

# Serving Behaviorally Challenged Individuals:

Using Performance Indicator Data  
to Pinpoint Systemic Strengths  
and Weaknesses

December 10, 2003

Sarah Taub ♦ Human Services Research Institute



# National Core Indicators: NCI 101

# What are the goals of NCI?

- Nationally recognized set of performance and outcome indicators for developmental disabilities service systems
- Reliable data collection methods & tools
- Baseline and trend data at the state & national level
- Benchmarks of performance

# Emergence of Performance Indicators

- First appeared in behavioral and acute care
- Provide some “cues” for managing these complex systems
- Examine impact of managed care
- Illuminate what’s working
- Provide early warning signs



# Characteristics of Performance Indicators

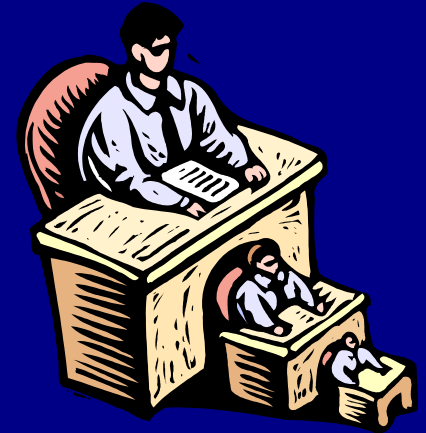
- Reflect major organizational or system goals
- Address issues that can be influenced by the organization or system
- Have face validity
- Point a direction
- Reflect rates or major events
- Related to associated standards

# Project History



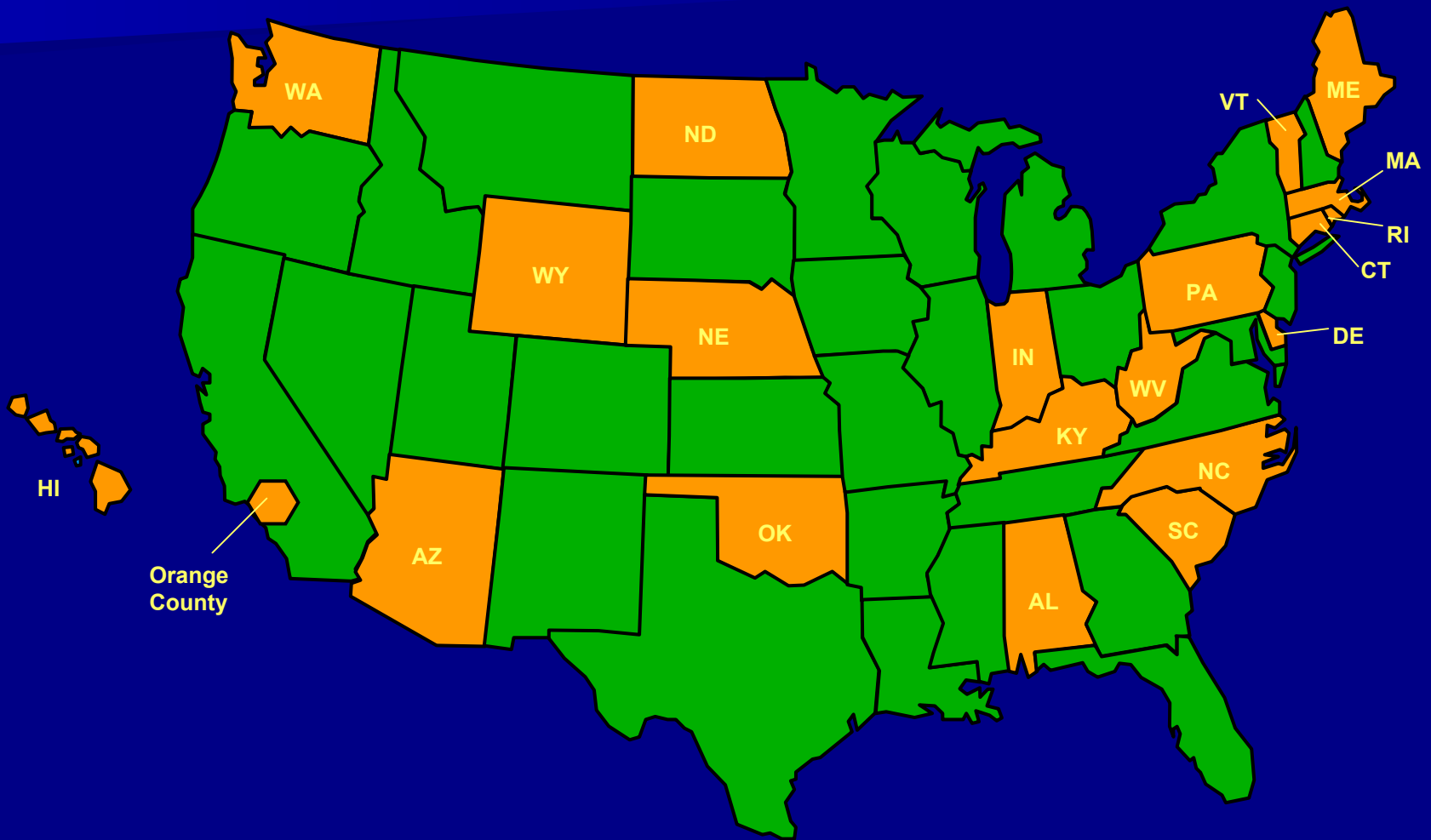
- Co-sponsored by NASDDDS and HSRI
- Launched in 1997
- Formed steering committee (including seven field test states)
- Compiled ~60 candidate performance indicators
- Developed and tested data collection instruments

