

The Core Indicators Project



How Do We Measure the Performance
of the Developmental Disabilities
System?

Project Beginnings

- NASDDDS and HSRI collaboration
- Launched in 1997
- Seven field test states + steering committee
- ~60 candidate performance indicators
- Development of data collection instruments

Current Participating States

- Arizona
- Connecticut
- Delaware
- Hawaii
- Illinois
- Iowa
- Indiana
- Kentucky
- Massachusetts
- Montana
- Nebraska
- North Carolina
- Oklahoma
- Pennsylvania
- Rhode Island
- Utah
- Vermont
- Washington
- West Virginia
- Wyoming

What will CIP accomplish?

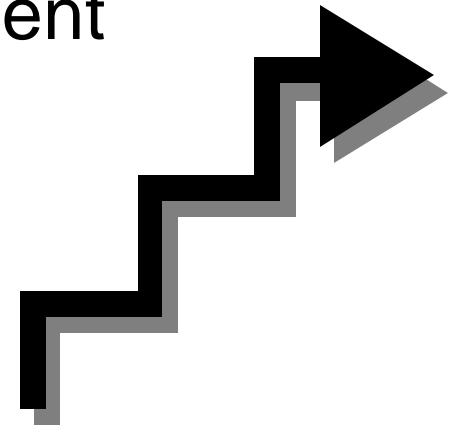
- **Nationally recognized** set of performance and outcome indicators for developmental disabilities service systems
- **Benchmarks** of performance
- **Trend data** at the state level
- Broad dissemination to all **stakeholders**

What are the Core Indicators?

- Consumer Outcomes:
 - Satisfaction, choice, employment, community inclusion, natural supports, family supports...
- System Performance:
 - Service expenditures and utilization, access...
- Protection of Health and Safety:
 - Injuries, crime victimization, mortality data...
- Provider Agency / Workforce Stability:
 - Staff turnover...

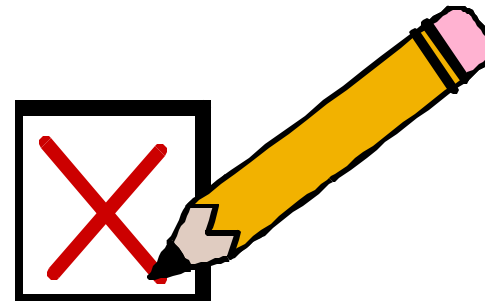
Why Performance Indicators?

- Systems are complex
- Performance indicators provide some “cues” for managing these complex systems
- Managed care and cost containment may pose threats
- Important to know what works
- Supplies early warning signs



Criteria for Selection of Indicators

- Whose Voice?
- Sound psychometric properties
- Clarity and objectivity
- Simple implementation
- Low cost
- Utility to service functions
- Easily interpretable
- Culturally sensitive

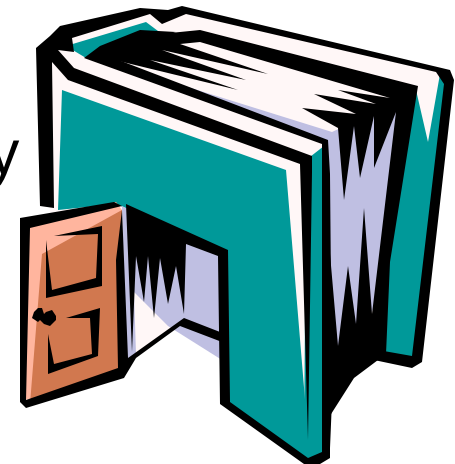


Characteristics of Performance Indicators

- 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

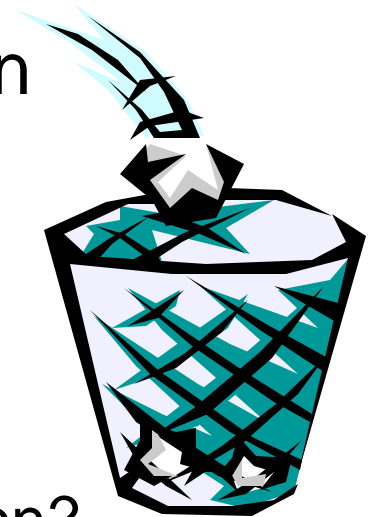
Organization of Indicators

- Categories
 - Consumer Outcomes
 - System Performance
 - Provider agency/workforce stability
 - Protection of health and safety
- Concern statements
- Indicators/measures
- Identify appropriate data source



Left on the Cutting Room Floor...

- Crisis response
- Measures of provider concentration
- More robust indicators concerning direct care staff
- Considerations...
 - Would results be comparable?
 - How much can be done in this iteration?
 - If we can't describe it, how can we measure it?



