Population Based Strategies for Supporting People Co-occurring Mental Illness and Intellectual/Developmental Disabilities

Olmstead Policy Academy
September 20, 2012

Charles Moseley Ed.D.
National Association of State Directors of Developmental Disabilities Services
Today

- National Context
- Developmental Disabilities Systems and Services
- People with Co-occurring IDD/MI
  - Characteristics and Supports
- State Strategies
- Examples
- Olmstead
- Recommendations
Struggling Economy: 30 States Projected or Addressed Shortfalls in 2013

Totaling $54 Billion in FY 2013

CBPP May 2012
State Budget Shortfalls are Improving but,...

Growth of 8.3% per Year Would not Restore Losses from Recession Until Fiscal Year 2019

Largest State Budget Shortfalls On Record

Total state budget shortfall in each fiscal year, in billions of dollars

- Last recession -


- $40 - $75 - $80 - $110 - $130 - $191 - $107* - $54*

*Reported to date

Source: CBPP survey, revised May 2012.
## States are Shifting to Community Supports

### No State Institutions

<table>
<thead>
<tr>
<th>Closure Date</th>
<th>State</th>
<th>State Pop</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>New Hampshire</td>
<td>1,315,000</td>
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<tr>
<td>2</td>
<td>District of Columbia</td>
<td>582,000</td>
</tr>
<tr>
<td>3</td>
<td>Vermont</td>
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<td>4</td>
<td>Rhode Island</td>
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<td>Maine</td>
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<td>Alaska</td>
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<tr>
<td>12</td>
<td>Alabama</td>
<td>4,779,736</td>
</tr>
</tbody>
</table>

UMinn RISP Rpt. 2010

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12 states have no institutions

7 states have no public or private settings larger than 15 beds (DC, VT, ME, NM, HI, OR, AL)

16 states have fewer than 200 people in their state institutions (AK, AZ, CO, DE, ID, IN, KY, MD, MN, MT, NB, NV, ND, RI, SD, WY)

11 states have more than 1,000 in institutions (TX*, NJ*, IL*, CA*, NC, OH*, MS, NY*, PA, LA*, AR)

*Currently Downsizing
Significant Numbers are Waiting for Services

Low Estimate (State Reported State Agency Reports of People Needing Residential Services Within Next 12 Months)

High Estimate (Kaiser Family Foundation)

Total Residential Capacity: 466,809
Growth Needed: 24.6%

Data not reported by: MS, NJ, NC, OH, TX, or WA

Source: UMN RTC/ICI 2009
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The Majority of Adults with IDD Live with Families

- Total in homes and residential settings: 1,058,989
- The Number of adults receiving services and supports in the family home continues to grow:
  - 51% in June 2000
  - 56% in 2010,
  - 5 states more than 70% in families
  - 23 states >50%

(Larson et al, 2010)
An Increased Focus on Sustainability in DD Systems and Valued Life Outcomes

- What can we (and future generations) afford?
- What can we justify based on:
  - Cost efficiency - Relative costs of various options
  - Cost effectiveness - Resources spent in comparison with others in need?
  - Outcomes achieved for resources spent?
- What should we justify based on the need to support:
  - Life in the most integrated settings,
  - Employment and community participation,
  - Opportunities for friendships, health and wellness

Adapted from NASDDDS/AUCD Evidence-Based Policy Initiative (2011)
Responding with Systems Change, Financial Sustainability

Focus on Sustainability

Rebalancing

Resource Allocation

Managed Care
## Re-evaluating current services – How many can we serve?

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Cost per Person</th>
<th>Cost to Serve the Waiting List 122,870</th>
<th>People Served with $5 M</th>
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<tr>
<td>ICF/MR</td>
<td>$128,275</td>
<td>$15,761,114,925</td>
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<tr>
<td>Non-family HCBS</td>
<td>$70,133</td>
<td>$8,617,241,710</td>
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<tr>
<td>Host Family</td>
<td>$44,122</td>
<td>$5,421,270,140</td>
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<td>Own Family</td>
<td>$25,072</td>
<td>$3,080,596,640</td>
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</table>

Factors Associated With Expenditures for Medicaid Home and Community Based Services (HCBS) and Intermediate Care Facilities for Persons With Mental Retardation (ICF/MR) Services for Persons With Intellectual and Developmental Disabilities: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES VOLUME 46, NUMBER 3: 200–214 JUNE 2008