# NCI Structure



- Currently 20 states plus Orange County in Phase V (FY2003)
- HSRI provides technical assistance under subcontract to NASDDDS
- Subcommittees address specific issues
- Meet with full steering committee annually

# Participating NCI States



# What are the Core Indicators?

- Consumer Outcomes:
  - Satisfaction, choice, employment
- Provider Agency/Workforce Stability:
  - Staff turnover
- System Performance
- Protection of Health and Safety

# What are the data sources?

## ■ Consumer Survey

## ■ Family Survey

- Adult Family Survey (at home, 18+)
- Family Guardian Survey (out-of-home)
- Children Family Survey (at home, <18)

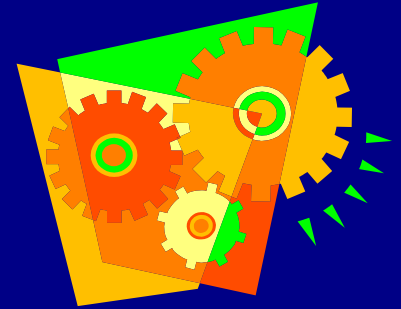
## ■ Provider Survey

- Staff Stability
- Board Representation

## ■ System Data

- Incidents
- Mortality

# Where does NCI fit in?



- One component of state Quality Management systems ~ crosswalks to the Quality Framework
- Widely-used process for measuring consumer and family satisfaction
- States integrate NCI data with other QA information
- Produces system-level data
- Some states also use NCI to measure county- and provider-level performance

# Consumer Survey

- Data source for almost half the indicators
- Designed specifically to measure the indicators
- Not just satisfaction
- Applies to everyone, regardless of where they live

# Reliability Testing

- Three rounds of inter-rater reliability tests
- Direct interview takes approximately 35-40 minutes
- Give everyone a chance to respond

# Analysis & Results

# Background

- What do we know about behavioral challenges?
  - Often associated with dual diagnosis (developmental disability and mental illness)
  - Common reason for psychiatric referrals (usually initiated by caregivers)
- Related issues of dual diagnosis
  - People with “dual diagnosis” labels can get caught in-between two service systems (Fisher 2004)

# Background

- Mental illness can be difficult to diagnose in people with DD
  - Communication challenges
  - Symptoms may present differently
  - “Diagnostic overshadowing” -- the tendency to attribute challenging behavior to the person’s intellectual disability and overlook the possible presence of mental illness (Summers et al 2004)
- Reliability of diagnostic labels can be problematic in the MR/DD service population

# Background

- Self-injurious behavior
  - Between 4% and 10% of people with DD display self-injurious behavior (Murray 2003)
  - May be related to genetics, neurological disorders, environment, communication problems, sensory impairments, mental illness...
  - Increasingly recognized as a means of communication

# Questions

- What percentage of individuals served by MR/DD systems have behavioral challenges?
- What types of behavioral challenges do people have and how frequently do they need behavioral supports?
- Where do people with behavioral challenges live, and who provides support to them?