Data Sources

- Consumer Survey
- Family Support Survey (plus new version for families with kids)
- Family/Guardian Survey
- Provider Survey (limited)
- DD System MIS

Consumer Outcomes



- Employment
- Community Inclusion
- Choice/self-determination
- Independence
- Relationships
- Quality of Life Rights
- Services / Supports Coordination
- Access
- Satisfaction

Employment Examples



- Feeling satisfied with your job
- Being able to get work if you want it
- The number of hours you work per week
- Being able to work the number of hours you want
- Having enough support so a job coach is not needed

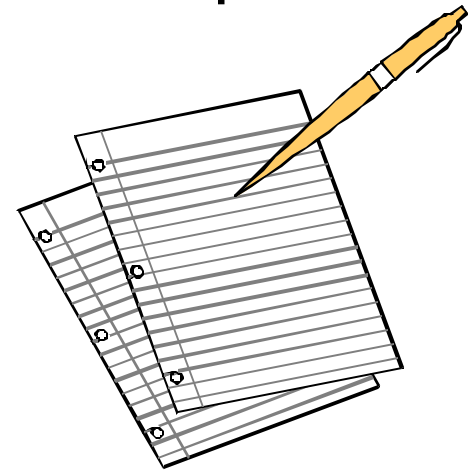
Consumer Survey

- Consumer outcome indicators dominate the indicator set
- Standard instrument developed to use in all field test states
- Scope
 - Adults receiving at least case management



Survey Design

- Developed by project staff and Technical Advisory Subcommittee, experts in survey design and administration
- Built on existing instruments used in pilot states and elsewhere



Consumer Survey Guidelines

- Standardized interviewer training in all states
- Minimum sample of 400
 - age 18+
 - receiving at least one service
- Informed consent obtained where required
- Internal or external interviewers
- Two sections: individual and proxy respondents

Survey Testing

- Focus group - test face validity
- Pilot study - 30 interviews
 - analyze inter-rater and test-retest reliability
 - develop coding rules for interviewers
 - fine-tune wording of questions
- Analysis of Phase I results to determine discriminant validity, “scalability,” etc.

Family Support Outcomes

- Areas of concern include:
 - availability/usefulness of information
 - choice/participation in planning
 - access to services and supports
 - linkages to other community supports
 - satisfaction

Provider/System Data

- “Provider Survey” collected data on
 - Staff turnover
 - Consumer and family representation on boards of directors
 - Consumer employment information
 - Other data as needed
- Injuries, restraints, crimes, and deaths data at state level

Unmet Demand/Access

- Numbers of people on waiting lists, age, supports required
- Proportion of racial/ethnic minorities served
- Number of people receiving more than one support

Health & Safety Outcomes



- Knowing how to file a grievance
- Feeling safe in your neighborhood
- Having checkups with doctor and dentist
- Being free from major/serious injuries
- Not taking psychotropic medications if you don't need to
- Being free from bad medications reactions
- Being safe from crime

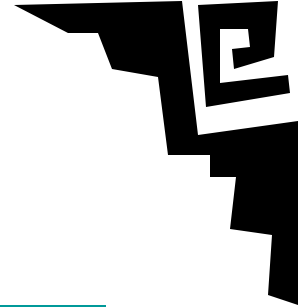
Staff Stability



- Rate of direct support turnover
- Average length of time on the job
- Vacancy rate
- Staff qualifications and competency considered but postponed; considered a staff survey

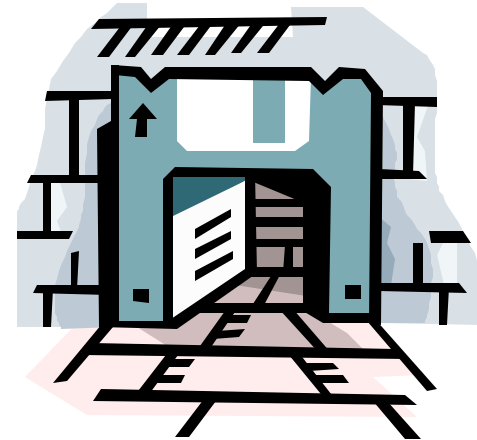
Mortality

- Deaths of people receiving services
- Age/gender adjustment
- Reliable base
- By cause (medico-legal v. natural death)



Analysis Questions...

- Uniformity/consistency of data:
 - How well do the protocols work to collect **comparable data** across states?
 - What is the potential for developing national **norms and benchmarks**?
 - What **trends** in performance can be identified across the participating states?



Analysis Questions...

- Usefulness of the data
 - Do these measures tell the states **what they need to know** about their performance?
 - What do we know about the **reliability** and **validity** of the baseline data?

