WELCOME TO
NATIONAL CORE INDICATORS

California NCI Advisory Committee
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NASDDDS
NATIONAL CORE INDICATORS

- Launched in 1997 in 13 participating states
- Currently 30 states and 4 sub-state regions
- Unparalleled 12-year database on over 12,000 individuals
- Addition of California almost doubles the numbers of individuals in the database
NCI Participating States 2009-2010

Orange County Regional Center

State plus counties
NCI VISION

- Influence national and state policy
- Improve practice at the state level
- Add knowledge to the field
- Inform strategic planning and priority setting
- Improve the participation and well-being of people with intellectual and developmental disabilities
NCI MEASURES OFFER A UNIQUE VIEW

- Individual characteristics
- The locations where people live
- The activities they engage in during the day
- The nature of their experiences with the supports that they receive
NCI FRAMEWORK

- 100 Core Performance and Outcome Measures
- Five Domains
NCI Performance Assessment

**Personal Outcomes**
- Employment & Community Inclusion
- Choice & Decision-making
- Relationships

**System Performance**
- Support Coordination
- Utilization
- Finance

**Family Perspectives**
- Choice & Control
- Satisfaction
<table>
<thead>
<tr>
<th>NCI Survey</th>
<th>Target Population</th>
<th>Method</th>
<th>Total States</th>
<th>Total Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Consumer Survey</td>
<td>Adults 18 years + receiving at least one service besides case management</td>
<td>In-person interview</td>
<td>24</td>
<td>12,058</td>
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<tr>
<td>Adult Family Survey</td>
<td>Families of adults 18+ living at home</td>
<td>Mail</td>
<td>15</td>
<td>6,321</td>
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<tr>
<td>Child Family Survey</td>
<td>Families of children under 18 living at home</td>
<td>Mail</td>
<td>8</td>
<td>2,711</td>
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<tr>
<td>Family Guardian Survey</td>
<td>Families or guardians of adults 18+ living outside the home</td>
<td>Mail</td>
<td>11</td>
<td>4,828</td>
</tr>
<tr>
<td>Provider Survey on Staff Stability</td>
<td>All provider agencies</td>
<td>Mail/E-mail</td>
<td>10</td>
<td>606</td>
</tr>
</tbody>
</table>
Consumer Survey Information

- **Individual Characteristics**
  - Age, gender, ethnicity, level of ID
  - Diagnoses, co-existing conditions
  - Primary means of expression
  - Frequency of medical care
  - Supports needed
Selected Findings

WORK, INCLUSION, SAFETY AND OTHER IMPORTANT OUTCOMES
Findings: Individual Characteristics

• 31% Co-existing DD & MI diagnoses
• 47% Receive medication for mood, behavior or psychiatric disorders
• 8% Autism (varied by state from 2.5% to 16.9%)
• 87% Had a physical exam within the past year
• 53% Received a dental exam in the past six months
2007-08 Consumer Survey: *Where People Live* (12,019)

- Parent/relative's home: 28.7%
- Group home: 23.5%
- Specialized Facility: 16.5%
- Independent home/apt: 13.0%
- Foster care/host home: 8.8%
- Apartment program: 5.4%
- Other: 2.9%
- Nursing facility: 0.9%
What People Do During the Day

Day and Employment Supports (2007-08)

- Non-Vocational Day Services: 40.3%
- Facility Based Vocational: 24.5%
- Individual Supported Employment: 12.6%
- Group Supported Employment: 6.3%
Percent of Individuals Participating in Each Community Activity in 2007-08

- **shopping**: 93%
- **errands**: 96%
- **entertainment**: 88%
- **eat out**: 91%
- **religion**: 60%
- **sports**: 37%
CONSUMER SURVEY RESULTS: WORK

- Results from supplemental employment survey in 2007-08 (N=6,538):
- 32.2% worked at least one hour over the past month. Of these:
  - 14% worked in a competitive employment setting
  - 11% in an individual supported employment setting
  - 15% in a group supported employment setting and/or
  - 63% in a facility-based work program
AVERAGE HOURS AND WAGES PER MONTH BY EMPLOYMENT SETTING IN 2007-08

Consumers who worked in group supported employment settings and facility-based work programs worked *more hours* and earned *less money* per month on average than those who worked in competitive or individual supported employment settings.

