Nuts and Bolts of PBE Research: Experiences from the Field

Panel Organizers:
Michelle Demore-Taber, ScD, LRC, CBIS
Laura Lorenz, PhD, MEd

Brain Injury Association of Massachusetts Annual Conference
March 24, 2016
Learning Objectives

Following the workshop, participants will be able to:

• Describe how a PBE research program can inform decision-making and quality of care;

• Engage colleagues in discussing benefits, challenges, and strengths related to developing a PBE research program in their setting;

• Identify ways to integrate PBE into local programming and quality improvement efforts.
Outline for Today’s Panel

• Sean Clark, PhD: *Practical approaches to collecting data*

• Therese O’Neil-Pirozzi, ScD, CCC-SLP: *Establishing a database to maintain and store research data*

• Kathee Jordan, DHA, MEd: *How we will link with the Massachusetts Health Information Highway*

• Hebatallah Naim, MD, MS: *Collecting and analyzing costs and return on investment*

• Sindi Samayoa, MS: *Brain injury outcomes and translating evidence to practice: MPAI-4*
What is PBE “research”? 

- PBE “research” means using programmatic data, routinely collected, to develop credible evidence for decision-making.
- PBE research is a practical alternative method to randomized controlled trials (RCTs).
- Practice-based evidence can:
  - Verify if treatment produces desired outcomes.
  - Allow providers to make better decisions.
  - Provide aggregate data to state policymakers.
Why is PBE needed?

The Problem

- Shift to Payer Driven Model
- Poor Public Policy
- Lack of Industry Data

Reduced Access to Care

The Solution

Develop Data Plan
- Identify Project Goals
- Identify Tools
- Identify Collection Processes
- Ensure Data Security

Collect & Manage Data
- Collect Data
- Identify Research Questions
- Analyze Data
- Publish Results
- Develop Benchmarks

Advocate for Access to Services
- Develop Care Standards
- Change Public Policy
- Impact legislation
- Shift away from Payer Driven model

Increase Access to Care

Murphy, 2015 ACRM
The Evidence Hierarchy

Systematic reviews and meta analyses
Randomised controlled trials
Cohort studies
Case-control studies
Cross-sectional surveys
Ecological studies
Case series and case reports
Ideas, editorials and opinions

Source: Millbank Memorial Fund, Center for Evidence-Based Policy, Feb 10, 2016
Collaboration Options

• Establish a *brain injury registry* for Massachusetts.

• Use *OutcomeInfo*, a national database developed with Phase I and Phase II STTR grants from NINDS. It is now a subscription service.
  
  – If interested in learning more, contact: Thomas Murphy, TMurphy@inventivesoftware.net

• Use *Netsmart* to benchmark outcomes.
  
  – If interested in learning more, contact: Ross Merritt, rmerritt@ntst.com

• Use *Mass Health Information HiWay* – to share data across healthcare providers to support transfers and care. Visit: [www.mass.gov/hhs/masshiway](http://www.mass.gov/hhs/masshiway)

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Elements for Success

• Registry or other data collaborations need to use a secure, web-based system that allows organizations to:
  
  • **Access their data** and information at anytime
  
  • **Compare** their data with state or national averages (Collaborative Reports) which reflect de-identified data for similar populations
  
  • **Save time and money**
  
  • **Access findings** that can impact decision-making to improve quality, adjust programming and services, determine policy
  
• **Imperative:** Use standardized measures and collect them systematically
Two Sources of Vetted Measures

• NINDS CDE (National Institute for Neurological Disorders and Stroke, Common Data Elements):
  – For TBI: https://commondataelements.ninds.nih.gov/tbi.aspx#tab=Data_Standards
  – For Stroke: https://commondataelements.ninds.nih.gov/Stroke.aspx #tab=Data_Standards
  – Also available for other neurological conditions

