Community Response to Individuals with IDD Who Are Experiencing Behavioral Crisis

Amie Lulinski, Richard Kiefer-O'Donnell, Stacey Ramirez, & Kim Bullock

Moderator: Glenn T. Fujiura

AUCD Annual Conference, November 11, 2014

Community Capacity to Provide Mental and Behavioral Health Services to People with Developmental Disabilities

Amie Lulinski, PhD

November 11, 2014

AUCD Annual Conference

Acknowledgements

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  - Sarah Parker Harris, PhD
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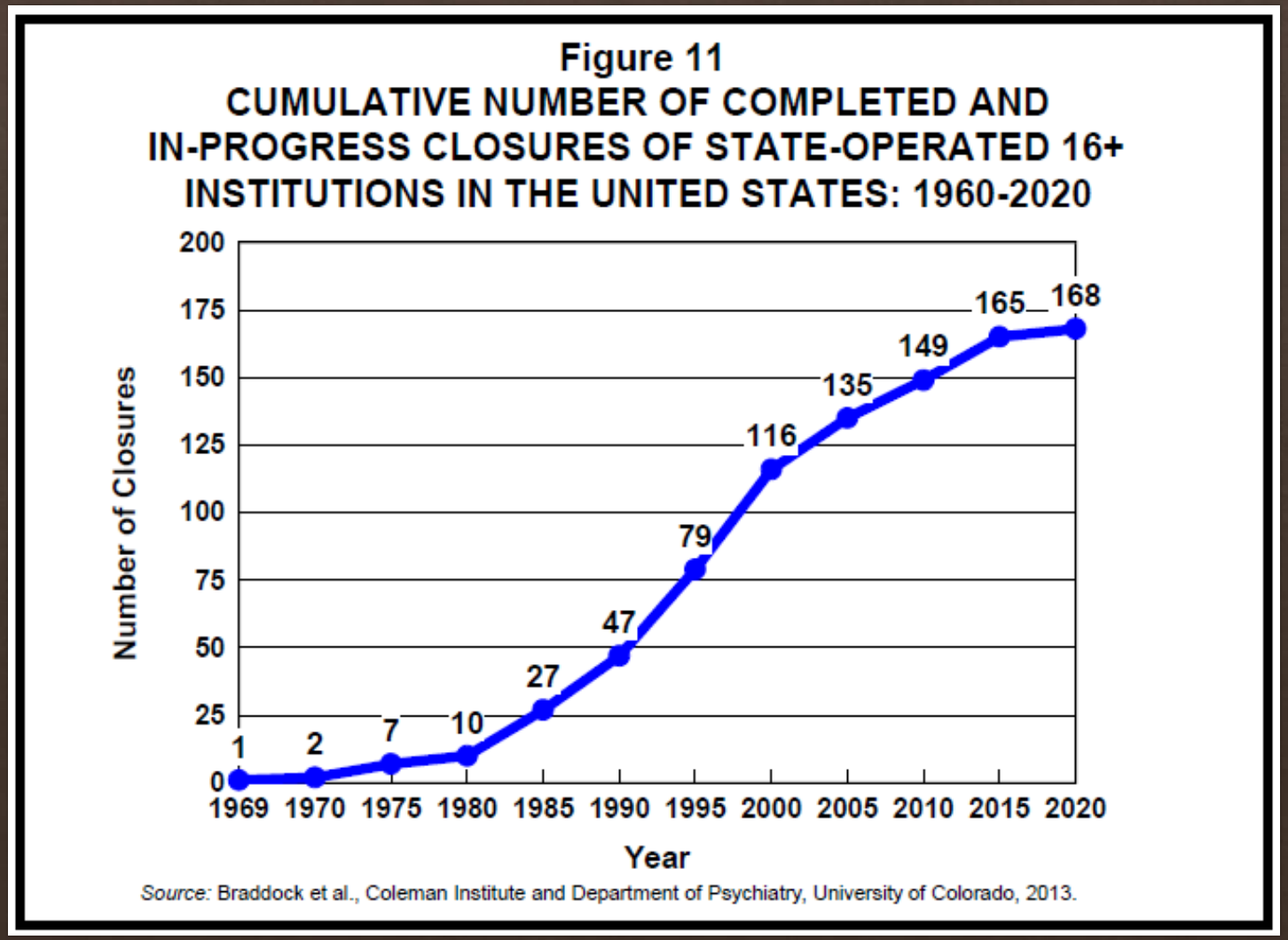
  - Yochai Eisenberg, MUPP
  - Richard Kiefer-O'Donnell, PhD

By 2020, a projected 168 institutions will have closed in the U.S.