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Changing Services to Achieve Better Outcomes

- Revisiting systems to support people in their family homes
  - Increasing utilization of support waivers
  - Redesigning resource allocation systems
- Decreasing reliance on facility based programs
  - Federal Incentives - Money Follows the Person
- Reconfiguring systems of resource allocation, rate setting and funding
- Improving supports for people with co-occurring mental illness and other challenging conditions
Known knowns:

- NCI Data – Prevalence & Characteristics
- State Strategies
  - Support
  - Services
  - Effective practice examples
National Core Indicators: System Performance Measurement

- Launched in 1997 in 13 participating states: NASDDDS, HSRI & participating state DD agencies
- Approximately 100 individual, family and system measures (choice, experience, employment, access to healthcare, rights)
- 36 states, the District of Columbia and 22 sub-state regions (including all CA Regional Centers)
- Unparalleled 15-year database annually gathering data on approximately 20,000 individuals and families
- Valid and reliable consumer survey
- Representative sample of DD service participants
- AIDD funded expansion to all states
NCI State Participation 2012-13

*Includes Clearwater Council of Governments and the Mid-East Ohio Regional Council

Orange states denote first year participation funded by ADD
Demographics

Gender

56% Male
44% Female

Average Age: 42.5 yrs

Level of ID

- No ID label: 36%
- Mild: 27%
- Moderate: 14%
- Severe: 12%
- Profound: 7%
- Don't know: 4%

Settings Where People Live

- Specialized Institutional facility: 6%
- Group Home: 27%
- Apartment Program: 4%
- Independent Home/Apt: 17%
- Parent or Relative's home: 34%
- Foster care/Host home: 6%
- Nursing Facility: 1%
- Other: 4%
- Don't know: 0%
NCI 2010-11: Other Disabilities

33% Dual Diagnosis

- Psych. Diag: 33%
- ASD: 10%
- CP: 15%
- Brain Inj: 3%
- Seizure Dis: 26%
- Sensory: 11%
- Phys Dis: 10%
- Comm Dis: 8%
- Alzheimer’s: 2%
- Down Syndrome: 9%
- Prader Willi: 1%
- Other: 23%

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Prevalence of IDD/MI: National Core Indicators Data

Ave. = 32.4%

Percent ID/MI

Number of States

Sample size

2006-07: 12,000
2007-08: 11,400
2008-09: 11,500
2009-10: 11,000
2010-11: 8,000

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Percentage with Co-occurring Conditions by Residential Setting

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NCI Consumer Survey 2008-09
Medications: Overall,

- 38% take medications for **mood disorders**
- 29% take medications for **anxiety**
- 25% take medications for **behavior problems**
- 18% take medications for **psychotic disorders**
- 53% take medications for **at least one of the conditions above**

*Remember, only 32.4% have an MI diagnosis*
Of those who take medications for \textit{at least one} condition/purpose, how many take meds for 1, 2, 3 and all 4 of them?

- 39% take for 1 purpose
- 29% take for 2 purposes
- 18% take for 3 purposes
- 14% take for 4 purposes

N = 3,977

\textit{Note:} this is not the same as the number of medications taken. A person may take one medication for more than one purpose/condition.
People who Take at Least One Psychotropic Medication by Living Arrangement

- Institution: 53%
- Community-based residence: 68%
- Independent home/apt: 53%
- Parents/relatives home: 36%

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Medications and Mental Illness

- **49%** of people who need support for behavior issues take meds for behavior problems
- Only **8%** of people who do not need support for behavior issues take meds for behavior problems
- **88%** of people with MI or a psychiatric disorder take meds for mood, anxiety, or psychotic disorders
- BUT **31%** of people not diagnosed with MI or a psychiatric disorder also take meds for mood, anxiety, or psychotic disorders
- Meds for mood or anxiety disorder are more common w/o an MI diagnosis than meds for psychotic disorder
Psychotropic medication use increases health complications

- Weight gain
- Abnormal glucose metabolism (diabetes)
- Cardiovascular disturbances
- Oral health issues
- Extra pyramidal symptoms, TD.