Risk Adjustment

Purpose: to control for affect of consumer characteristics on performance outcomes (measured by the ICAP)

- Physical limitations
- Adaptive and maladaptive behavior
- Age
- Gender



Phase II Selected Results



Consumer employment data

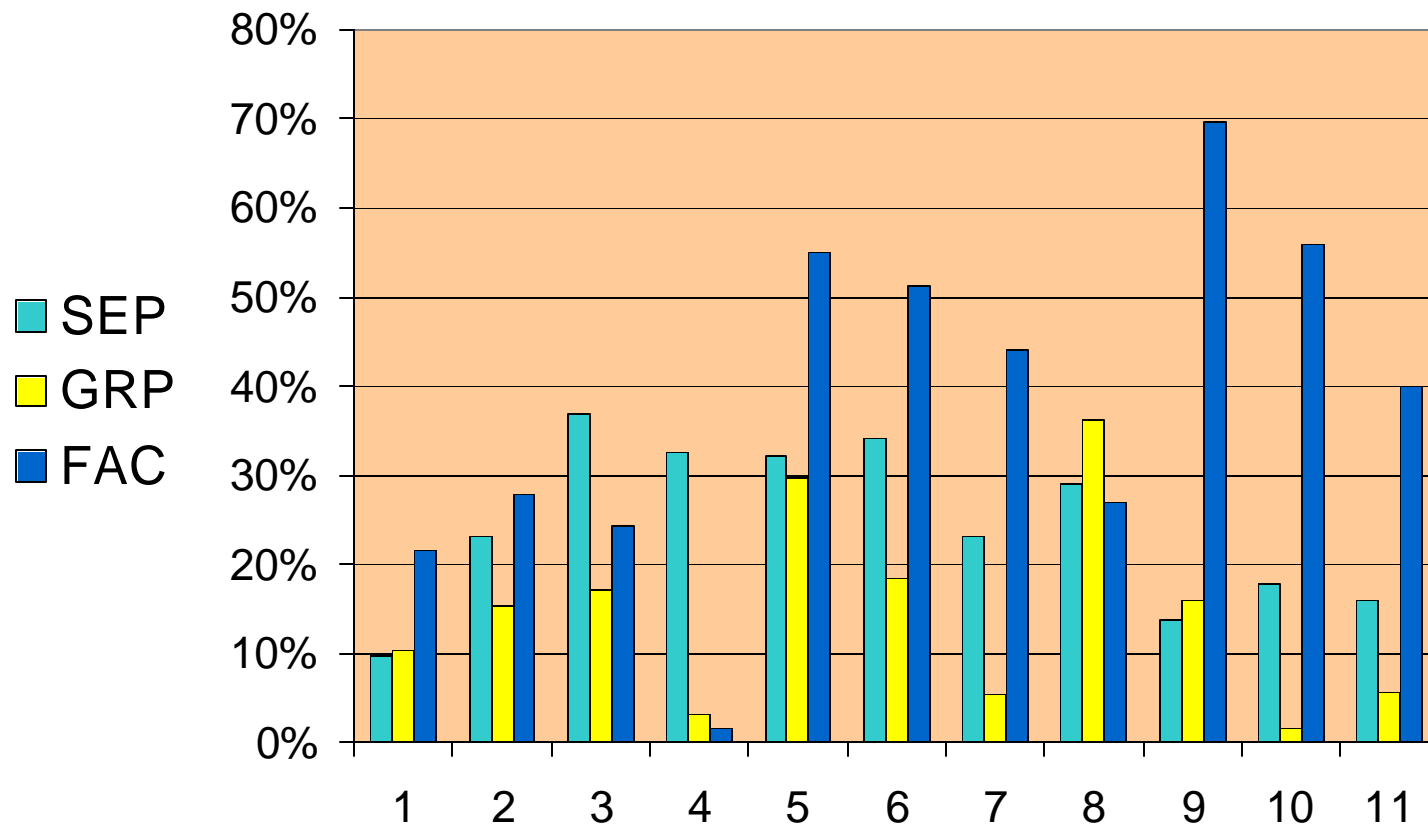
Where people work:

Duplicated counts

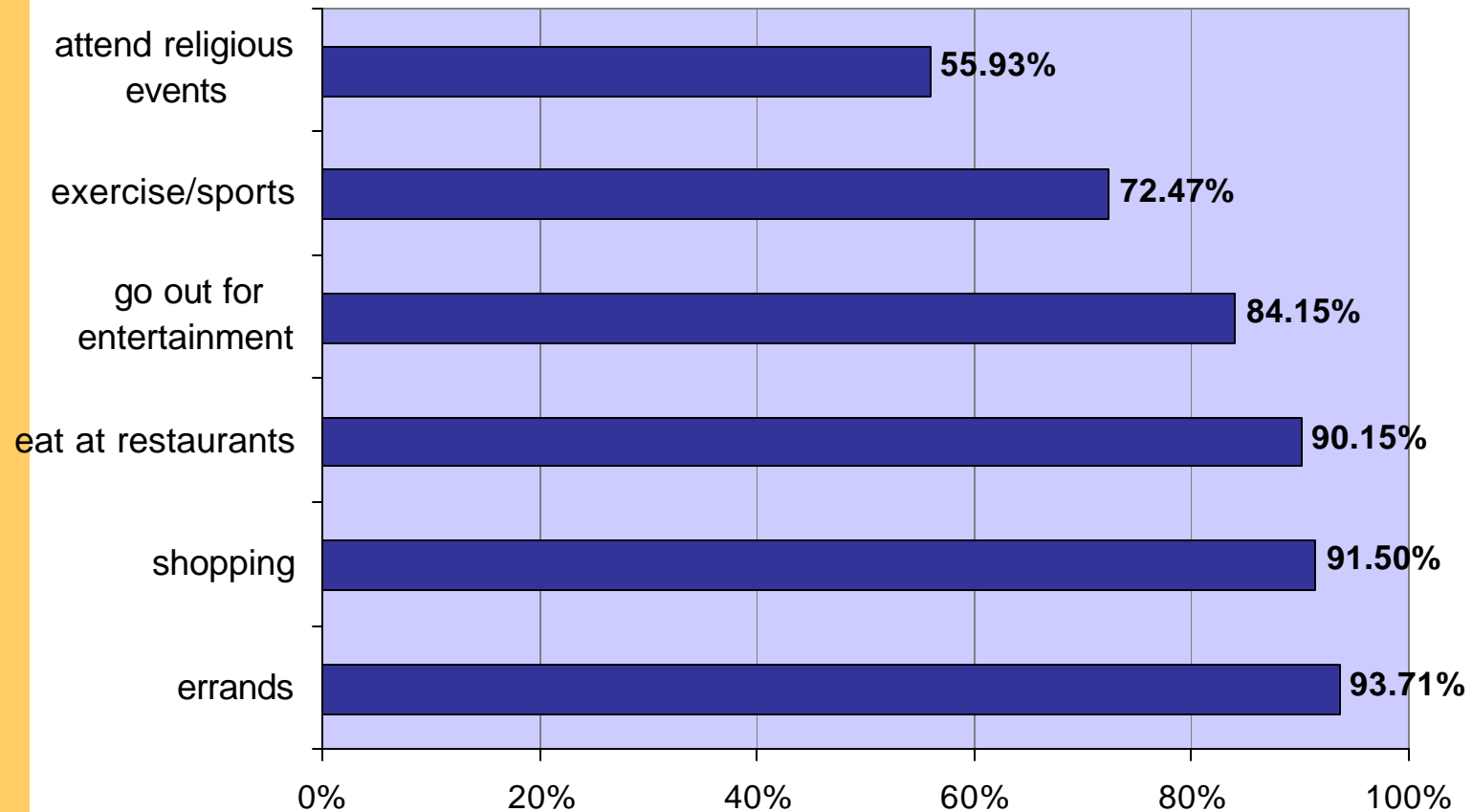
Aggregate N = 3900 (11 states)

- 27.7% -- supported employment
- 21.7% -- group employment (enclave/crew)
- 40.4% -- facility-based employment
- 36.8% -- non-vocational day supports