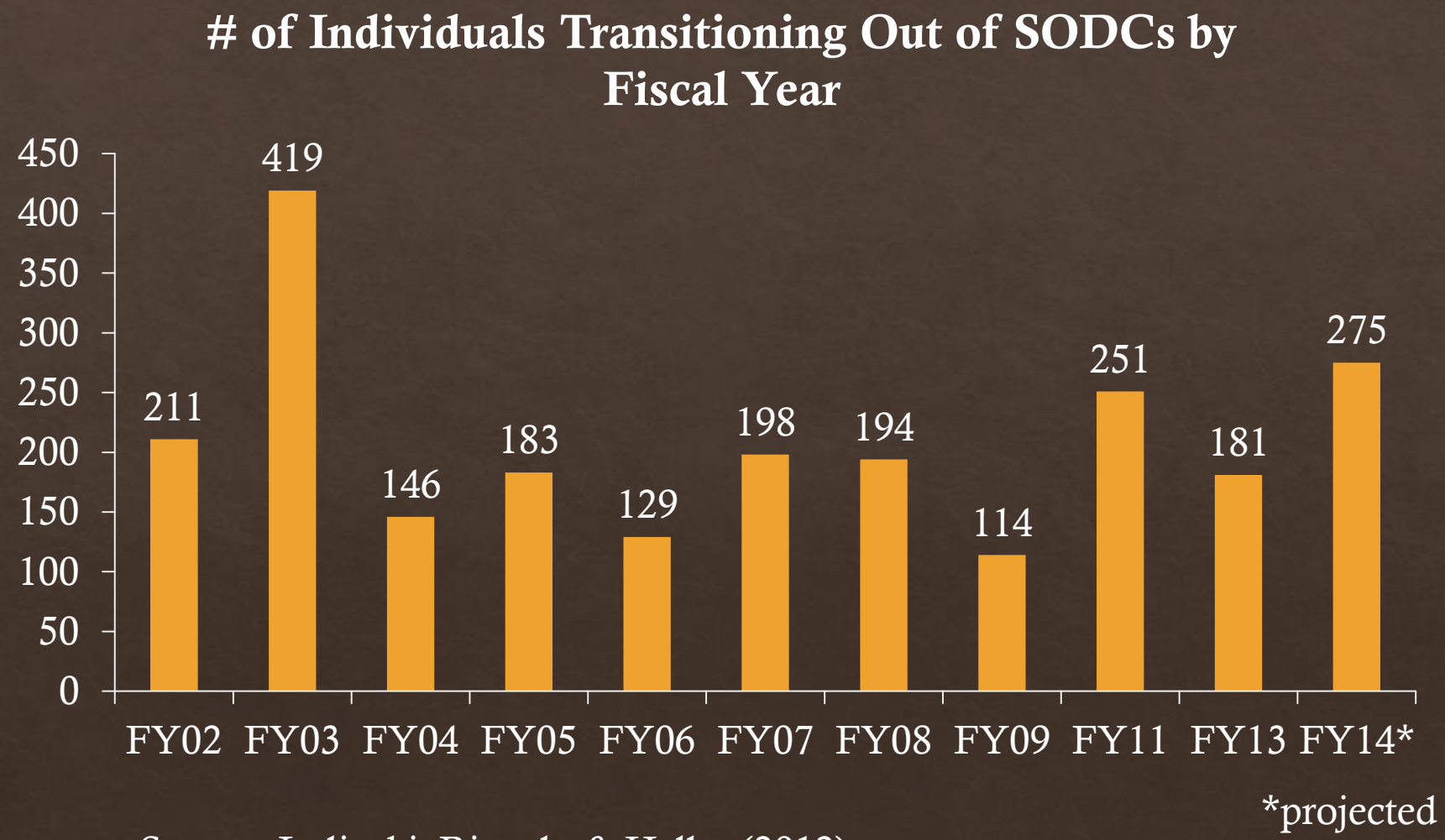


IL has closed nine institutions

Facility	Year Opened as IDD Facility	Fiscal Year of Closure	# of Residents at Time of Closure Announcement
Adler	1967	1982	16
Bowen	1965	1982	105
Dixon	1918	1987	820
Galesburg	1969	1985	350
Howe	1973	2010	251
Jacksonville	1851	2013	200
Lincoln	1877	2004	153
Meyer	1970	1993	53
Murray	1964	2014 (in progress)	275
Singer	1966	2003	45

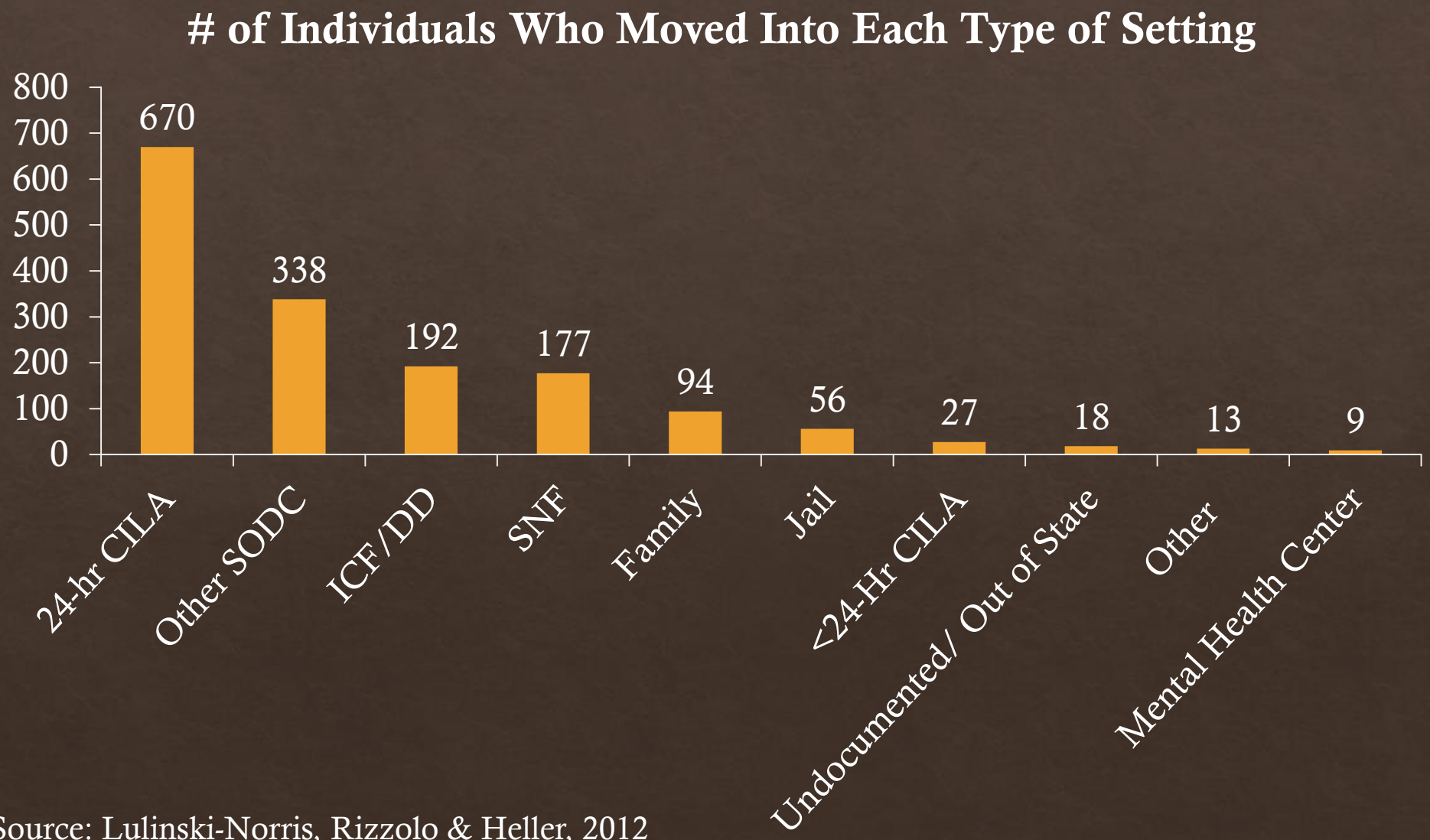
Source: Braddock, et al., 2013

By end of FY14, **at least 2,301** will have transitioned out of an SODC since FY02



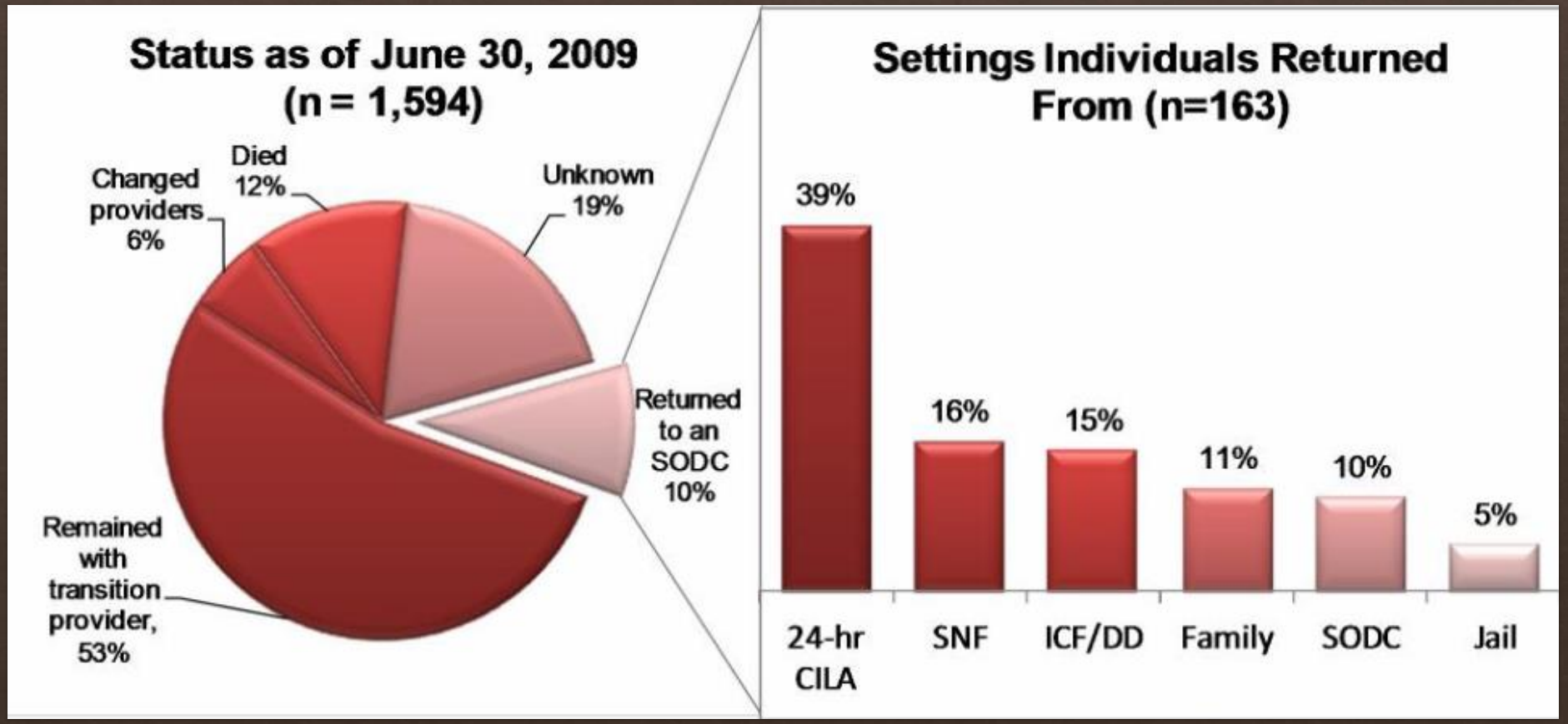
Source: Lulinski, Rizzolo & Heller (2012)