Sample Size: Comp. Emp. Hours (N=303) & Wages (N=215), Ind. Sup. Emp. Hours (N=240) & Wages (N=183); Group Sup. Emp. Hours (N=319) & Wages (N=267), Fac. Based WP Hours (N=1,330) & Wages (N=1,080)
COMMUNITY PARTICIPATION

- Roughly 90% participated in several community activities in 2007-08 (see chart below).
- Fewer went to religious services and took part in integrated sports activities.
  - 37% of individuals participated in community-integrated sports
  - 33% participating in non-integrated sports
  - only 30% were inactive, not participating in any sports

Sample Size: Sports (N=9,299), Religion (N= 8,964), Eat out (N=9,262), Entertainment (N=9,316), Errands (N=9,282), and Shopping (N=9,310)
CONSUMER SATISFACTION

• Very high levels of satisfaction with work and home life in 2007-08:
  - 95% of consumers were satisfied with where they lived and where they worked
  - 90% felt their home staff were respectful
  - 94% felt their work staff were respectful

• There were minimal state differences in home and work satisfaction.

• Significantly more consumers in RI, AR, IN, LA, NM, ME, and PA felt their home or day support staff treated them with respect than those in other states.
Individuals who chose where to live, lived with family, and received HCBS funding were more likely to usually/always like where they lived*.

FIVE YEAR TRENDS IN HOME-RELATED CHOICE

- Consumers were more likely to choose their home staff than where they lived.
- Consumers were more likely to choose their home and home staff than who they lived with.
- Increase in proportion of consumers who were able to choose their case manager over time:
  - 2003-06: roughly 47%
  - 2006-08: roughly 52%
FIVE YEAR TRENDS IN HOME-RELATED CHOICE

- 56% in '03-04
- 60% in '04-05
- 59% in '05-06
- 63% in '06-07
- 58% in '07-08

- 52% in '03-04
- 55% in '04-05
- 52% in '05-06
- 56% in '06-07
- 51% in '07-08

- 44% in '03-04
- 46% in '04-05
- 44% in '05-06
- 48% in '06-07
- 41% in '07-08

- chose home staff
- chose home
- chose roommates
Between 2003-04 and 2007-08, most consumers said they had friends, particularly friends who were not staff or family.

During this time, on average 35% of consumers stated they were sometimes lonely and 12% were often lonely.
Participants who were afraid at home or in their neighborhood, did not like where they lived, and had less contact with their family and friends were significantly more lonely*.

Consistently high rates of consumer privacy and rights between 2003-04 and 2007-08

Chart: average rates between 2003-04 and 2007-08

- Can be alone
- No restrictions on being alone with guests: 87%
- People enter home only with permission: 83%
- People enter bedroom only with permission: 89%
- People read mail only with permission: 86%
- No restrictions on using the telephone: 93%

Sample Size: Can be alone (N=5,671), Alone with guests (N=6,162), Enter home (N=5,721), Enter room (N=5,371), Read mail (N=8,051), and Phone (N=6,982)
FAMILY SURVEY RESULTS: INFORMATION AND PLANNING

- Adult and child family survey respondents who received information about services their family member receives (in 2007-08):
  - 42% of adult family and 39% of child family respondents received this info *usually or always*
  - 38% of adult family and 40% of child family respondents received this info *sometimes*
  - 55% of both groups of respondents felt this information was *usually or always* easy to understand
  - 38% of both groups of respondents felt this information was *sometimes* easy to understand
CHOICE AND CONTROL

- Ability to choose agencies and providers who worked with their family member (in 2007-08):
  - 65% of adult family and 59% of child family survey respondents *usually or always* chose
  - 17% of adult family and 22% of child family survey respondents *sometimes* chose
Adult family, family guardian, and child family survey respondents have been increasingly likely to know how much money was spent on their family member’s services over the past few years.
<table>
<thead>
<tr>
<th>ACCESS AND SUPPORT DELIVERY</th>
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<tr>
<td><strong>In 2007-08, according to adult and child family survey respondents:</strong></td>
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<tr>
<td>• roughly 90% of family members had access to health services and medications</td>
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<tr>
<td>• 87% of child family respondents’ family members had access to dental services</td>
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<tr>
<td>• 74% of adult family respondents’ family members had access to dental services</td>
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</table>
One area of concern: whether supports were available in a crisis or emergency

- roughly one-third of adult and child family respondents felt these supports were *seldom or never* available
- roughly 20% felt these supports were *sometimes* available
- only 40 to 50% reported they were *usually or always* available

Sample Size: Adult Family (N=2,786), Child Family (N=1,069)
Between 2003-04 and 2007-08, family respondents said their family members had higher community access than participation.