# Questions

- What types of services and supports do people with behavioral challenges receive?
- Where are people with behavioral challenges employed?

# Questions

- Are there differences between people with and without behavioral challenges in terms of...
  - Getting access to health care?
  - Making choices about their lives?
  - Being included in their communities?
  - Feeling satisfied with services?
  - Maintaining relationships with family and friends?

“An approximate answer to the right problem is worth a good deal more than an exact answer to an approximate problem.”

John W. Tukey (*statistician*)

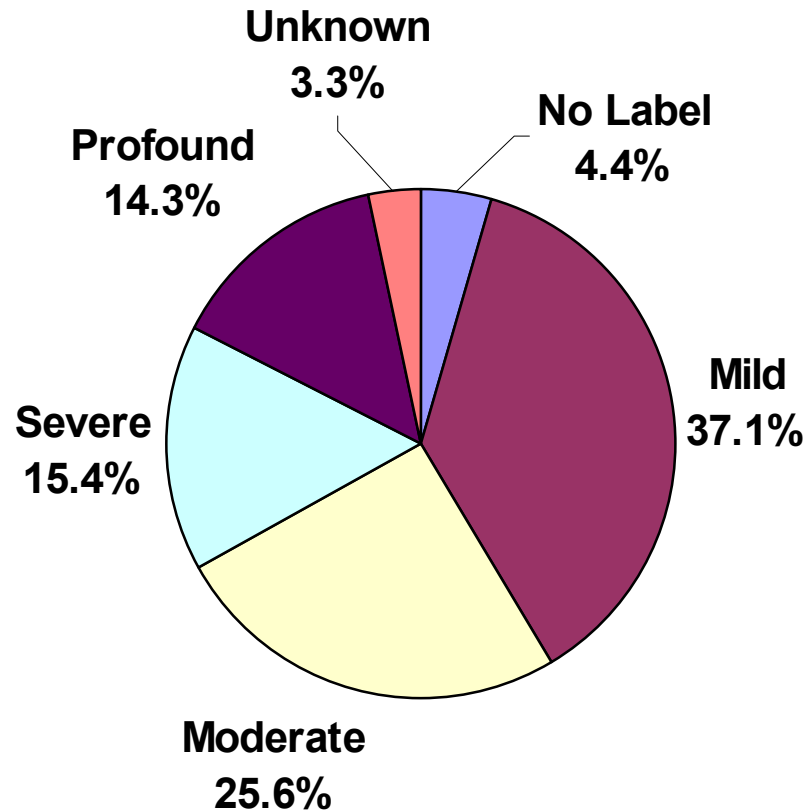
# Consumer Survey

- 9552 surveys completed in Phase V (FY2003)
- 66% of people interviewed were able to respond to Section I
- For this analysis, N=8812 (some cases missing behavioral items)