Where did people move?



Source: Lulinski-Norris, Rizzolo & Heller, 2012

Status as of 6/30/2009



Source: Lulinski-Norris, Rizzolo & Heller, 2012

Reasons for Return to an SODC

Reason for Return	#	%
Behavioral Issues	118	72.4%*
Undocumented	18	11.0%
Medical	17	10.4%
Other	10	6.1%
Total	163	Does not equal 100% due to rounding

Source: Lulinski-Norris, Rizzolo & Heller, 2012

Research Questions

1) **What types of mental/behavioral supports are available to individuals with IDD residing in Illinois community-based settings?;**
2) Does the availability of mental/behavioral supports differ with respect to geography and population characteristics?; and
3) How does the availability of mental/behavioral supports impact an individual's transition from an SODC to a community-based setting?

Organizational Variables - Survey

- Basic agency information
- # people served across all programs
- Crisis intervention training provided
- In-house mental/behavioral health professional
  - Clinical psychologist
  - Psychiatrist
  - Licensed Clinical Social Worker (LCSW)
  - Licensed Clinical Professional Counselor (LCPD)
  - Board Certified Behavior Analyst (BCBA)
  - Associate Behavior Analyst
  - Other

Survey, continued

- In-house mental/behavioral health treatment(s) provided
  - Individual counseling/psychotherapy
  - Group counseling/psychotherapy
  - Applied Behavior Analysis (ABA)
  - Relationship Development Intervention (RDI)
  - Telehealth
  - Other

Survey, continued

- Utilization of community services
  - Community Mental Health Centers
  - Inpatient psychiatric treatment/services
  - DHS/DDD Community supports (e.g., CART & SST)
  - Private sector
  - Federally Qualified Health Centers (FQHCs)
  - Rural Health Centers
  - University based (e.g., UIC Family Clinics)
  - Emergency Room (ER)
  - Police/911/Emergency Medical Services (EMS)
  - Other

Survey, continued

- Community services
  - Reason sought (e.g., type of behaviors)
    - Harmful to self/others
    - Property destruction
    - Sexually inappropriate behaviors
    - Illegal behaviors
    - Unusual behaviors
    - Other
  - Satisfaction with service
    - Scale of 1-5;
      - 1 = very dissatisfied and 5 = very satisfied

Survey, continued

- Overall assessment of the current availability and capacity of community mental/behavioral health services for people with IDD
  - Scale 1-5;
  - 1 = very poor and 5 = very good
- Assessment of change in services over past 3-5 years
  - Scale 1-5
  - 1 = worsened greatly and 5 = improved greatly

Survey, continued

- Open ended questions
  - Positive aspects of the mental/behavioral health service system for people with IDD;
  - Barriers to the provision of mental/behavioral health services for people with IDD;
  - How do barriers impact organizational ability to provide services to people transitioning out of SODCs;
  - Suggestions for systems improvement; and
  - Additional comments/insight.

Individual Variables

- Participants
  - Any individual who transitioned out of any IL SODC for any reason and into a community-based setting between October 1, 2001 and December 31, 2012
- Settings
  - Community-based settings (for 15 or fewer persons)

Individual Variables

- Data Collection
  - Individual data was obtained from DHS/DDD staff
- Demographics
    - Age, length of stay at SODC, gender, level of ID, ASD diagnosis, adaptive skills, psychiatric diagnosis & health risk score
- Measurement Instruments
  - Health Risk Screening Tool
  - Inventory for Client and Agency Planning (ICAP)
    - Service Level Scores

Individual Variables

- Transition placement
  - Organization providing services
  - Type of setting (ICF/DD, CILA, etc.)
  - # of residents in setting
- Transition Status
  - Remained in transition placement (“stayers”)
  - Returned to an SODC (“returners”)
    - Reason for return (medical, behavioral, dietary, etc.)
- Receipt of Technical Assistance (TA)

Findings: Question 1

What types of mental/ behavioral supports are available to individuals with IDD residing in IL community-based residences?

Participating Organizations

- 65 organizations responded (55.6%)
  - Average size = 120 (sd = 185, range 2 - 1,300)
  - 2/3 served 100 or less
- Respondents
  - 35.4% CEO/President/ED
  - 21.5% VP/Associate ED
  - 24.6% Director
  - 16.9% Manager/Coordinator/Administrator

In-house professionals

Professional	# of Respondents that have access	%
Psychiatrist	30	46.2%
Board Certified Behavior Analyst	28	43.1%
Clinical Psychologist	26	40.0%
Licensed Clinical Social Worker	24	36.9%
Social Worker	20	30.8%
Licensed Clinical Professional Counselor	18	27.7%
Associate Behavior Analyst	15	23.1%
Other professional	9	13.8%
Licensed Marriage & Family Therapist	2	3.1%

In-house treatments

Therapy	#	%
Individual counseling/ psychotherapy	31	47.7%
Applied behavior analysis (ABA)	27	41.5%
Group counseling/therapy	21	32.3%
Telehealth	6	9.2%
Other	5	7.7%
Relationship Development Intervention (RDI)	1	1.5%

Use of Community Services

Community-based service	#	%	Satisfaction Score
Police/911/Emergency Medical Services	59	90.8%	3.5
DHS/DDD supports	58	89.2%	2.8
Emergency Room	54	83.1%	2.9
Inpatient psychiatric treatment/crisis services	53	81.5%	3.1
Community Mental Health Centers	43	72.6%	3.2
Private sector mental health services	29	44.6%	3.8
University based clinics	16	24.6%	3.8
Federally Qualified Health Centers	10	15.4%	3.6
Rural Health Centers	9	13.8%	3.5
Other	3	4.6%	n/a

