Quality of Life Data and Trends

Sue Kelly, Delmarva Foundation
Drew Smith, Council on Quality Leadership
Valerie Bradley, Human Services Research Institute

AAIDD Conference, Louisville, KY
June 2, 2015
Provider Performance and Driver Outcomes

Provider Systems That Predict Key Outcomes for Individuals

Delmarva Foundation
Sue Kelly, Senior Scientist
Overview

Quality Assurance/Improvement Programs in FL and GA

Individuals with IDD receiving HCBS Waiver or State Funded Services

Person Centered and Provider Reviews

Conduct individual and staff interviews, observations, and record reviews

Outcome Predictors: Driver Outcomes and Provider Performance
Person Centered Reviews (PCR)

- Start with interviewing the person
- Determine quality of supports & services, and
- How well person is supported to meet goals

Provider Reviews (PDR, QEPR)

- Multi faceted approach
- Assess compliance with standards
- Evaluate person centered practices for individuals served
- Evaluate overall service delivery systems
Results from Florida Study

Analysis in 2006 indicated several provider performance areas that best predict the percent of Personal Outcome Measures (POM) present:

- Communication
  - Importance of interaction among providers
  - Create an environment of cohesive action
  - Outcomes are everyone’s responsibility
- Ensuring individuals are developing desired social roles
- Ensuring individuals have privacy
Results from Georgia Study

2012 analysis showed significantly more outcomes when provider documentation showed:

- How person is given choice of services and supports
- Efforts to support person to develop social roles
- Person’s progress in achieving desired goals
- Person centered focus
- A clear description of services and supports provided
- How supports/services change as needed
Provider Systems and Driver Outcomes
Georgia Quality Management System

Provider Performance (Record Review from PCR and QEPR) + Control Variables

Driver Outcomes (Individual Interviews)

Identified by Principal Component Model

Tested using Logistic Regression Model
Individual Interview Outcomes
6 Focused Outcome Areas (15 indicators)
Develop Driver Outcomes

- Health
- Rights
- Choice
- Person Centered Practices
- Community
- Safety

Person
Strongest Driver Outcome

Person Centered Planning

- The person is afforded choice of services and supports.
- The person is involved in the design of the service plan.
- The person's goals and dreams are reflected in supports and services.
- The person is achieving desired outcomes and goals.
Second Driver Outcome

Community Integration and Rights

✓ The person actively participates in decisions concerning his or her life.

✓ The person is educated and assisted to learn about and exercise rights.

✓ The person has opportunities to access and participate in community activities.

✓ The person is developing desired social roles.
Provider Record Reviews
To Identify Predictors

- 15 indicators represent each Focused Outcome Area
- Assess the quality of provider documentation
- Review records for all services the individual receives
- Documentation shows how well providers implement policies and support individuals served
Logistic Regression Model

- Dependent
- Person Centered Planning
- Community /Rights
Logistic Regression Model

- **Explanatory/Independent Variables**
  - Residence
  - Age
  - Disability
  - Region
  - Service
  - PPR Indicators of provider performance

- **Control Variables**
Strongest PRR Predictors
(OR = PCP and C/R Odds Ratio)

Strongest predictor of both driver outcomes is if the person is provided a choice of community services and supports (OR 2.52, 3.54)

If provider ensures a choice of services and supports, person is much more likely to have both driver outcomes (OR 2.20, 2.23)

If documentation shows providers assist person to direct supports and services, both driver outcomes are more likely to be present (OR 1.91, 1.86)
Strongest PRR Predictors
(OR = PCP and C/R Odds Ratio)

Providers who use a person centered focus in their documentation positively impact driver outcomes (OR 1.70, 1.68)

Documenting how the person is progressing toward and achieving desired goals positively impacts driver outcomes (OR 1.57, 1.56)

Having the means to identify health status and safety needs increases the persons community integration (OR 1.77)
Other Findings

- Receiving Supported Employment is more beneficial than any other service in supporting Community/Rights driver outcomes.

- People living in group homes were less likely to have elements of both driver outcomes present.