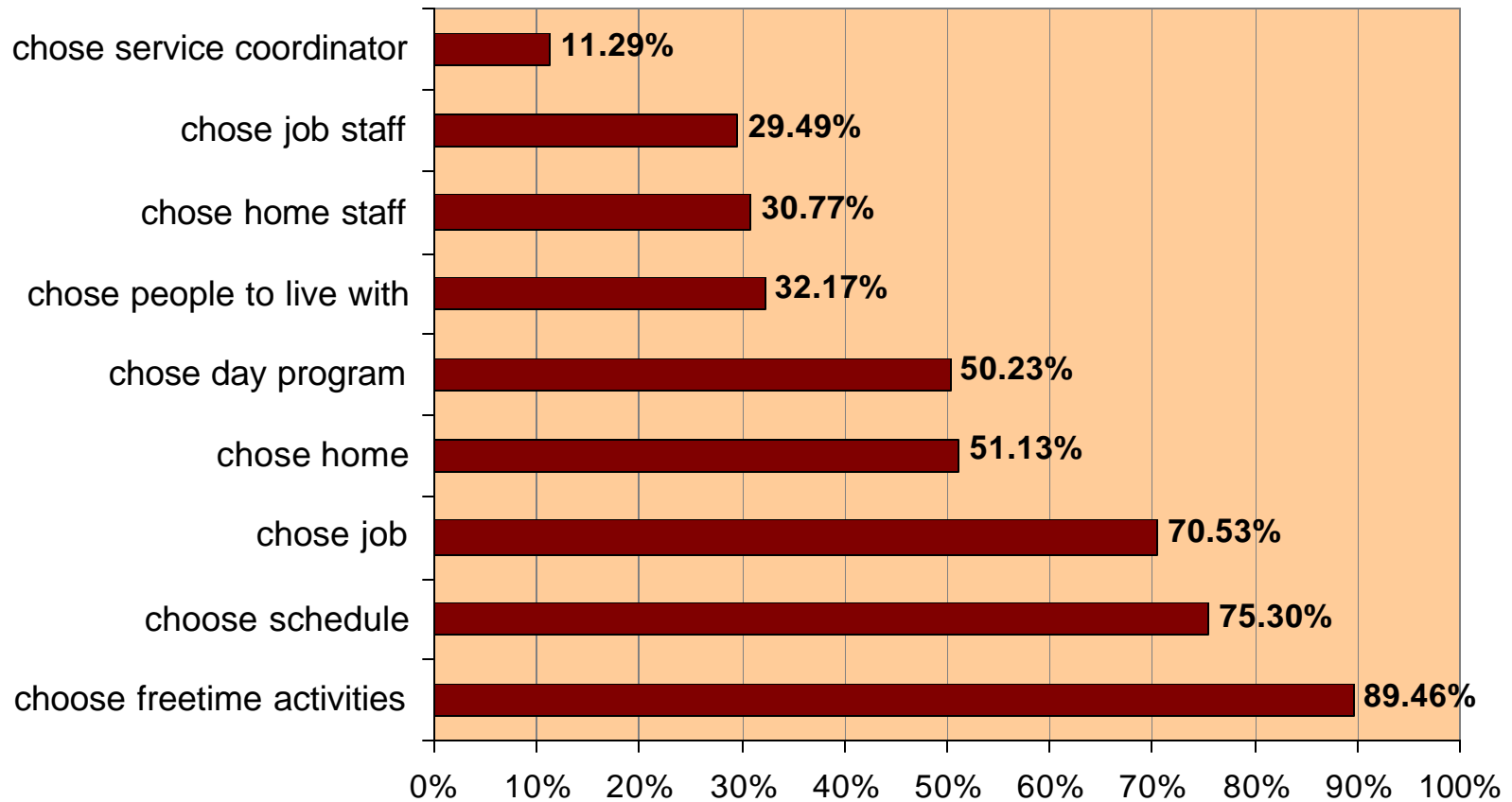
Types of Employment Supports by State



Community Inclusion



Choice and Decision-Making



Consumer Outcomes

- Access
 - **81%** of respondents reported that they almost always have a way to get where they want to go
- Safety
 - **93%** of respondents report feeling safe in their neighborhoods
 - **96%** report feeling safe at home