USEAGE AND SATISFACTION WITH COMMUNITY SERVICES

	Police/ 911/ EMS (n=59)	DHS/ DDD supports (n=58)	ER (n=54)	Inpatient psychiatric services (n=53)	CMHC (n=43)	Private sector (n=29)	University-based (n=16)	FQHC (n=10)	Rural Health Centers (n=9)
Overall use* (n=65)	90.8%	89.2%	83.1%	81.5%	66.2%	44.6%	24.6%	15.4%	13.8%
Behavior									
Harm to self	69.2%	61.5%	70.8%	76.9%	60.5%	26.2%	56.3%	40.0%	66.7%
Harm to Others	75.4%	56.9%	64.6%	72.3%	65.1%	24.6%	56.3%	40.0%	66.7%
Property destruction	52.3%	46.2%	40.0%	38.5%	55.8%	18.5%	25.0%	30.0%	55.6%
Sexually inappropriate	4.6%	20.0%	7.7%	3.1%	27.9%	12.3%	12.5%	10.0%	11.1%
Illegal	16.9%	12.3%	4.6%	10.8%	20.9%	10.8%	6.3%	10.0%	0.0%
Unusual	20.0%	29.2%	16.9%	20.0%	39.5%	20.0%	31.3%	10.0%	11.1%
Other	3.1%	4.6%	0.0%	4.6%	23.3%	9.2%	18.8%	20.0%	11.1%
Mean satisfaction score	3.5 (n=57)	2.8 (n=53)	2.9 (n=53)	3.1 (n=53)	3.2 (n=40)	3.8 (n=28)	3.8 (n=16)	3.6 (n=10)	3.5 (n=8)

*Percentage of respondents that reported using service

Positive aspects of system

- Access
- Availability
- Competence
- Funding
- Responsive community relationships
- Self-sufficiency
- SSTs
- Specific programs

Barriers to the provision of services

- Access to psychiatric treatment
- Lack of timely crisis services
- Lack of skilled professionals
- Medicaid rates

"Too few psych units will accept clients and those that do are often full or too far away. Also, while currently have a good psychiatrist, most of them either do not want to serve this population, are not available or are only available limited hours, or do not have admitting privileges."

Impact of barriers on organizational ability to provide services

- Deterrent
  - *"We are hesitant to take individual[s] from state operated facilities due to the lack of close psychiatric care…"*
  - *"Due to limited resources to cover the added costs of supporting individuals with behavioral needs, [our] agency has been less willing to consider those persons who may have significant behavioral issues."*
  - *"We might simply decline them…"*

Suggestions

- Increase:
  - Access to services
  - Reimbursement rates
  - Training
  - Collaboration
  - Policy change
  - Targeted transition

- *"In patient treatment options for short term respite or medication adjustments would be beneficial."*
- *"Short term crisis units that allow for drug holidays and 24 hour professional medical oversight for medication changes."*

Summary

- ~10% of community placements result in reinstitutionalization
  - Mainly due to behavioral issues
- Access to and capacity of community mental/behavioral health services is lacking
- Overall low satisfaction scores

Implications

- Research implications
  - Need for additional research
    - TA & crisis response
- Policy implications
  - TA & crisis response
  - Increased training of mental health professionals
  - Improved collaboration between state DD and MH agencies
  - Increased Medicaid rates

Three Interventions

- Alaska's Complex Behavior Collaborative Program
- Georgia's Crisis Intervention Team
- Developmental Disabilities Administration Health Initiative (DDA HI)

Community Response to Individuals with IDD Who Are Experiencing Behavioral Crisis: *Alaska's Complex Behavior Collaborative Program*

Dr. Richard Kiefer-O'Donnell
Associate Director/Associate Professor
UAA Center for Human Development
AUCD Annual Meeting
November, 2014

Agenda

- Overview Alaska's somewhat unique needs for serving children, youth and adults with cognitive impairments and challenging behaviors
- Discuss it's response: the Complex Behavior Collaborative
- Review services and preliminary data on outcomes

Alaskan Context and Capacity

1. Current state population of 735,132 with over half residing in Anchorage; another 75,000 on road system.
2. *Oct 1997*: Closure of the only state institution for developmentally disabled (Valdez, 160 beds, licensed as ICF-MR).
3. *Dec 1999*: Voluntary de-certification of 40 ICF-MR community-based beds (5 homes) with all now served by HCBW. All had been children and youth.
4. I/DD Waiver program now serves approximately 2850 individuals statewide, with 185 served by one of 17 Tribal Health Corps.

Alaskan Context and Capacity

5. Two state initiatives (*Alaska Youth Initiative* and *Bring the Kids Home*) to return the 500+ children, youth and adults who are served outside of the state.
6. As of 2009, only ONE registered BCBA in the state but she was retired. No graduate program to develop professionals with related skill sets.
7. Jan 2009: Development of CHD's specialized program to train BCBAs to serve individuals with Autism. State now has 27 BCBAs.
8. CBC evolved from a state-funded evaluation of in- and out-of-state needs in 2009 and low workforce capacity, beginning in in 2012.

What is the Alaskan Complex Behavior Collaborative

- Intense & specialized consultation and training services provided by the center and 3 other Alaskan organizations
- Operated by Alaska's state DD and BH divisions which then solicit referrals from providers.
- State recruits and reviews consultant credentials, and awards Fee for Service contracts to provide services.
- State project officer determines best match and participates in service planning.

State of Alaska goals for the Complex Behavior Collaborative

1. Improve the quality of life for Alaskans with disabilities and complex needs …
   a) Stabilize behaviors and residential placement;
   b) Expand social and communication skills to promote increased community inclusion.
2. Development of infrastructure for collaborative interventions, continuity of care
3. Development of robust, competent workforce
4. Avoid ADA violations
5. Cost savings for state

http://dhss.alaska.gov/dbh/Pages/ComplexBehavior/Default.aspx

Complex Behavior Collaborative

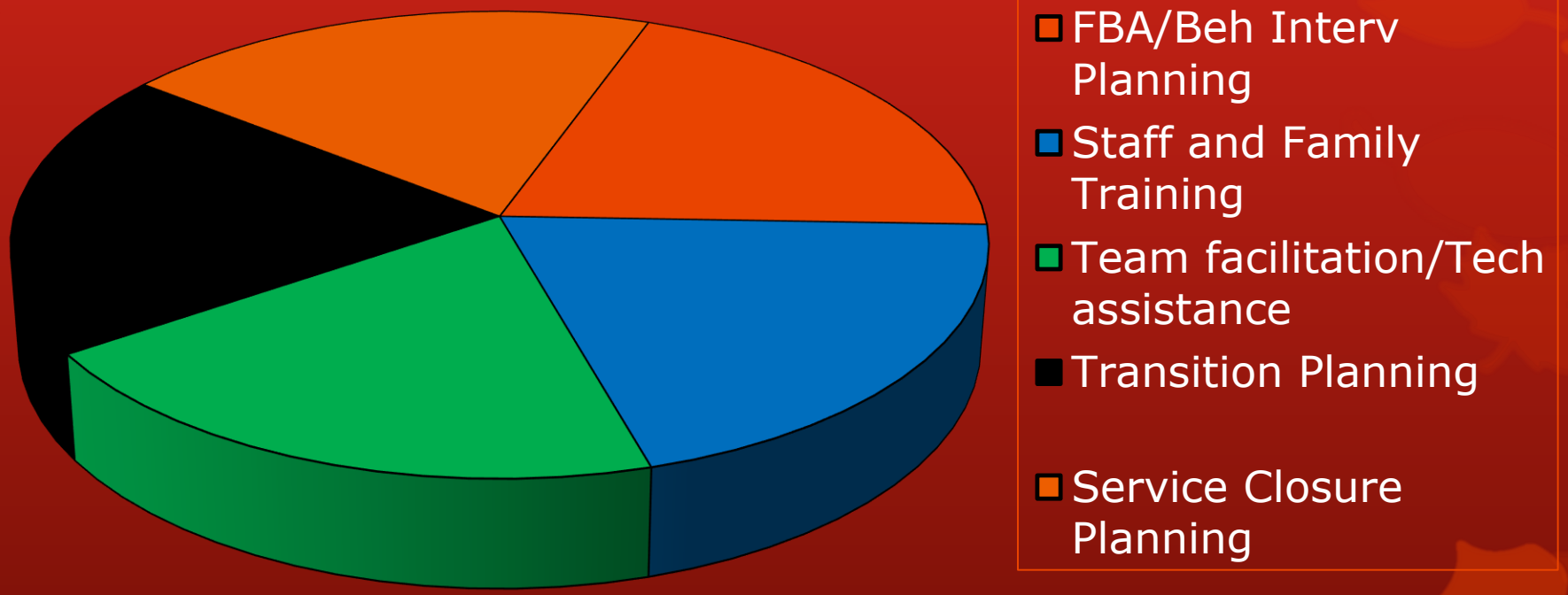
Individuals over the age of 6 who experience:

- Intellectual and developmental disability
- Chronic mental health concerns (often co-occurring with I/DD or FASD)
- Acquired traumatic brain injury
- Substance abuse (often with FASD)
- Dementia/Alzheimer's

Participants in program must be:

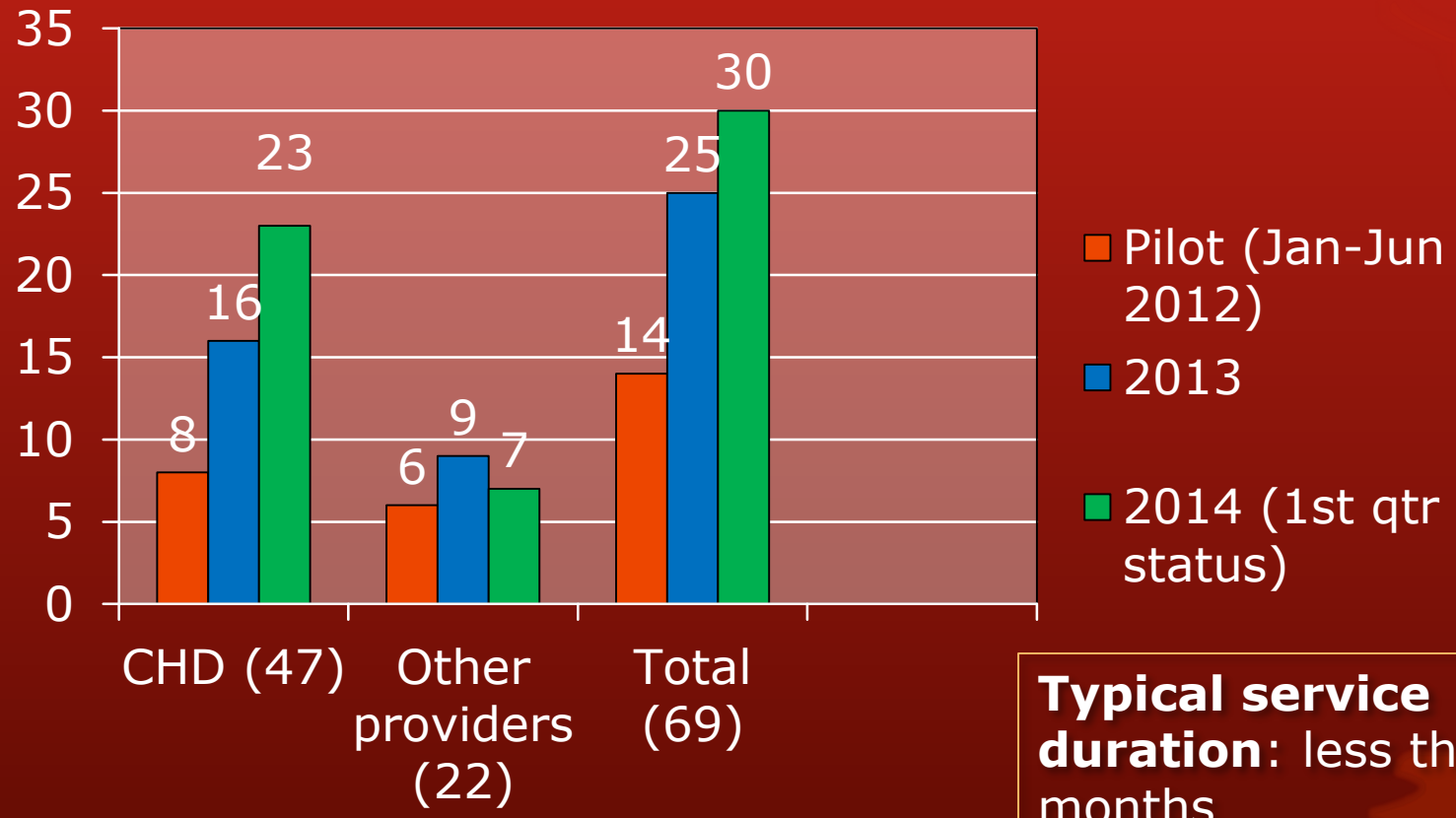
- Currently receiving services from Senior & Disabilities Services or Behavioral Health
- Have housing where they can be assessed and get services.
- Demonstrate behaviors that are so complex that they are
  1. outside the range of expertise of local caregivers and providers, OR
  2. available treatment has been exhausted without success for the individual

CBC Program Services



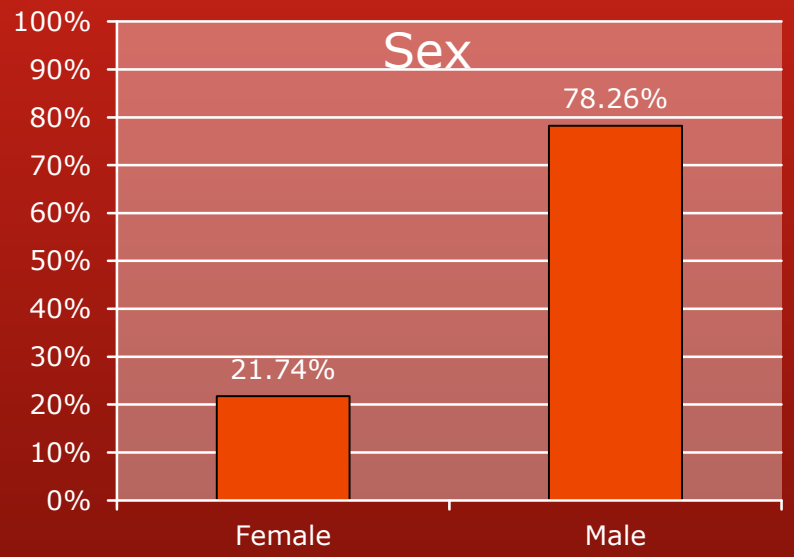
- FBA initiated within 48 hrs. of receipt of referral and BIP approved/implemented within 20 business days of referral.
- Includes development of data collection system and initial analysis
- Initiated 20-40 business days prior to closure of services