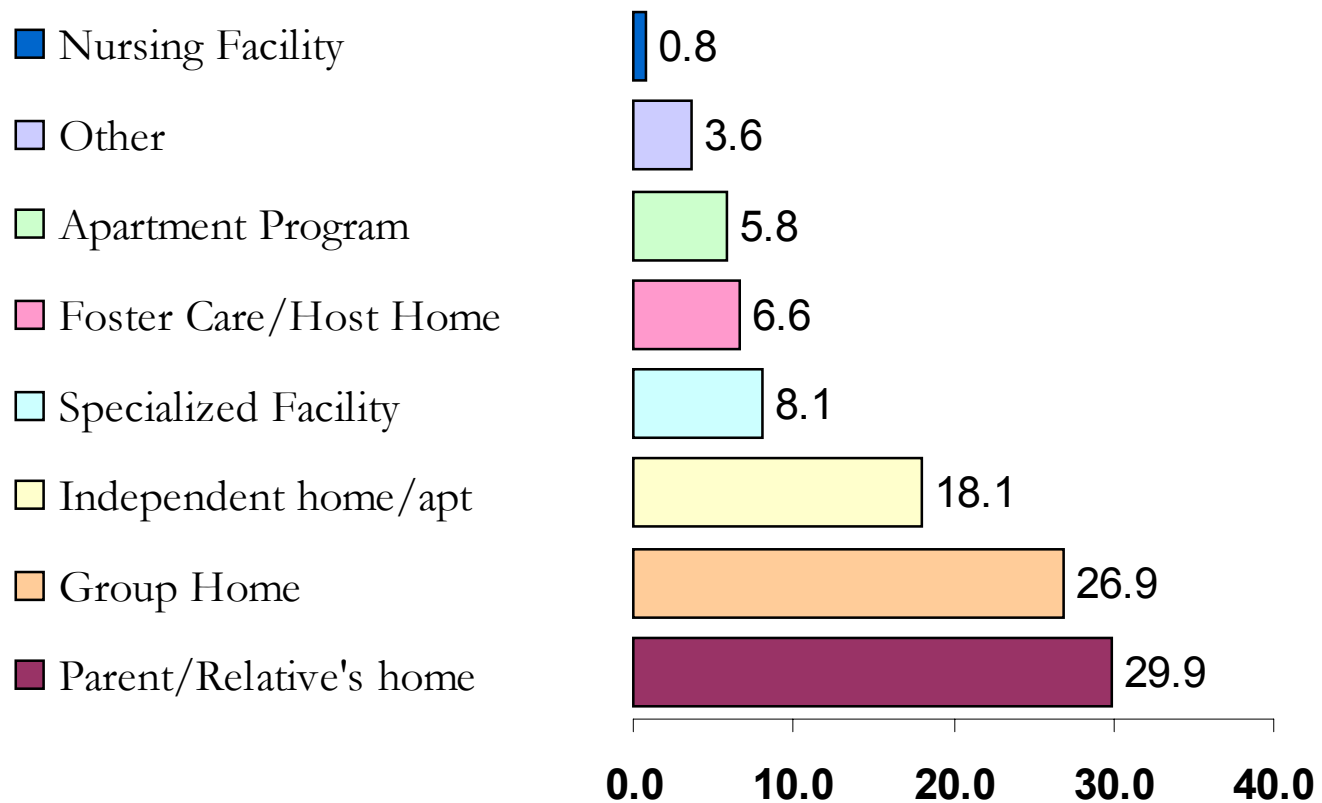
# Consumer Survey Phase V

## Level of MR



# Consumer Survey Phase V

## Place of Residence



# Definitions Used in Survey

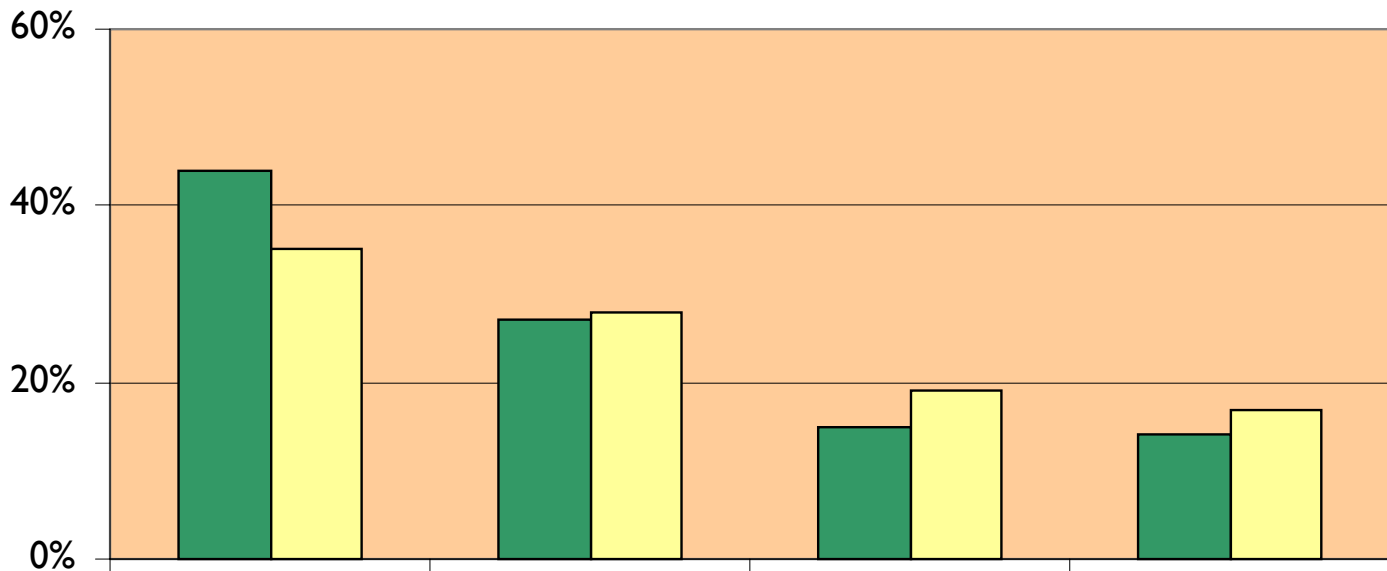
- Self-injurious behavior => causing physical harm to self
- Disruptive behavior => externally directed, threatening or disturbing others, starting fights, etc.
- Uncooperative behavior => defiant, breaking rules, refusing to go to work, etc.