- People with Mild/Moderate ID were about 40% more likely to have Community Integration/Rights driver outcomes present than individuals with Profound ID.
Key Findings

- Elements of Person Centered Planning are the most important driver outcome—impact presence of other outcomes

- Findings show importance of having the person involved in planning and choosing services that reflect desired goals.
Key Findings

- Providers who offer choice of services and supports, choice of community supports, and ensure the person directs services are 2 to 2.5 times more likely to impact Person Centered Planning outcomes, and thus the overall quality of life for the person
Contacts

Sue Kelly, Sr. Scientist, Delmarva Foundation
kellys@delmarvafoundation.org

Eddie Towson,
Director of Quality Assurance, GA Division of DD
eltowson@dhr.state.ga.us
MEASURING OUTCOMES
AT THE INDIVIDUAL LEVEL

DREW SMITH
CQL | Director of Research and Data
dsmith@thecouncil.org
About CQL | The Council on Quality and Leadership

- What does the data tell us:
  - 20 years of Personal Outcome Measures® Data
  - Looking at predictor outcomes
  - Measuring Social Capital with POM

- How is the information being used
CQL’s work centers around 3 tools:

### Personal Outcome Measures®
- Developed in 1997
- Values-based, individualized quality of life measurement tool
- Valid and reliable assessment
- 21 factors measuring outcomes and presence of supports
- Used in accreditation, person-centered planning, ISPs, organizational learning, state reporting

### Basic Assurances®
- Provider level regulatory review
- Person-centered approaches intertwined with regulation
- 10 Factors and 46 sub-factors
- Indicators evaluated using two measures: System in Place and System in Practice
- Used in accreditation and state reporting

### Person-Centered Excellence
- Multi-stakeholder assessment of provider level performance
- Used in provider level strategic planning
- 8 key factors and 34 success indicators focused on Person-Centered Excellence
- All indicators meant to drive better accountability in services, greater choice and community inclusion
Overview of CQL Data Collection

• All POM data presented comes from:
  • CQL Certified Interviewers
  • CQL Staff

• Records are not necessarily the same people from year-to-year

• Data used to show trends in services

• More finite research can be conducted at the individual, provider and/or state by state level
My Self (n = 8,560) 1993 - 2013

- 70%
- 69%
- 71%
- 88%
- 84%
- 86%
- 80%
- 76%
- 76%
- 76%
- 75%
- 81%
- 79%
- 86%
- 86%
- 85%
- 76%

- connected to natural support networks
- have intimate relationships
- are safe
- have best possible health
- exercise rights
- are treated fairly
- are free from abuse and neglect
- experience continuity and security
- decide when to share personal information

1993-1998
1999-2004
2005-2009
2010-2013
All Data Average
MEASURING OUTCOMES

My World (n = 8,560) 1993 - 2013

Choose where and with whom they live
Choose where they work
Use their environments
Live-in integrated environments
Interact with members of the community
Perform different social roles
Choose services

My Dreams (n = 8,560) 1993 - 2013

MEASURING OUTCOMES

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>choose personal goals</td>
<td>37%</td>
<td>60%</td>
<td>67%</td>
<td>79%</td>
<td>75%</td>
</tr>
<tr>
<td>realize personal goals</td>
<td>50%</td>
<td>67%</td>
<td>79%</td>
<td>75%</td>
<td>75%</td>
</tr>
<tr>
<td>participate in life of the community</td>
<td>50%</td>
<td>70%</td>
<td>72%</td>
<td>65%</td>
<td>72%</td>
</tr>
<tr>
<td>have friends</td>
<td>53%</td>
<td>57%</td>
<td>53%</td>
<td>53%</td>
<td>53%</td>
</tr>
<tr>
<td>are respected</td>
<td>66%</td>
<td>66%</td>
<td>66%</td>
<td>82%</td>
<td>76%</td>
</tr>
</tbody>
</table>
### Specific Outcomes Correlated With Total Outcomes