Lunsky & Elserafi (2011) Research in Developmental Disabilities
Use of Psychotropic Medications and Obesity

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Changes in percentage of state institution residents with mild or moderate ID and co-occurring behavior or psychiatric disorder over time

- **Behavior disorders up 27%**
- **Psychiatric disorders up 59%**
- **% Mild or moderate ID almost doubled**

Sheryl A. Larson, Naomi Scott, Patricia Salmi and K. Charlie Lakin

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NCI data in summary

- 53% take at least one medication for mood/anxiety/behavior/psychotic disorders
- High percentage of people without an MI diagnosis still take these meds
- Those who take meds are more likely to live in group homes and less likely to live with parents or relatives
- Those who take meds are more likely to be diagnosed with ASD and less likely to be diagnosed with CP or Down Syndrome
Prevalence of mental illness is higher among people with IDD than the general population

- More difficulty coping with normal life stressors
- Increased vulnerability to abuse in the home due to increased strain on the family.
- Increased vulnerability to abuse in the community due to poor judgment and lack of self-protective skills.
- Greater difficulty accessing treatment and assistance for mental illness due to communication and processing problems
- Lack of trained clinicians
People with Intellectual or Developmental Disabilities are....

- At increased risk for abuse as compared to the general population (Gil, 1970; Ryan, 1994; Mahoney & Camilo, 1998).
- 4 to 10 more times as likely to be victims of crime than others without disabilities (Sobsey, et al., 1995).
- Twice the risk of physical and sexual abuse compared to children without disabilities (Crosse et. al., 1993).
- Children with ID are 4 times as likely as children without disabilities to be sexually abused. (Sullivan & Knutson, 2000).
- Individuals with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities (Westat Ind., 1993).
- Risk of abuse increases by 78 percent due to exposure to the "disabilities service system." (Sobsey & Doe, 1991). And, Sexual abuse incidents are almost four times as common in institutional settings as in the community (Blatt & Brown, 1986).
- Between 60% and 100% (depending on sample) of individuals with DD have experienced trauma, usually repeated incidents of abuse (Sobsey, 1994).
Causes of Challenging Behavior

- Undiagnosed or untreated mood disorder
- Undiagnosed or untreated post traumatic stress
  - Sexual abuse >75%
  - Exclusion, rejection, bullying and humiliation 100%
  - Frustration from awareness of limitations
- Undiagnosed or untreated depression
  - Biological
  - Environmental/social – loneliness
- Little knowledge of neurological challenges i.e. Autism, Fragile X etc.
- Support models and practices that are not person-centered
- Little awareness of treatment options
  - DBT
  - EMDR

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Positive behavioral supports

Dialectical Behavior Therapy - decreasing behaviors, increasing behavioral skills and validating the individual

Reducing stress through EMDR.
- Integrates cognitive behavioral, affective, psychodynamic and sensory treatment modalities
- Does not require verbal or intuitive abilities to progress in treatment

Trauma Informed Care

Ecological approaches that change the environment

Addressing undiagnosed medical conditions (60%-85% Ryan 2001)
Perhaps most of all people need to support to get a life

- Stable home and home environment
- Consistent and predictable staffing
- Support for new friendships and relationships
- Finding the right match between the person and support staff
- Employment
- Meaningful community participation and engagement
- Trained clinicians
- Small settings
- Flexible funding
NASDDDS Study of State Strategies

**Survey**
- Funding and support
- Service barriers
- Clinical, crisis response & long term support
- Achieving positive outcomes

**In-Depth Review**
- Structure & Function
- Finance
- Eligibility and access
- Planning, Coordination
- Service provision
- Emergency back-up
- Collaboration
Co-existing Conditions

*Service related decisions do not differ:*

- Eligibility determined
- Needs assessed
- Services planned and coordinated
- Funding levels determined
- Service providers located
- Quality monitored and assured
Long term support is challenging

Not because of service type, rather…

- The complexity of their conditions requires
- The degree of skill, training, commitment & follow-thru required by staff
- Unequal distribution of resources across the state
- Difficulty accessing providers with the expertise an infrastructure needed
Major Issues to Address

1. Availability of funding, targeted flexible dollars
2. Providers with sufficient expertise and interest
3. Access to appropriate psychiatric treatment and related services
4. Lack of trained staff MH and DD staff
5. Effective and timely crisis supports
Typical State

- Effective DD/MH collaboration
- Ineffective DD/DOC collaboration
- Funding distributed by service
  - Long-term by DD
  - Short-term psychiatric by MH

- Regional crisis service
- Crisis services funded by DD &/or MH
- Quality assessed by DD alone or with MH

Barriers
- Staff with expertise
- Qualified providers
- Provider unwillingness
- Crisis support
Typical State contd..