What percentage of individuals served by MR/DD systems have behavioral challenges?

# Prevalence of Behavioral Challenges

- Of the total sample (N=8812), 49% of respondents are reported to have behavioral challenges
- Of those, almost half (45%) have more than one type of problem behavior
- Prevalence varied significantly across states: Range = 32% to 68%

# Level of MR

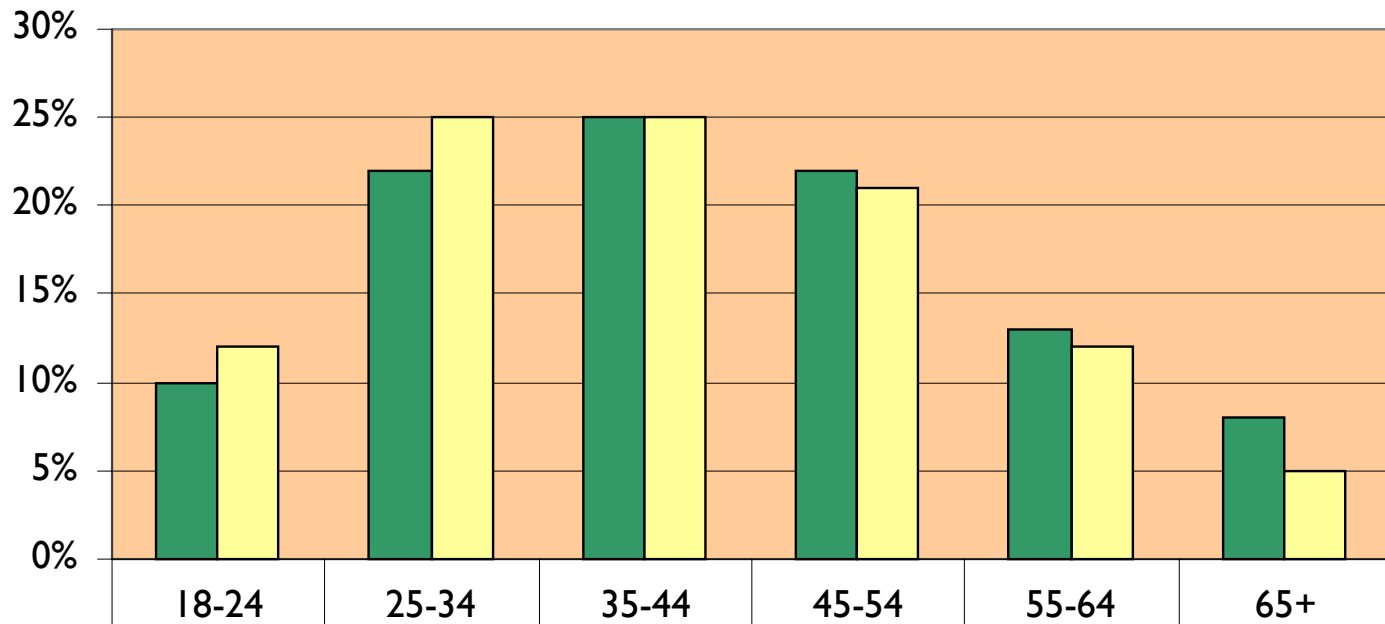


■ No Behavior	44%	27%	15%	14%
