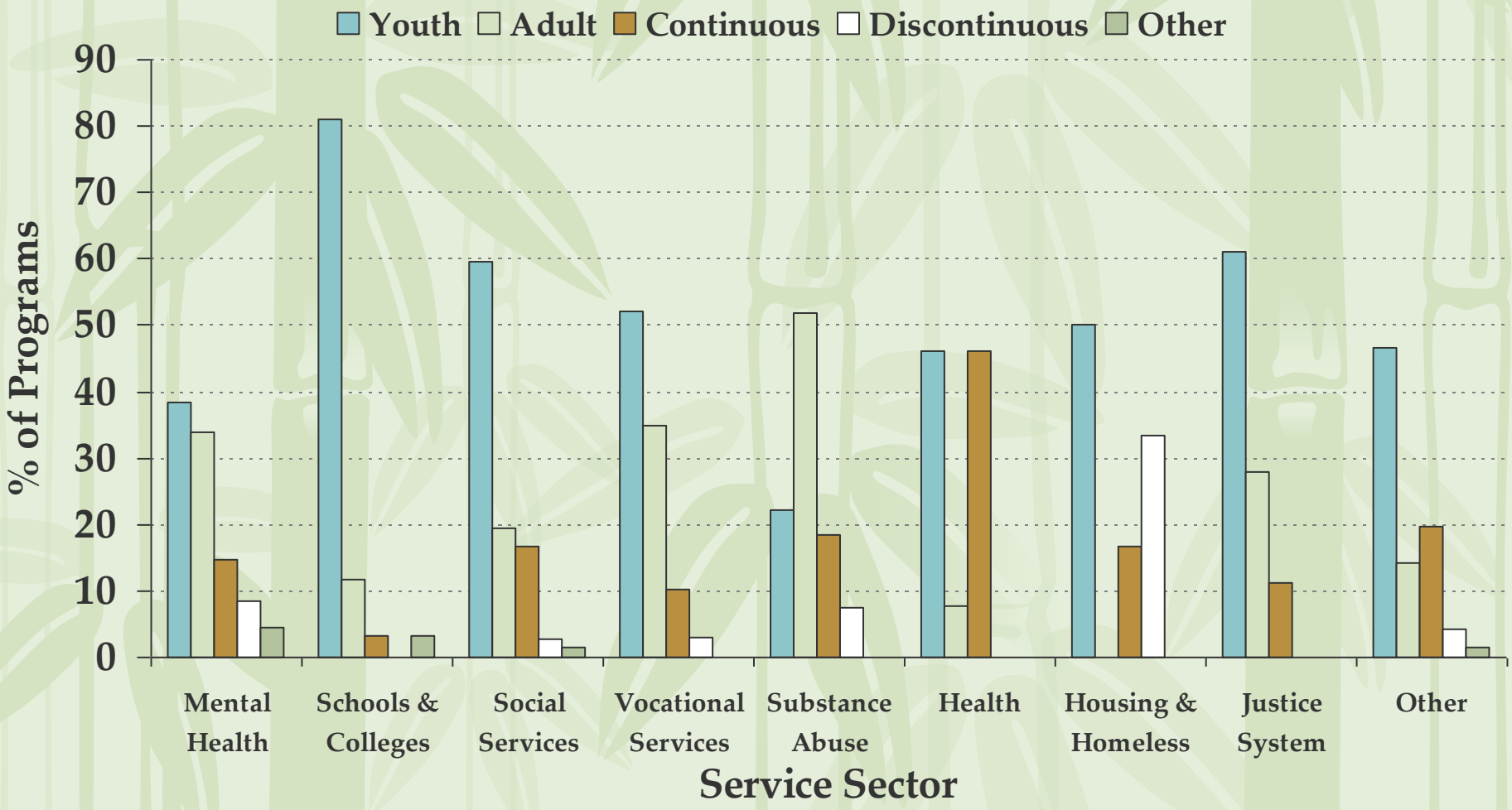
- Systems are built around their target population, underlies many of the conflicts between child/adult systems
- Supports the false dichotomy of adulthood/adolescence
- Circular argument that you provide services to priority population, and you don't others because others aren't served well
- Denies ownership of the whole mental health population

Distribution of Programs *by Age Groups Served* (n=103)