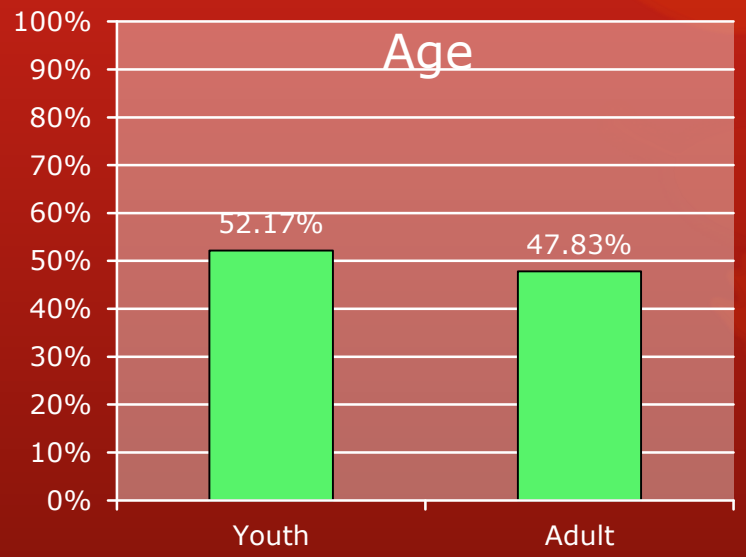
Growth of Services

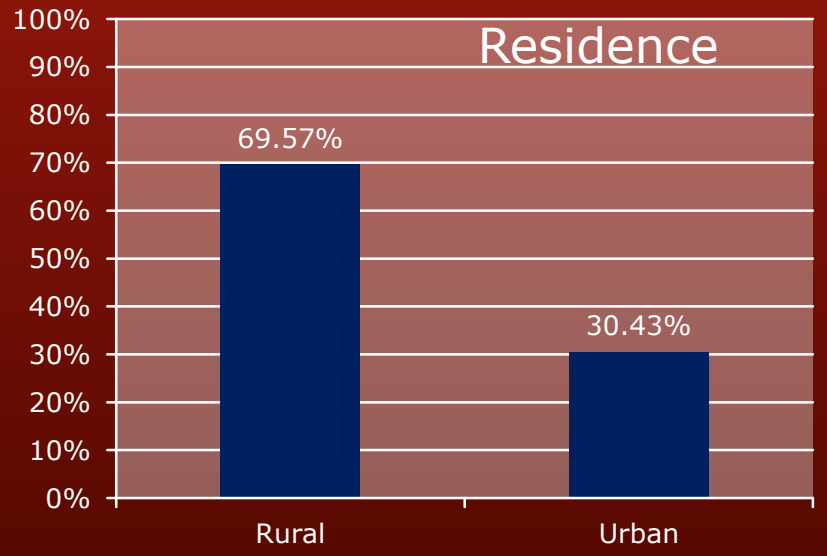


Typical service duration: less than 11 months

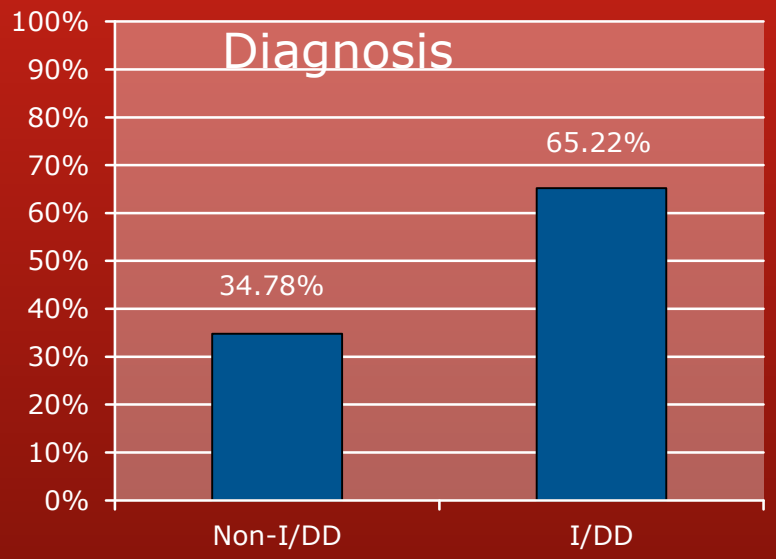
Demographics

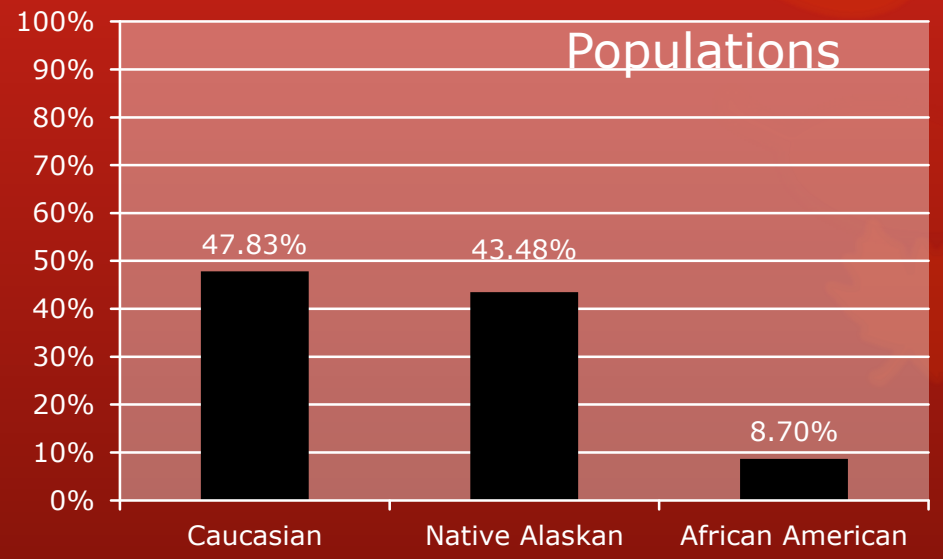




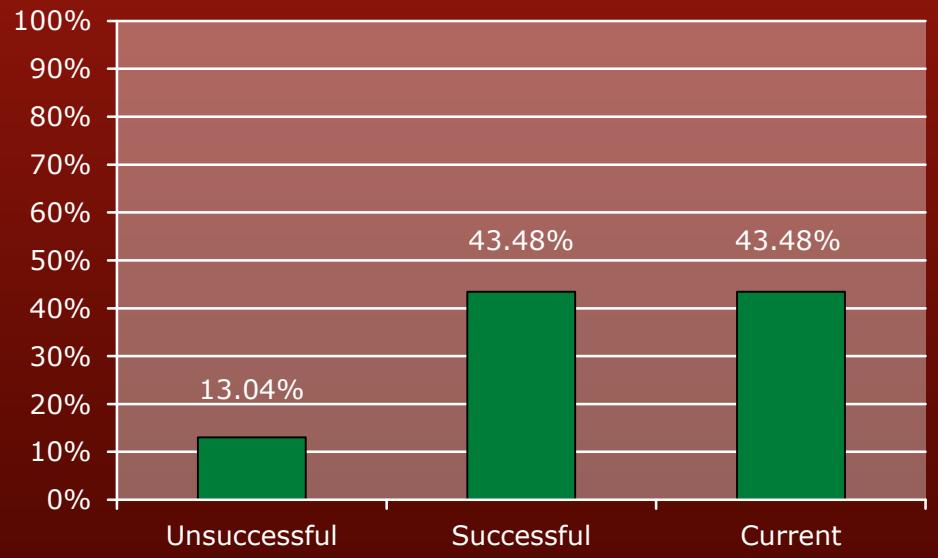


Demographics and Service





Outcome from service



Program evaluation: In addition to individual measures/data

Outcomes from service

1. Five measures of reduction of behavior; increase of positive social skill
2. Four measures of increased access to natural supports & routines; included settings; choice.