■ Has Behavior	35%	28%	19%	17%

# Related Factors

- Prevalence of behavioral challenges increases as level of MR diagnosis increases
- People with behavioral challenges are more than twice as likely to have a dual diagnosis (41% compared with 18%)
- Of those respondents with a dual diagnosis, 70% reportedly have behavioral challenges

# Age Group



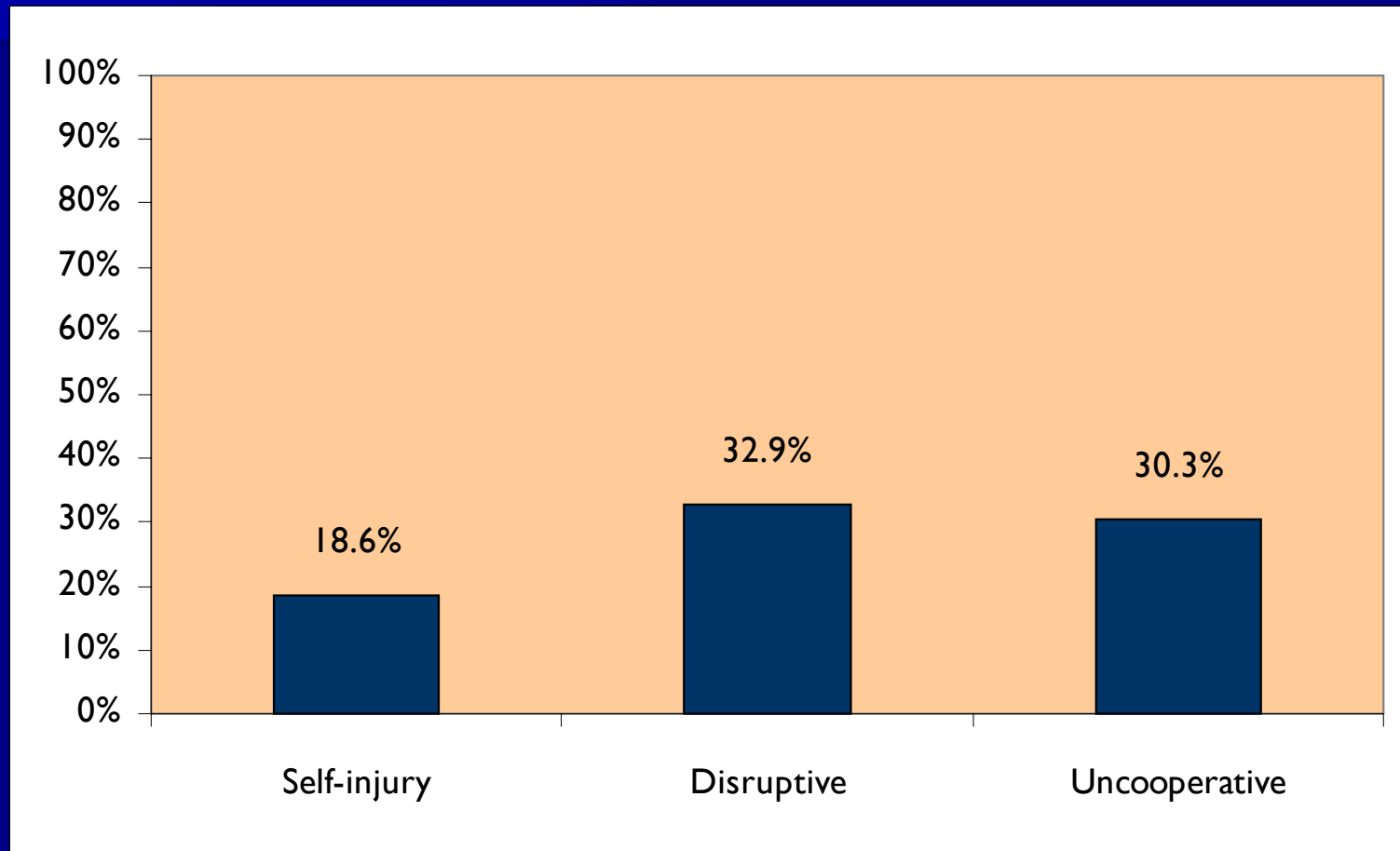
■ No Behavior	10%	22%	25%	22%	13%	8%
■ Has Behavior	12%	25%	25%	21%	12%	5%