<table>
<thead>
<tr>
<th>HIGHEST</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise Rights</td>
<td>.537</td>
</tr>
<tr>
<td>Are Treated Fairly</td>
<td>.523</td>
</tr>
<tr>
<td>Choose where and with whom they live</td>
<td>.517</td>
</tr>
<tr>
<td>Interact with members of the community</td>
<td>.501</td>
</tr>
<tr>
<td>Choose where they work</td>
<td>.499</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LOWEST</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Decide when to share information</td>
<td>.337</td>
</tr>
<tr>
<td>Have the best possible health</td>
<td>.310</td>
</tr>
<tr>
<td>Free from abuse and neglect</td>
<td>.284</td>
</tr>
<tr>
<td>Experience continuity and security</td>
<td>.276</td>
</tr>
<tr>
<td>Are safe</td>
<td>.192</td>
</tr>
</tbody>
</table>

n = 7,806
* All correlations are significant at the 0.05 level (2-tailed)
Bonding Social Capital

Five personal outcomes make up the Bonding factor. These outcomes are entry points for developing social capital. They are related to our current world and the people and places we already know. They represent the initiation of bonds that make social capital more likely. They are the glue that holds us together.

Bridging Social Capital

Three personal outcomes make up the bridging factor. They represent the connections we have to the world around us beyond the confines of who we already know, where we already go and what we already do. They represent potential for increased social ties and connections. They are the WD-40 of social interactions.

Social Capital Index

Measuring their collective value enables us to make inferences about the level of social capital for organizations, people and communities. These inferences from the social capital index can facilitate change at the organizational and community level.
Social Capital Index 1993 - 2014

- **1993-1998**: 61.6%
- **1999-2004**: 61.7%
- **2005-2009**: 64.3%
- **2010-2014**: 61.1%
- **All Years Average**: 61.1%

**Legend**:
- **SOCIAL CAPITAL INDEX**
- **BONDING SOCIAL CAPITAL**
- **BRIDGING SOCIAL CAPITAL**
Individual Level
• Information for the ISP
• Advocacy

Provider Level
• Local Quality Monitoring (w/BA)
• Trend Analysis
• Accreditation

State Level
• Aggregated Data for QA/QM
• Systems Learning and Monitoring
• CMS Reporting

All users will have enhanced data and information due to the new extended online data system.
MEASURING OUTCOMES

NEW ONLINE POM DATA SYSTEM

• Extended demographics section
  • Aligning with other national data efforts
• Increased data points to identify what – if anything – is causing outcomes and/or supports to be present or not
  • Moved from 42 variables to 250+ variables
• No changes to the existing structure of the POM interview
POM 1 - Natural Supports - Outcome Present by Hours of Support
(n= 72)

- **24/7 - Around the clock support**: Present (16), Not Present (2)
- **12 hours/day or more**: Present (14), Not Present (3)
- **6 to 12 hours/day**: Present (6), Not Present (4)
- **3 to 6 hours/day**: Present (6), Not Present (4)
- **0 to 3 hours/day**: Present (6), Not Present (4)
- **On call - supports as needed**: Present (4), Not Present (4)
- **Other, please specify**: Present (4), Not Present (4)
MEASURING OUTCOMES

NEW ONLINE POM DATA SYSTEM

POM 5 - Exercise Rights - Outcome Present by Hours of Support (n = 68)

- Independent Decision Making
- Supported Decision Making
- Limited Guardianship
- Full/Plenary Guardianship
- Other

Present
Not Present
## MEASURING OUTCOMES

### IN-DEPTH OUTCOME REVIEW

### People Exercise Rights

5.1 - Indicate whether the person exercises this right as a citizen?