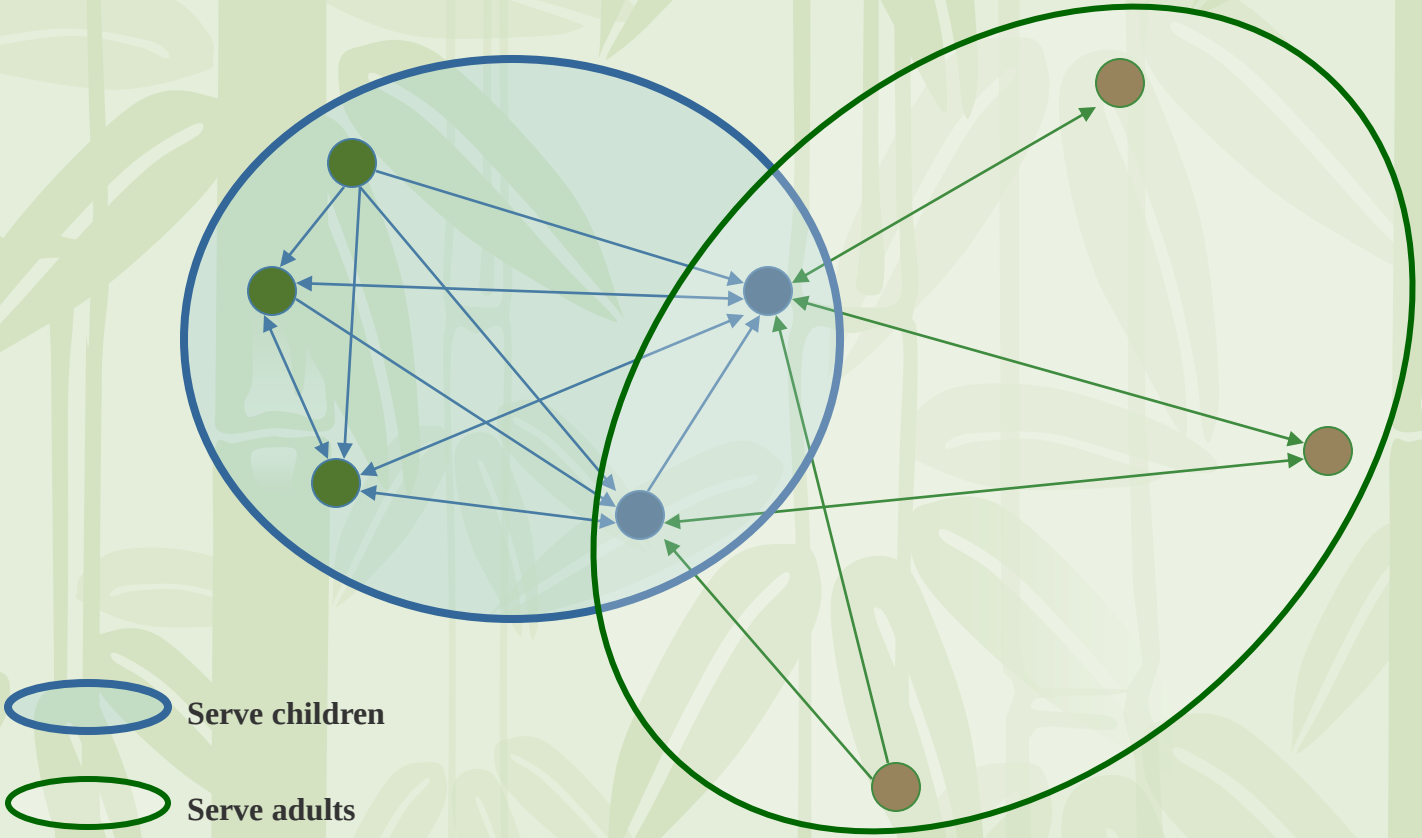
"Youth Only"=up to 18 or 21, "Adult Only"=18 or 21 and older

Ages served by Various Systems



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

Type of Service	% with Any	
	Adult†	Child
Special Comprehensive Services**	19.0	38.1
Supported/Supervised Housing/Group Homes	23.8	31.0
Vocational Support, Counseling or Preparation	11.9	19.0
Specialized Case Management††	11.9	7.1
Other	4.8	16.7
Educational Support	2.4	11.9
Independent Living Preparation	0.0	11.9

Type of Service	% with Any	
	Adult†	Child
MH Treatment	4.8	4.8
Psychosocial Rehabilitation	7.1	0.0
Residential Treatment	7.1	--
Social Skills	4.8	2.4
Dual Diagnosis Treatment	2.4	2.4
Homeless Mentally Ill	2.4	0.0
Any Transition Services	50.0	73.8

From Davis, Geller, & Hunt (submitted)

Fragmentation

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

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

From Davis & Hunt, (2005)

Factors State Adult Administrators Identified as Needed to Improve Transition

Fundamental Change Prerequisites	# states	Rank

Some Remedies…

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

Life Domain	*# programs*
Medical Health Treatment (includes Mental Health)	6
Behavioral Health Specific Programs	7
Basic Supports (e.g. food stamps)	4
School-Based Transition Programs	5
Higher Education	7
Independent Living for Persons with Disabilities and Other Special Populations	7
Generic Independent Living (Skills training, employment-related services, etc.)	6
Housing	7
Family Planning and Parenting Assistance	2
Social Services	3
Youth In or At Risk of Juvenile Justice	2
TOTAL	55

Confusion!

- **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.**

Confusion cont'd

- 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