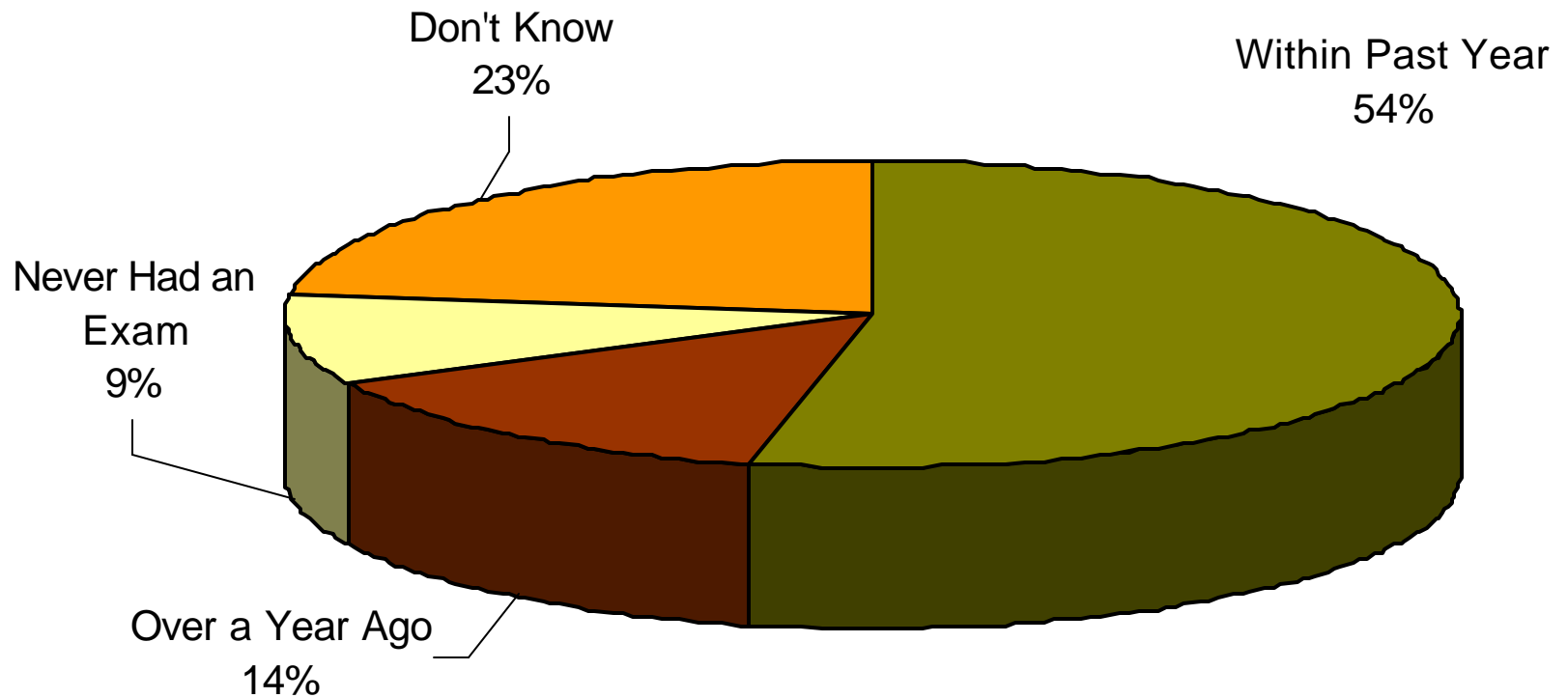
Consumer Outcomes

- Health

- Across the board, women's access to yearly OB/GYN exams is low (only 53.5% had an exam in the past year and 9.4% have never had one)
- The percentage of respondents who take psychotropic medications is 40.2% across all states