<table>
<thead>
<tr>
<th>Right to Exercise</th>
<th>Yes</th>
<th>No</th>
<th>Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right to voice opinion</td>
<td>58 (80.6%)</td>
<td>14 (19.4%)</td>
<td>72</td>
</tr>
<tr>
<td>Right to vote</td>
<td>42 (61.8%)</td>
<td>26 (38.2%)</td>
<td>68</td>
</tr>
<tr>
<td>Right to move about the community</td>
<td>54 (78.3%)</td>
<td>15 (21.7%)</td>
<td>69</td>
</tr>
<tr>
<td>Right to associate with others</td>
<td>57 (81.4%)</td>
<td>13 (18.6%)</td>
<td>70</td>
</tr>
<tr>
<td>Right to practice their religion</td>
<td>53 (77.9%)</td>
<td>15 (22.1%)</td>
<td>68</td>
</tr>
<tr>
<td>Right to privacy</td>
<td>50 (73.5%)</td>
<td>18 (26.5%)</td>
<td>68</td>
</tr>
<tr>
<td>Right to access their possessions</td>
<td>58 (81.7%)</td>
<td>13 (18.3%)</td>
<td>71</td>
</tr>
<tr>
<td>Right to access food/refrigerator</td>
<td>45 (65.2%)</td>
<td>24 (34.8%)</td>
<td>69</td>
</tr>
<tr>
<td>Right to have visitors at any time</td>
<td>53 (75.7%)</td>
<td>17 (24.3%)</td>
<td>70</td>
</tr>
<tr>
<td>Right to access their money</td>
<td>46 (65.7%)</td>
<td>24 (34.3%)</td>
<td>70</td>
</tr>
<tr>
<td>Right for personal decision-making</td>
<td>48 (68.6%)</td>
<td>22 (31.4%)</td>
<td>70</td>
</tr>
<tr>
<td>Right to fair wages</td>
<td>35 (58.3%)</td>
<td>25 (41.7%)</td>
<td>60</td>
</tr>
<tr>
<td>Right to non-discrimination at work</td>
<td>45 (78.9%)</td>
<td>12 (21.1%)</td>
<td>57</td>
</tr>
</tbody>
</table>

5.1 – Who, if anyone, most limits the person’s ability to exercise this right?

<table>
<thead>
<tr>
<th>Right to Exercise</th>
<th>Guardian</th>
<th>Family</th>
<th>Provider org/sup port staff</th>
<th>Employer/colleague</th>
<th>Other</th>
<th>Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right to voice opinion</td>
<td>3 (14.3%)</td>
<td>2 (9.5%)</td>
<td>2 (9.5%)</td>
<td>6 (28.6%)</td>
<td>8 (38.1%)</td>
<td>21</td>
</tr>
<tr>
<td>Right to vote</td>
<td>6 (19.4%)</td>
<td>4 (12.9%)</td>
<td>8 (25.8%)</td>
<td>3 (9.7%)</td>
<td>10 (32.3%)</td>
<td>31</td>
</tr>
<tr>
<td>Right to move about the community</td>
<td>2 (7.1%)</td>
<td>5 (17.9%)</td>
<td>14 (50.0%)</td>
<td>2 (7.1%)</td>
<td>5 (17.9%)</td>
<td>28</td>
</tr>
<tr>
<td>Right to associate with others</td>
<td>5 (23.8%)</td>
<td>5 (23.8%)</td>
<td>7 (33.3%)</td>
<td>2 (9.5%)</td>
<td>2 (9.5%)</td>
<td>21</td>
</tr>
<tr>
<td>Right to practice their religion</td>
<td>4 (23.5%)</td>
<td>5 (29.4%)</td>
<td>3 (17.6%)</td>
<td>2 (11.8%)</td>
<td>3 (17.6%)</td>
<td>17</td>
</tr>
<tr>
<td>Right to privacy</td>
<td>10 (40.0%)</td>
<td>4 (16.0%)</td>
<td>9 (36.0%)</td>
<td>1 (4.0%)</td>
<td>1 (4.0%)</td>
<td>25</td>
</tr>
<tr>
<td>Right to access their possessions</td>
<td>9 (39.1%)</td>
<td>7 (30.4%)</td>
<td>6 (26.1%)</td>
<td>0 (0.0%)</td>
<td>1 (4.3%)</td>
<td>23</td>
</tr>
<tr>
<td>Right to access food/refrigerator</td>
<td>9 (33.3%)</td>
<td>3 (11.1%)</td>
<td>10 (37.0%)</td>
<td>2 (7.4%)</td>
<td>3 (11.1%)</td>
<td>27</td>
</tr>
<tr>
<td>Right to have visitors at any time</td>
<td>5 (25.0%)</td>
<td>3 (15.0%)</td>
<td>4 (20.0%)</td>
<td>2 (10.0%)</td>
<td>6 (30.0%)</td>
<td>20</td>
</tr>
<tr>
<td>Right to access their money</td>
<td>3 (10.3%)</td>
<td>3 (10.3%)</td>
<td>11 (37.9%)</td>
<td>2 (6.9%)</td>
<td>10 (34.5%)</td>
<td>29</td>
</tr>
<tr>
<td>Right for personal decision-making</td>
<td>11 (39.3%)</td>
<td>6 (21.4%)</td>
<td>4 (14.3%)</td>
<td>2 (7.1%)</td>
<td>5 (17.9%)</td>
<td>28</td>
</tr>
<tr>
<td>Right to fair wages</td>
<td>11 (39.3%)</td>
<td>2 (7.1%)</td>
<td>10 (35.7%)</td>
<td>2 (7.1%)</td>
<td>3 (10.7%)</td>
<td>28</td>
</tr>
<tr>
<td>Right to non-discrimination at work</td>
<td>2 (11.8%)</td>
<td>2 (11.8%)</td>
<td>3 (17.6%)</td>
<td>3 (17.6%)</td>
<td>7 (41.2%)</td>
<td>17</td>
</tr>
</tbody>
</table>
### People Experience Continuity & Security