- **DD services** are furnished by or through counties or regional entities, private providers, families, individual employees

- **MH services** are provided through regional community mental health centers, provider agencies or private professionals

- **Crisis Services** are furnished through the community DD or MH agency based at county, or regional level
Top Challenges

- Access to appropriate psychiatric services
- Provider capacity
- Overmedication
- Improving current MH services
- Restricted MH state plan services
- Accessing temp respite from MH

- Restrictions on MH billing for support
- Over-utilization of police, emergency wards
- DD residents in state hospitals
- DD staff give prn medications
MH State Plan Services are available, *but* access is frequently difficult......

MH programs are:

- Under-funded
- Stretched to the limit
- Lack expertise to meet needs of people with ID/DD
- Unable to bill for necessary activities
- Include structural barriers
  - Case management,
  - Service coordination
  - Resource allocation
Emergency Response Crisis Support

- One of the most critical services
- Important measure of the state’s community system
- States use different approaches and models of crisis service provision
  - Community Network (VT, NM, HI, MI)
  - Start (NC)
  - Regional Based (AL, CA, MO)
  - Combination (OH, OR, WA)
- Most involve MH
Emergency Support and Response in 13 States

- DD exclusively in 5 of 13 states (38%)
- MH exclusively by 3 of 13 states (24%)
- Mixed in 5 states (38%)
  - Usually MH but DD may support
  - Usually DD but MH may support
  - DD provides but MH contributes funding
State Examples
Alabama

- Proposed transferring resources from the institutions to support 5 regional offices
- Received $ to build 3 Community Support Teams
- Partlow provides crisis support

- Recognized the need to build crisis supports in the community
- RFP in 2010 for two models
  - Comprehensive crisis support provider
  - Coalition of providers and resources to develop person-centered alternatives
If the CSS team is unable to effectively address the person’s needs in the community, he or she may be eligible for placement in at the state developmental center for:

- evaluation,
- short term respite or
- crisis stabilization.

By law, short-term admissions for crisis stabilization can be made:

- When no alternative option for residence, treatment and support is available from their current setting.
- Only if no less restrictive environment is available or adequate to appropriately address the person’s needs.
- Only on a temporary basis
Georgia’s Crisis Response System

- Set up Crisis response teams as an alternative to temporary facility placements
- Prevent use of emergency rooms, law enforcement and institutional placement
- Mobile crisis team, on and off site supports

- including:
  - on-site stabilization,
  - intensive in-home supports,
  - Intensive out of home supports in a crisis home
  - professional consult
- Temporary placement in a psychiatric bed
- Training:
  - Providers
  - Judges, law enforcement
  - Families
  - Case managers
Oklahoma

- **Alternative Group Homes (AGH) – Waiver funded community based group homes**
  - Residential Habilitation
  - Employment
  - 24 hour Emergency /crisis support
  - Behavior support
  - Community protection

- **Robert M. Greer Center**
  - ICF/ID
  - Diagnosis, evaluation, treatment for people w ID/DD and MI, behavior or emotional conditions
  - Temporary, up to 1 year
  - Not forensic services.
Oklahoma – Crisis Supports

- DDSD does not employ a dedicated regional or statewide crisis response system.
- Providers are prohibited from discontinuing services to an individual unless an adequate transition plan is in place (zero reject).

- Review by treatment team & case manager
  - Temporary funding increase
  - Out-of-home temporary or long term placement in another program or agency.
  - Greer Center placement
- Closed last state institution in 2009
- No longer participates in the ICF/ID program
- Supports through the state’s comprehensive Medicaid waiver program

- Enhanced foster-care settings – 24hr supervision
- Private group homes with enhanced staff and support
- State Operated Community Programs – 24hr. Intensive supervision and support
- 2 Group homes funded by DD and MH
Outpatient mental health services accessed through the Oregon Health Plan

ODDS tiered crisis response
  - State
  - Region (groups of counties)
  - County
  - Provider

GRO Training (Growing Resources in Oregon)