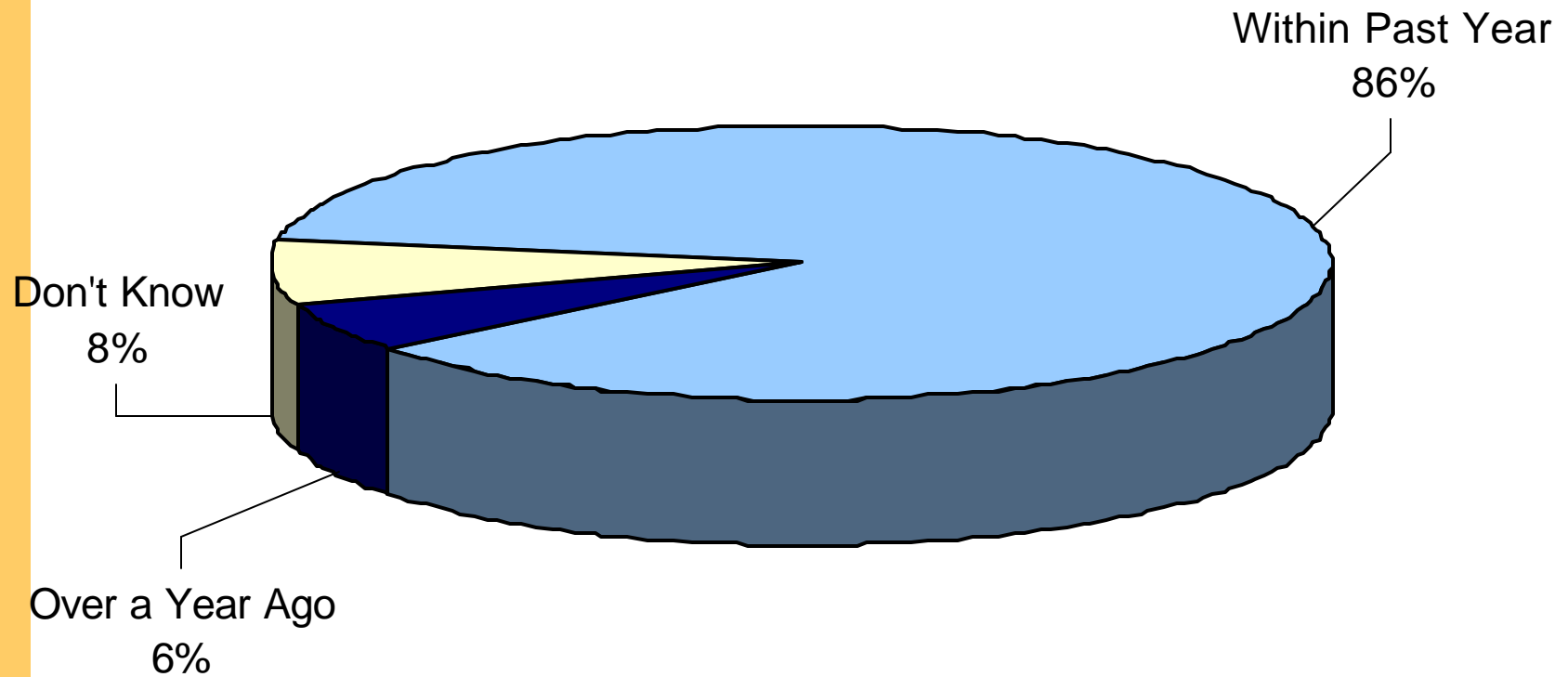
Health Outcomes

Last OB/GYN Exam



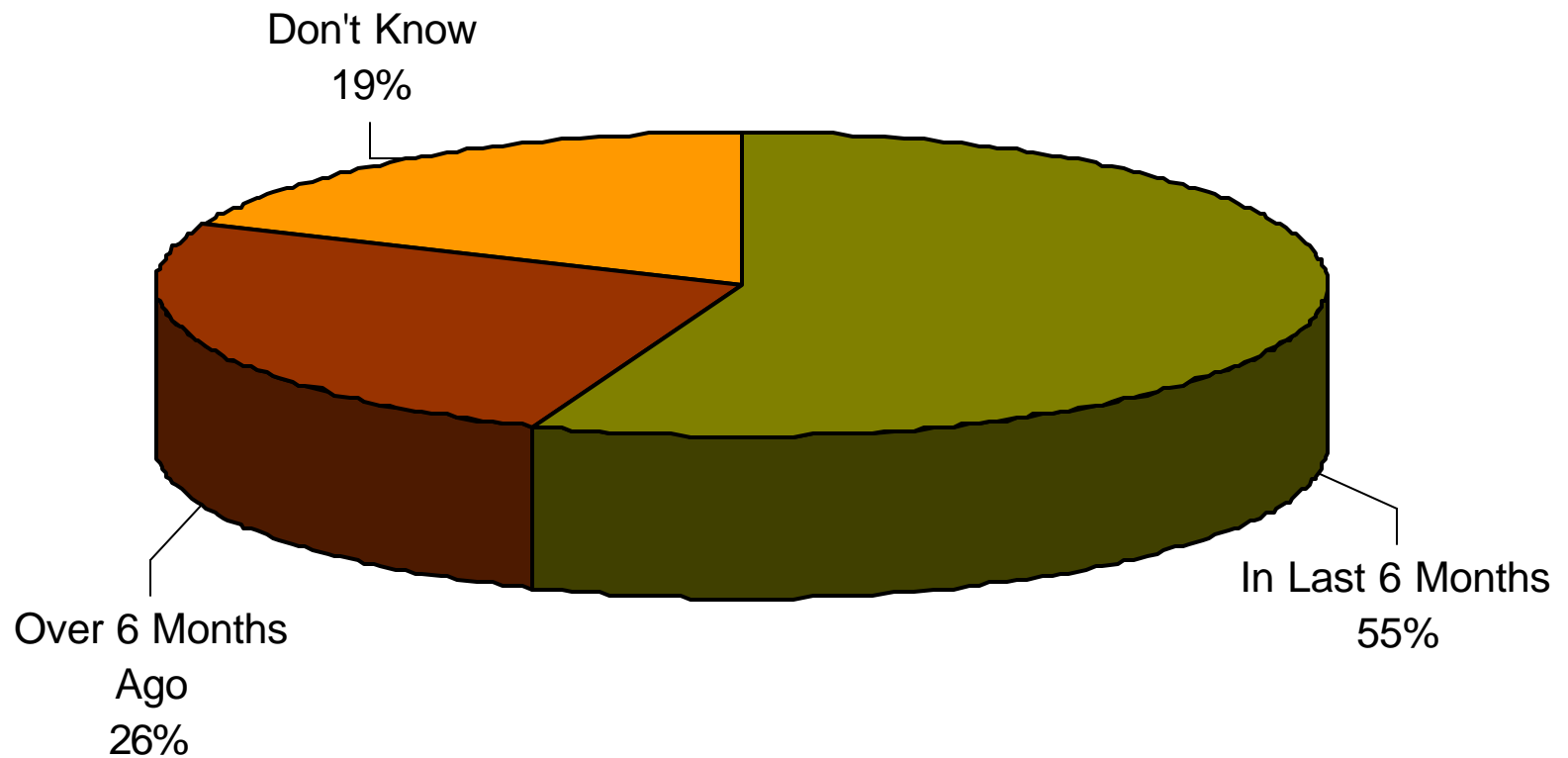
Health Outcomes

Last Physical Exam



Health Outcomes

Last Routine Dental Exam



Family Survey Comparisons

- More positive responses on Family/Guardian Survey (this group was generally older and received more supports)
- Out-of-home families more satisfied with individual supports than those with family members living at home (84% vs. 64%)
- Much greater variation on satisfaction ratings for the in-home group (50% to 70%)

Family Support Survey – Comments

- Across states:
 - High satisfaction with staff and services received
 - Need more options for day programs and activities
- State-specific themes:
 - Need more transportation
 - Need transition services and job-training
 - Need for multi-lingual staff
 - Concerns about quality of day programs (facilities, staff, and amount of activities)