# Related Factors

- Presence of behavioral challenges higher among ages 18-34 and lower in over 65 group
- Of respondents with self-injurious behavior, 32% have a non-verbal primary means of expression, compared to only 15% of respondents without SIB

What types of behavioral challenges do people have and how frequently do they need behavioral supports?

# Type of Behavior

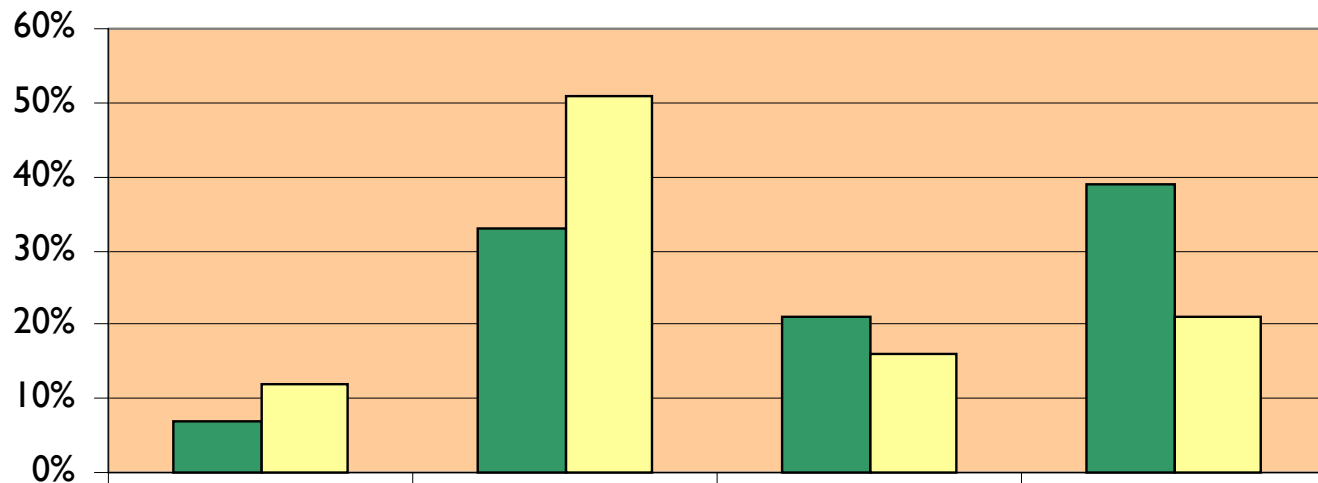


# Frequency of Behavior

- Of those with self-injurious behavior, 37% exhibit this behavior at least once/week
- 40% of those with disruptive behavior and 39% of those with uncooperative behavior exhibit behavior at least once/week

Where do people with behavioral challenges live, and who provides support to them?

# Type of Residence



■ No Behavior	7%	33%	21%	39%
■ Has Behavior	12%	51%	16%	21%

# Type of Residence

- People with behavioral challenges are...
  - More likely to live in a specialized facility or community residence
  - Less likely to live in their own home or apartment or with family
- Over one third (34%) of respondents living at home with a parent or relative reportedly have behavioral challenges

What types of services and supports do people with behavioral challenges receive?

# Services and Supports: Full Sample

N=8259	No Behavior	Has Behavior	Sig.
Service Coordination	96%	97%	
Community Participation	51%	63%	p<.001
Assistive Technology	17%	16%	
Clinical Services	35%	62%	p<.001
Transportation	67%	73%	p<.001

# Services and Supports: Living with Family Only

N=2595	No Behavior	Has Behavior	Sig.
Service Coordination	93%	96%	p<.001
Community Participation	41%	49%	p<.001
Assistive Technology	12%	10%	
Clinical Services	19%	39%	p<.001
Respite	34%	42%	p<.001
Transportation	58%	61%	

Where are people with behavioral challenges employed?