Provide:
  - technical assistance,
  - funding
  - Out of home placement
  - State Operated Community Programs, small group homes with increased staffing and support
  - Monitoring, data gathering
  - Training
Closed institutions in 1997
Shifted state operated programs to the community
Structured as a community provider
Focused on individuals with challenging needs
- Co-occurring diagnoses ID-MI
- Complex medical needs
- Crisis support

Supported community providers
- Identified staff with good communication skills
- Focused on the needs of the person and helping community staff learn who they were
- Demonstrated competence with challenging people
- Allowed temporary returns
NM – Crisis Supports

- Set up a statewide Office of Behavioral Services (OBS)
  - Director
  - Clinical Director
  - Statewide Crisis Coordinator
  - Crisis Administrator
  - Regional Office Behavior Specialists
- System capacity build on a regional basis
- Similar to VT, HI, MI

- Tier I – Training and technical assistance provided to providers by OBS staff
- Tier II – On-site support and mentoring to assist providers gain skills
- Tier III – Direct crisis support in home or temporary placement
Other States’ Strategies

- State operated community programs (OR, NY)
- Shifting key institutional resources to the community (SD)
  - Healthcare: PA - Health Care Coordination Units
  - Training (VT, NM, OR)
  - Case management
- Contracting with MH for support for people with co-occurring conditions (AZ)

- Creating rate incentives, with higher reimbursements for people moving out of institutions (MFP, OH, VT, ** several others)
- Coordinating Centers of Excellence (OH)
- Cross-Systems planning (WA)
- Flexible funding (NM, VT, OR, OK, AL, ... many others)
Olmstead enforcement is a central priority of the Obama Administration

- The President declared 2010 as the “Year of Community Living”
- Directed DOJ “redouble its efforts to enforce the integration mandate.” in the Olmstead Ruling
- Requiring states to remove unnecessary segregation and provide community-based services for persons with disabilities who are otherwise entitled to institutional services consistent with the American with Disabilities Act (ADA) Title II.
Under Olmstead, we cannot simply ask whether people are being well treated after they are put in institutions; we need to ask the logically prior question whether they belong in institutions in the first place.

Sam Bagenstos,
Principal Deputy Assistant Attorney General Civil Rights Division
U.S. Department of Justice
University of Cincinnati, March 3, 2010
Olmstead enforcement efforts have been driven by three goals (Thomas Perez):

*People with disabilities should have:*

1. Opportunities to live life like people without disabilities;
2. Opportunities for true integration, independence, recovery, choice and self-determination in all aspects of life including where they live, spend their days, work, or participate in their community; and
3. Quality services that meet their individual needs.
It is very clear that the DOJ is moving beyond conditions in institutions to focus on the extent to which existing community services prevent institutionalization.
Placing individuals in the community at risk of institutionalization because of the lack of community services

Failing to ensure a sufficient quantity of crisis and respite services to prevent admissions during crises

Failing to ensure that community services have the resources necessary to support individuals with medical and behavioral conditions

Over-reliance on segregated sheltered workshops and other models

“These deficiencies place people at risk even after they are discharged”
Top Challenges

- Access to appropriate psychiatric services
- Provider capacity
- Overmedication
- Improving current MH services
- Restricted MH state plan services
- Accessing temp respite from MH
- Restrictions on MH billing for support
- Over-utilization of police, emergency wards
- DD residents in state hospitals
- DD staff give prn medications
Top 5 Most Challenging Barriers in 2004

1. Insufficient Number of Providers
2. Provider Unwillingness
3. System Structure Gets in the Way
4. Lack of Coordination
5. Lack of Targeted Funding
Top Barriers in 2010

1. Availability of funding, targeted flexible dollars
2. Providers with sufficient expertise and interest
3. Access to appropriate psychiatric treatment and related services
4. Lack of trained staff MH and DD staff
5. Effective and timely crisis supports
Recommendations

Focus on the Development Effective System Elements

- Committed Leadership
- Clear lines of authority
- Independence
- Protection
- Collaboration
- Employment
- Meaningful community engagement
Consider NADD Accreditation

Smaller is better

Focus on the individual, relationships and effective treatment

Determining what is important **TO** the person and what is important **FOR** the person.

- Michael Smull
Focus on what works

- Ability to individualize services and supports (73% of states)
- Availability of effective systems for immediate response, support and treatment (71% of states)
- Presence of effective person-centered program planning and support coordination (68% of states)
- Training (60% of states)

NASDDDS Survey of States 2008
For more information

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