Satisfaction with quality

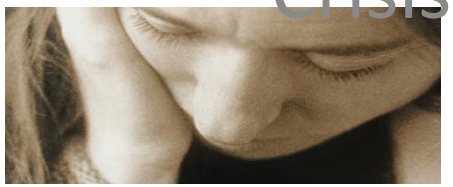
1. Anchored to specific services and typical skills trained
2. Includes collaboration and communication tasks performed
3. Informal: Importance of building relation - ships

Impact of training

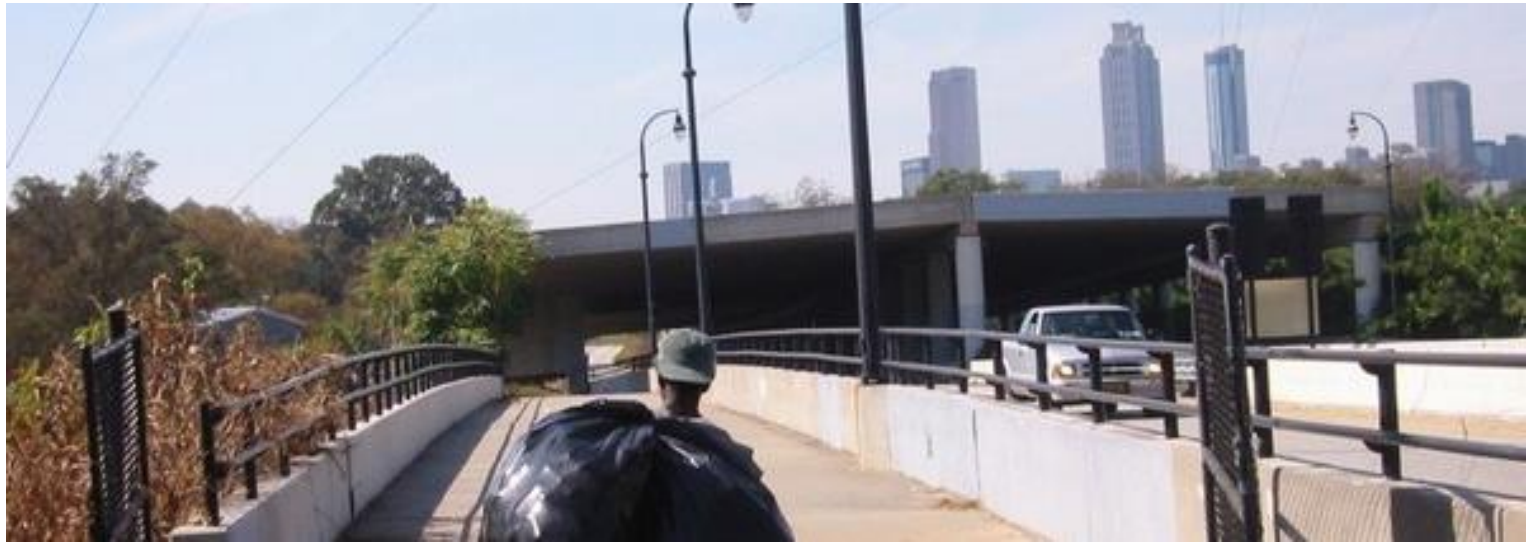
1. Post – pre approach for 20 skill areas
2. Increasing use of fidelity measures
3. Impact of staff turn-over

Georgia CIT

Crisis Intervention Team



Georgia CIT Vision



Vision: A Georgia where people with mental illnesses and other behavioral health disorders are treated, not incarcerated

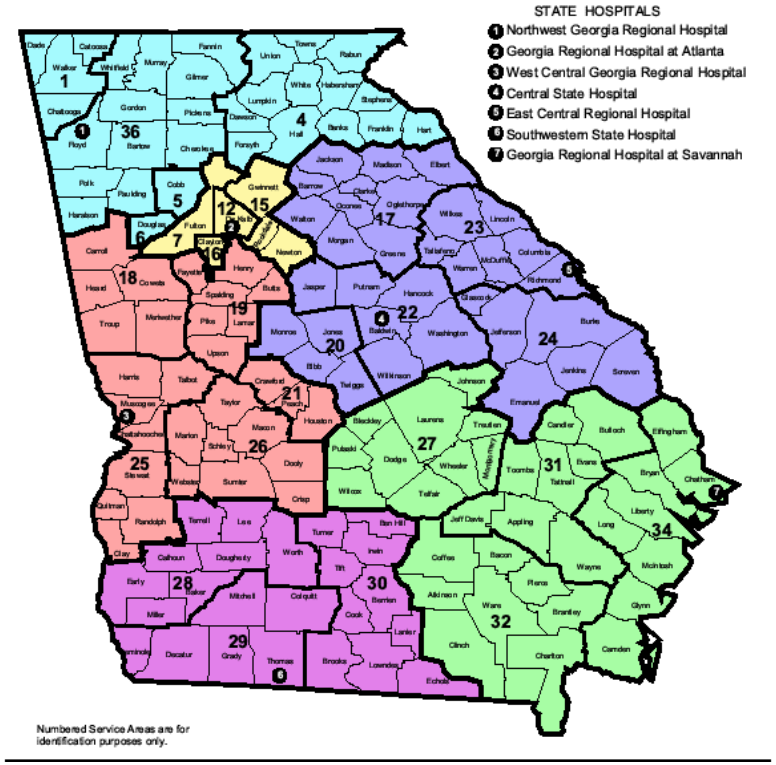
Georgia CIT Mission

Mission:

Equip Georgia CIT Officers with the skills to assist people with mental illnesses and other behavioral health disabilities in crisis, thereby advancing public safety and reducing stigma

Statewide CIT Goal

GEORGIA



Goal:

Train all of Georgia Law Enforcement in CIT

Partnerships

Law Enforcement & Public Safety

Community Providers

CIT

NAMI Georgia

& Other Advocates

Memphis Model CIT

- In 1987, an unarmed man with a mental illness was shot and killed by Memphis police; a public outcry followed
- In response, the Memphis PD and the local NAMI affiliate developed CIT (Crisis Intervention Team)

Why Georgia CIT?


- 33-75% jail population with mental illness, developmental disability, or addiction related offenses
- 15-16% Georgia Department of Corrections inmates with MI, DD, or AD (low compared to Nat’l stats)
- 75% of YDC population with MI or SED

Georgia CIT Program


- Georgia partnership of NAMI, law enforcement and mental health professionals traveled to Memphis for 2 day orientation, and returned for 40-hour course

- In 2004 Georgia adopts Memphis Model for state CIT program

Georgia CIT Program

- Georgia CIT officers are represented throughout the continuum of law enforcement (police, deputies, parole/probation, corrections, GBI, State patrol, etc.
- Many CIT officers have family or friends with a mental illness or other behavioral health disorders
- This program has to come from the heart

Georgia CIT Program

- 108 Police Departments
- 58 Sheriffs Offices
- 17 Colleges and Universities
- 10 State Agencies
- 6 Federal Agencies

Georgia CIT Program

- Received 2008 IACP Award for Multi-Agency Collaboration
- Received 2013 CIT International Coordinator of the Year Award
- 2013 accompanied Carter Center to Liberia to begin work developing CIT Program for Liberia National Police
- Most researched CIT program

NAMI CIT Objectives

- Whenever possible, ensure the person in focus receives treatment or alternative placement rather than jail
- Avoid unnecessary force by ensuring the CIT officer recognizes a mental illness or other behavioral health disorders
- Ensure CIT officer has skills to de-escalate a person in crisis

Combating Stigma

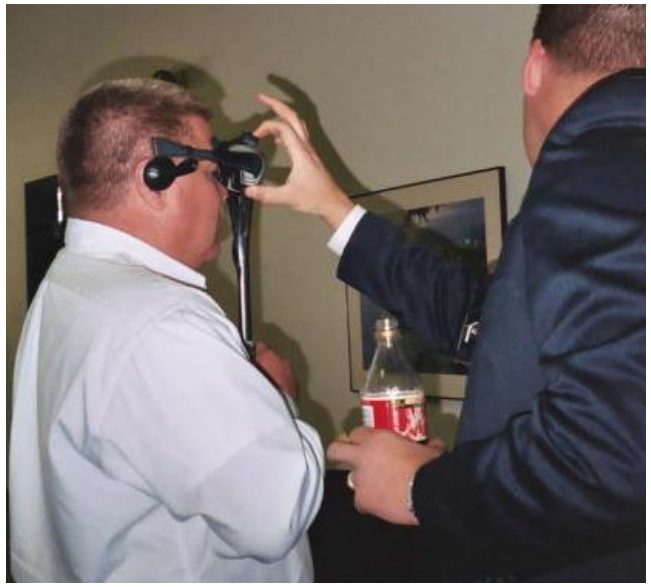

One of the hallmarks of CIT is reducing the stigma associated with mental illness and developmental disabilities. We do this by:

- Dis-spelling myths about MI/DD and addiction
- Learning behaviors as symptoms
- Interacting with people with disabilities
- Using perspective to reduce fear and social distance

40-Hour CIT Curriculum

Monday	Tuesday	Wednesday	Thursday	Friday
Mental Illnesses and Other Behavioral Health Disorders	Site Visits/ Consumer Interaction	Mental Illnesses and Other Behavioral Health Disorders	De-Escalation Skills	De-Escalation Skills
Lunch	*Lunch*	*Lunch*	*Lunch*	*Lunch*
Mental Illnesses and Other Behavioral Health Disorders	Site Visits/ Consumer Interaction	De-Escalation Skills	Mental Illnesses and Other Behavioral Health Disorders	Post-Test & Graduation

40-Hour CIT Curriculum



- Volunteer experts from the community provide training
- P.O.S.T. approved by the Georgia Peace Officer Standards and Training Council
- Includes end of week test

Immediate Response

- Ideally, 911 dispatch identifies a call where a consumer with a mental illness or other behavioral health disability is in crisis

- The closest CIT officer is dispatched to the scene along with other law enforcement

Crisis Intervention

De-escalation Training

- The CIT officer attempts from the beginning to learn and use the person's name
- The CIT officer uses compassion, respect, listening skills and knowledge of crisis intervention stages
- The officer explains the CIT process to individuals with a disability and families

Positive CIT Outcomes

This is why we do it!

- Decreased number of people with MI, DD, AD incarcerated
- Decreased officer and consumer injuries
- CIT officers become consumer advocates
- Consumers more willing to call police for HELP
- CIT officers more willing to call MH/DD providers to help consumers!!
- CIT officers more aware of resources

Georgia CIT Data

Overview of program:

Dr. Michael T. Compton, professor and director of research initiatives, Department of Psychiatry and Behavioral Sciences at The George Washington University

Georgia CIT Summary


CIT is More than Just Training!

It is collaboration of formal and informal systems converging for a common good

Behavioral Health and Emergency Department Crisis Intervention: Improving IDD Patient Care

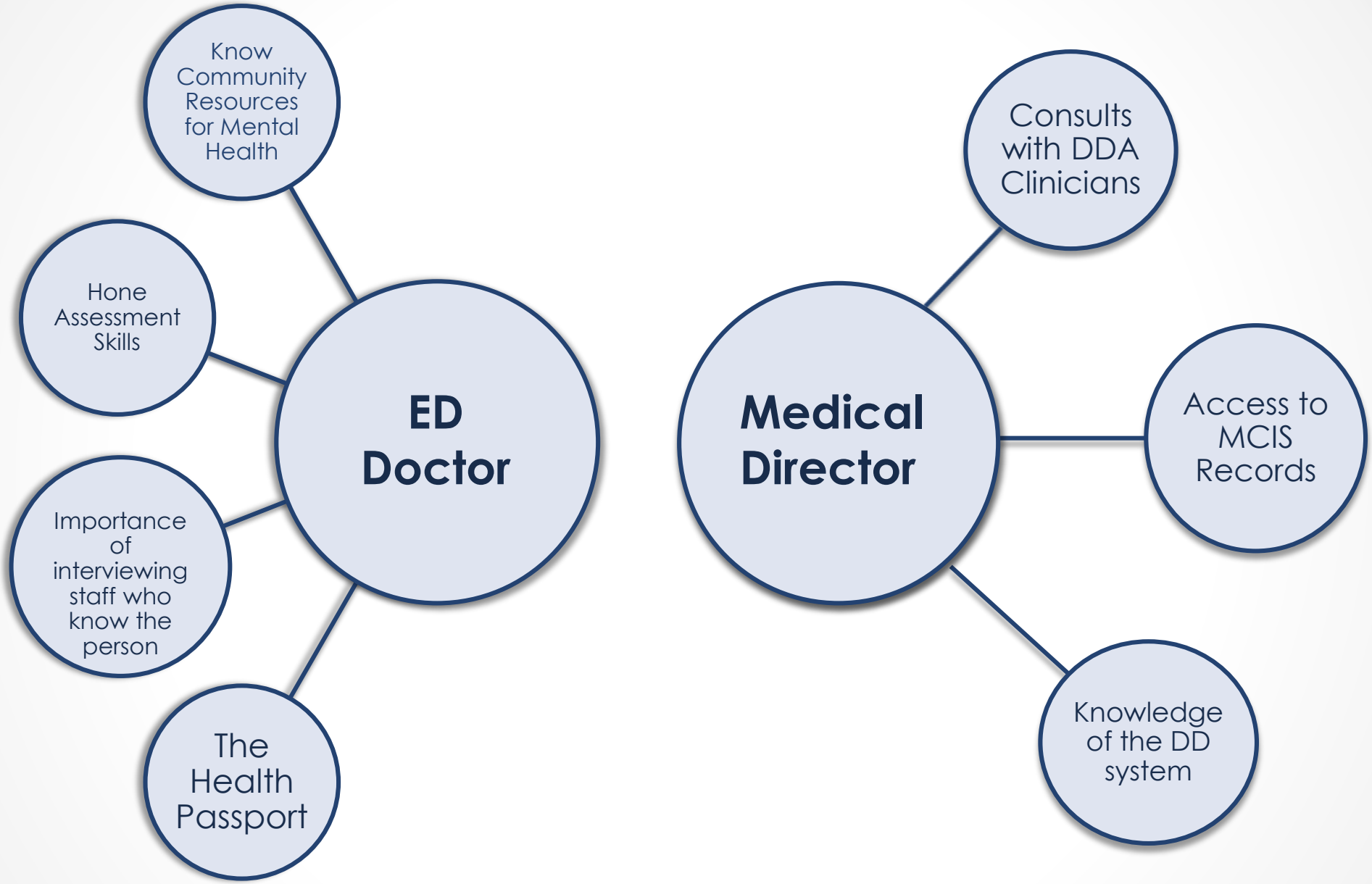
Kim Bullock, MD, FAAP

Developmental Disability Administration Health Initiative

- Medical Consultation
- Transition of Care
- End of Life Consultation
- Health Education
- Nursing Education
- Evaluation
- Parent Supports

http://www.gucchdgeorgetown.net/ucedd/DDA/index.html

Or Google "DDA Health Initiative"


Know Community Resources for Mental Health
Hone Assessment Skills
ED Doctor
Importance of interviewing staff who know the person
The Health Passport
Consults with DDA Clinicians
Medical Director
Access to MCIS Records
Knowledge of the DD system

Assessment Components

- **Identify the trigger**
  - Is this a change from the baseline?
  - When did this behavioral change start?

- **What is the treatment profile?**
  - Interface with the psychiatrist
  - Medical history (Health Passport)
  - Family and community supports

If admitted…

Coordination of discharge plan

- Determine if the individual has had a dementia and depressing screening

Next Steps- Capacity Building

- Trauma- Informed Care
- Increase the number of psychiatrists
- Increase the skills of the support team members

Questions?

Thank you!