Access and participation were highest for adults who did not live with their families.

Community access and participation in 2007-08

Sample Size: Child Family Access (N=2,269), Participation (N=2,360); Adult Family Access (N=5,312), Participation (N=5,492); Family Guardian Access (N=4,110), Participation (N=3,968).
FAMILY OUTCOMES

- In 2007-08, over 65% of adult family, family guardian, and child family survey respondents said that services and supports have usually or always made a positive difference in their family member’s life.

- Roughly 70% of adult and child family survey respondents said that services have usually or always made a difference in helping to keep their family member living at home.
CONSUMER SURVEY RESULTS: HEALTH

- Between 2003-04 and 2007-08:
  - over 90% of individuals had a health exam in the past year
  - almost 70% of women had a gynecological exam in the past year
  - over 60% of individuals had a dental exam in the past six months
MEDICATIONS

- More consumers took psychotrophic medications than were diagnosed with a mental illness or psychiatric disorder.
- Between 2003-04 and 2007-08, almost one-third (30%) of consumers on average were diagnosed with a psychiatric illness.
- Almost one-half (46%) of consumer on average took at least one psychotrophic medication.
• Over 80% of consumers felt safe in their home and neighborhood between 2003-04 and 2007-08
• In 2007-08 over 10% felt afraid sometimes in their home (13%) or neighborhood (11%).
• Almost 5% felt afraid in their home or neighborhood most of the time.
STAFF STABILITY AND COMPETENCE

- Steady decrease in staff turnover in residential and day service settings from 2005-06 to 2007-08

- In Fiscal Year (FY) 2007, residential and day service providers had a 7% vacancy rate for their full-time positions, and a 13% vacancy rate for their part-time positions.

- 40% of residential and day staff that left their jobs in FY2007 had worked in their position for over one year.

- 39% of residential and 38% of day staff that left their jobs had worked six months or less
DIRECT CONTACT STAFF TURNOVER: FY2005 TO FY2007

- Residential:
  - FY2005: 45%
  - FY2006: 43%
  - FY2007: 40%

- Day:
  - FY2005: 36%
  - FY2006: 38%
  - FY2007: 38%
• Roughly 90% of individuals have consistently reported knowing who their case manager is.

• However, individuals were more likely to report that their case manager got them the support and services they needed and asked them what was important to them in 2004-05 and 2005-06 than in other years.
SERVICE COORDINATION BETWEEN 2003-04 AND 2007-08

- 87% in 2003-04
- 87% in 2004-05
- 89% in 2005-06
- 90% in 2006-07
- 90% in 2007-08

100%

80%

60%

'03-04 '04-05 '05-06 '06-07 '07-08

knows case manager

case manager gets what's needed

case manager asks what's important
State Applications
• Have created an annual National Core Indicators Review Panel Report
• Gives Recommendations and Ideas for Action to Washington’s Division of Developmental Disabilities and the DD Council themselves
• Example: Because about 1/3 of respondents state that they seldom or never get emergency services/supports, the Panel recommends the Division create a 24/7 response system for people with disabilities and their families.
Established State and Regional Quality Councils
Reviewing NCI and other state data
Using data to assess person centered practices
Alabama

- Choice and decision-making was identified as area for improvement; state responded with five year plan to increase # of PCP facilitators and offering SRV training to families
- Also using consumer and family surveys to measure satisfaction pre- and post- community placement from closing of state facility
Arizona

- Steps taken to improve women’s health care outcomes resulted in rate of annual visits increasing from 30% to 70%
- Asking the questions increases awareness about options (e.g., families can change support coordinators)
Orange County Regional Center

- Discovered that young parents were not included in their communities
- Talked to families and realized that young families did not know about the opportunities that were available
- Worked with families and community agencies (e.g., parks) to inform families about availability and to expand opportunities
- Also use data with the Board to set priorities and to conduct strategic planning
How are Results Disseminated?

- Reports of state results vs. national results posted on websites (LA, NJ, GA)
- Presentations to staff, providers, community
- Summaries shared with families who filled out surveys (AZ)
- Accessible reports to participants (VT)
LINKS AND NCI TEAM

For more information, please visit the National Core Indicators website- www.nationalcoreindicators.org

National Association of State Directors of Developmental Disabilities Services (NASDDDS) www.nasddds.org
Human Services Research Institute (HSRI) www.hsri.org

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Questions?

What did she say?