Staff Stability

- **Day support** providers report:
 - Lower turnover
 - Current staff have been employed longer
 - Half as many vacant positions (both FT and PT)
- **Both types** of agencies report:
 - Staff who left within the last year were employed on average about 19 months
 - Part-time position vacancies are much higher than full-time position vacancies

Staff Turnover

- Day Support Agencies

- 31.2% turnover (n=294)
- Separated staff employed average of 19.4 months (n=242)
- Current staff employed average of 40.3 months (n=290)

- Residential Support Agencies

- 35.2% turnover (n=283)
- Separated staff employed average of 19.5 months (n=259)
- Current staff employed average of 37.8 months (n=272)

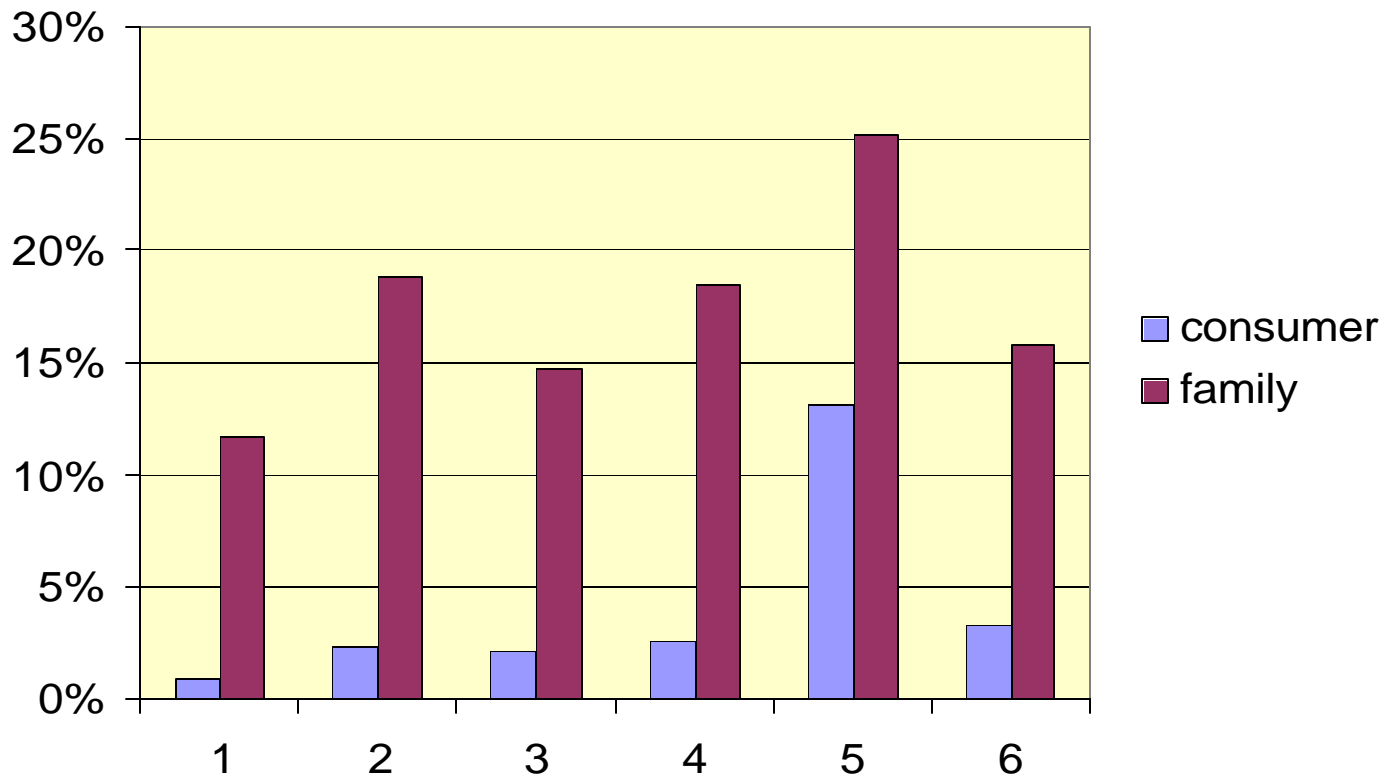
Staff Vacancies

- Day Support Agencies
 - 5.9% of full-time positions are vacant (n=222)
 - 8.7% of part-time positions are vacant (n=167)
- Residential Support Agencies
 - 9.9% of full-time positions are vacant (n=217)
 - 18.9% of part-time positions are vacant (n=199)

Representation on Boards

- Across all providers reporting (N = 302)
 - 3.2% of board members are consumers
 - 19.0% of board members are family

Board Representation by State





For more information...



Visit HSRI's website:

www.hsri.org/cip/core.html