# Employment

	No Behavior	Has Behavior	Sig.
Supported Empl	20%	18%	
Group employment (work crew, etc.)	9%	9%	
Facility-based	35%	43%	p<.001
Non-voc day services	35%	38%	
Worked in community 10 of last 12 months	42%	35%	p<.001

Are there differences in outcomes  
for people with and without  
behavioral challenges?

# Health Care Indicators

	No Behavior	Has Behavior	
Takes psychotropic meds	25%	56%	p<.001
Physical exam within past year	87%	90%	
Dental visit within past six months	61%	67%	p<.001
GYN exam within past year	70%	71%	

# Choice and Decision-making

Person makes decisions about...	No Behavior	Has Behavior	Sig.
Where to live	17%	14%	p<.001
Who to live with	33%	22%	p<.001
Daily schedule	52%	44%	p<.001
Free-time activities	67%	64%	p<.001
Job or day activity	22%	17%	p<.001
What to buy	57%	51%	p<.001

# Choice and Decision-making

- Research suggests that challenging behaviors may decrease when people are given opportunities to make choices and exercise control (Romaniuk & Miltenberger 2001)
- Clearly has implications for designing behavioral supports
- How do we interpret results?

# Community Inclusion Indicators

	No Behavior	Has Behavior	Sig.
Shopping	95%	95%	
Errands/Appointments	96%	97%	
Entertainment	86%	87%	
Eats out	91%	93%	
Religious Services	61%	53%	p<.001
Clubs/community mtgs	37%	31%	p<.001
Exercise/sports	70%	74%	p<.001

# Satisfaction Indicators

	No Behavior	Has Behavior	Sig.
Like work or day program	97%	95%	p<.001
Like where I live	96%	93%	p<.001

# Relationship Indicators

	No Behavior	Has Behavior	Sig.
Has friends outside service system	72%	69%	
Feels lonely	49%	54%	p<.001
Can see family	82%	77%	p<.001
Can see friends	82%	80%	

# Summary of Findings

- 1/2 of respondents have behavioral challenges
- Behavioral challenges are associated with
  - higher levels of MR
  - presence of mental illness
  - younger age groups
  - non-verbal communication
- 37% to 40% of people with challenging behaviors need support AT LEAST weekly
- People with behavioral challenges are more likely to live in a provider-operated setting

# Summary of Findings

- 1/3 of people living w/family have behavioral challenges
- People with behavioral challenges receive:
  - More community participation supports, clinical services, and transportation
  - Less assistive technology support
- Those living w/family receive more service coordination and respite services

# Summary of Findings

- Both groups have about the same rate of access to basic health care exams, except for dental care
- People with behavioral challenges score lower on all choice items, in particular those associated with residential setting
- People with behavioral challenges are twice as likely to be taking psychotropic medication (for mood, anxiety, or behavior)

# Summary of Findings

- Both groups score high on community inclusion items
- People with behavioral challenges are less included in...
  - Religious activities
  - Clubs and community organizations
- ...but have higher participation in...
  - Integrated sports or exercise

# Summary of Findings

- People with behavioral challenges are...
  - Less satisfied with where they live and work
  - More likely to report feeling lonely and not being able to see family when they want to

# Policy Implications



- People with behavioral challenges are not just a sub-population (50%)
- Are systems providing enough support to caregivers (paid staff and family)?
- Further areas to explore:
  - Unmet needs in communication and assistive technology, particularly for those living at home
  - Support for building and maintaining relationships, social connections

# Policy Implications

- Relationship between making choices and the occurrence of challenging behavior...impact on support planning AND outcomes
- Link between performance measurement and individual assessment and planning processes



# For More Information

- Final Reports for Phase V (FY2003) are available on HSRI's website:  
[www.hsri.org](http://www.hsri.org)
- Contact: [staub@hsri.org](mailto:staub@hsri.org) or  
[cmoseley@nasddds.org](mailto:cmoseley@nasddds.org)