<table>
<thead>
<tr>
<th>Response</th>
<th>Chart</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present</td>
<td><img src="chart.png" alt="Green Bar" /></td>
<td>54.1%</td>
<td>40</td>
</tr>
<tr>
<td>Not Present</td>
<td><img src="chart.png" alt="Red Bar" /></td>
<td>45.9%</td>
<td>34</td>
</tr>
</tbody>
</table>

**Total Responses:** 74
MEASURING OUTCOMES

ADDITIONAL RESOURCES

CQL Toolkit for States – CMS Reporting

www.c-q-l.org/cmstoolkit

20 Years of Personal Outcome Measures®

www.c-q-l.org/resource-library/publications

New Online POM Data System

www.c-q-l.org/data
DREW SMITH
CQL | Director of Research and Data
dsmith@thecouncil.org
www.c-q-l.org
Outcomes and Level of ID: A Closer Look

Valerie Bradley
HSRI President
Agenda

• National Core Indicators
• NCI Outcomes Measurement: Relationship of Level of ID to Outcomes
  ▪ How do outcomes differ for individuals with different levels of ID?
• Which indicators remain correlated through all levels of ID?
• Why is this important?
• Questions?
What are the National Core Indicators?
NATIONAL CORE INDICATORS (NCI)?

- NASDDDS – HSRI Collaboration
  - Multi-state collaboration of state DD agencies
  - Launched in 1997 in 6 participating states with a 15 state steering-committee – now in 42 states (including DC) and 22 sub-state areas

- Goal: Measure performance of public systems for people with intellectual and developmental disabilities
  - Help state DD systems assess performance by benchmarking, comparing to other states

- Assesses performance in several areas, including:
  - employment, community inclusion, choice, rights, and health and safety

- Now expanded to elderly and people with disabilities through the NCI-AD
NCI is a Person-Centered Tool that Provides Information on:

- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare
NCI State Participation 2014-15

42 states including the District of Columbia and 22 sub-state regions

- State contract awarded in 2014-15 through AIDD funding
- CA*: Includes 21 Regional Centers
- OH*: Also includes the Mid-East Ohio Regional Council
How Does NCI Collect Data?

• Adult Consumer Survey
  ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
  ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.

• Adult Family, Child Family, and Family/Guardian Surveys Mail surveys – separate sample from Adult Consumer Survey

• Other NCI state level data: Staff Stability
NCI Outcomes Measurement: Relationship of Level of ID to Outcomes
What are Outcomes and Indicators?

- **Outcomes:**
  - The changes for individuals or populations during or after participation in programs.
    - In the NCI context, outcomes include: choice, relationships, case management, inclusion, rights and respect, safety, etc.

- **Indicators:**
  - Ways to measure outcomes. Provides evidence that certain results have/have not been achieved.
    - For instance, the proportion of people who chose where they live; the proportion of people who can go on a date
NCI Outcomes Are Influenced by Level of Disability

- Past analyses have shown that the variable that measures level of ID is significantly related to outcomes.

- “[If this person is diagnosed with an ID], what level of ID?
  - _1 Mild ID
  - _2 Moderate ID
  - _3 Severe ID
  - _4 Profound ID
  - _5 Unspecified level of ID
  - _6 ID level unknown”
Level of ID
2013-14 Adult Consumer Survey Data Cycle
(N=15,525; 29 states & 1 sub-state entity)

Level of ID (N=13,144)
Residence, shown differently

Breakdown of Level of ID Within Each Residence Type

- **Institution**
  - Mild ID: 10%
  - Moderate ID: 15%
  - Severe ID: 19%
  - Profound ID: 57%

- **Community-based residence**
  - Mild ID: 35%
  - Moderate ID: 34%
  - Severe ID: 18%
  - Profound ID: 13%

- **Independent home/apartment**
  - Mild ID: 54%
  - Moderate ID: 23%
  - Severe ID: 11%
  - Profound ID: 1%

- **Parent/relative's home**
  - Mild ID: 41%
  - Moderate ID: 16%
  - Severe ID: 8%
  - Profound ID: 16%

- **Foster care/host home**
  - Mild ID: 35%
  - Moderate ID: 34%
  - Severe ID: 16%
  - Profound ID: 15%

- **Other**
  - Mild ID: 30%
  - Moderate ID: 15%
  - Severe ID: 15%
  - Profound ID: 5%

**National Core Indicators (NCI)**
Examples: Outcomes Vary by Level of ID

**Paid Community Job**

- Mild ID: 26%
- Moderate ID: 14%
- Severe ID: 5%
- Profound ID: 2%
- NCI Average: 16%

**Has Friends Who Are Not Family or Staff**

- Mild ID: 77%
- Moderate ID: 76%
- Severe ID: 69%
- Profound ID: 64%
- NCI Average: 76%
Examples: Outcomes Vary by Level of ID

Individual Had At Least Some Input in the Following Choices

- Chose Home
- Chose Roommates
- Chose Staff
- Chose Daily Schedule
- Chose Freetime
- Chose Day Activity
- Chose What to Buy
- Chose Case Manager

Levels: Mild ID, Moderate ID, Severe ID, Profound ID
Which indicators remain correlated through all levels of ID?

- Looked at inter-relatedness of all indicators.
  - Correlation matrix
- Identified indicators that were significantly related to other indicators
  - And significance persisted for all levels of ID
- This means that these indicators *may be* outcome predictors
Which indicators demonstrate a high number of correlations through all levels of ID?

- **Relationships:**
  - Can go on date with or without restrictions
  - Has best friend
  - Can see friends when wants to
  - Has opportunities to help others

- **Access & Service Coordination**
  - CM/SC asks what you want
  - Always has a way to get places
  - Staff have needed training

- **Choice**
  - All variables

- **Community Inclusion Scale**
Caveats

• This is a preliminary analysis
• Other demographic characteristics may have more of an influence on outcomes. Needs more investigation
  ▪ Residence type
  ▪ State of residence
  ▪ Mobility
  ▪ Preferred means of expression
• States are moving away from a “mild, moderate, severe, profound” measurement system towards a more functional assessment of disability.
Why is this important?

• Indicates need for further research:
  ▪ Focusing on outcomes for all individuals who receiving services may miss areas for improvement for segments of population
What did she say?
Contacts

• Valerie Bradley: vbradley@hsri.org

• NCI website: www.nationalcoreindicators.org