• COMBI (Center for Outcome Measures in Brain Injury): http://www.tbims.org/combi/
### Some Suggested Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
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<tbody>
<tr>
<td>MPAI-4</td>
<td>Mayo-Portland Adaptability Index -4</td>
</tr>
<tr>
<td>ABS/BIAF</td>
<td>Agitated Behavior Scale/Behavior Identification Assessment Score</td>
</tr>
<tr>
<td>CRS</td>
<td>JFK Coma Recovery Scale</td>
</tr>
<tr>
<td>DRS</td>
<td>Disability Rating Scale</td>
</tr>
<tr>
<td>SRS</td>
<td>Supervision Rating Scale</td>
</tr>
<tr>
<td>SWLS</td>
<td>Satisfaction With Life Scale</td>
</tr>
<tr>
<td>WHO-QOL Brief</td>
<td>World Health Organization – Quality of Life (QOL)</td>
</tr>
<tr>
<td>EuroQOL</td>
<td>Self-report QOL for Economic/Cost-effectiveness Analysis</td>
</tr>
</tbody>
</table>
In Conclusion...

• Practice-based evidence can inform providers, organizations, and policy

• Ideally, groups of providers can agree on common measures to collect, how to collect them (e.g., dedicated staff), and when (frequency)

• Data on consumer perspectives are also needed – how collect and incorporate them?
Our Panelists...

Have organized their presentations using a standard outline (for the most part!):

- **What** - they are doing to collect and use standardized measures
- **Purpose(s)**
- **Challenges**
- **Supports**
- **Utilization**
- **Best Practices/Recommendations**

- Each presentation will be about 10 minutes
- Please save your questions for the end
Sean Clark, Ph.D.

*Practical approaches to collecting data*

Dr. Clark is Professor and Department Chair at Gordon College and Director of the Gordon College Center for Balance, Mobility and Wellness.
Center for Balance, Mobility, and Wellness

- Outpatient physical therapy for individuals with neurological, vestibular, and balance and gait disorders
- Membership-based fitness and wellness program for individuals 50 years of age and older
- Select programs
  - Fall-proof / Fall-prevention
  - Community Wellness Program (Parkinson’s)
  - Functional Fitness and Wellness Program (TBI)
Center for Balance, Mobility, and Wellness

- Photo of people working out at center (not included here due to file size – will be in actual slides)
Program and Activities

• Program Details
  – Ten week program, meets twice a week, each session is approximately one hour

  – Activities include
    • Stretching
    • Aerobic fitness and endurance
    • Strength training
    • Agility and coordination
    • Balance and mobility
Assessment & Data Collection

– Information of interest
  • Aerobic fitness and endurance
  • Functional performance
  • Muscular strength

– Is the program effective in producing change in the level of functional fitness and wellness of the participants?
When Collected – and By Whom

• Collect measures on the initial and final sessions of the program
  – Exercise log for each fitness session

• Assessments performed primarily by the Center’s fitness manager
  – Assisted by student interns and volunteers
Individual Adjustments

• Individualized assessment
  – “Framework” for measurements
  – Dependent on the physical ability of each participant

• Aerobic fitness and endurance
  – One-mile walk test
  – 6-minute walk test (or modified 3-minute)
  – NuStep recumbent stepper
Types of Measures

• Functional Performance Measures
  – 30-second sit-to-stand
  – Berg Balance Scale

• Muscular Strength
  – Lower body
    • Seated, single-leg press
  – Upper body
    • Biceps curl, seated/standing rows
How Are Assessments Useful?

• Assessments have been helpful for
  – Evaluating individual changes across the 10 weeks
  – Identifying areas for improvement in programming

• Challenges
  – Heterogeneity of the population
  – Identifying most appropriate assessment tests
  – Training for test administration
Next Steps for Data Collection

• Moving Forward
  – Reevaluate assessment measures
  – Consider mid-program assessment
  – Provide assessment-specific training for student interns and volunteers
Establishing a database to maintain and store research data

Dr. O’Neil-Pirozzi is Associate Professor at Northeastern University and Associate Project Director for the Spaulding/Harvard TBI Model System.
Considerations

- Purpose of the Research
- Challenge of Balancing Security & Accessibility
- $ and Time
- ITS Support
Database Options

• Excel
• Custom-built Database
• Confluence
• JIRA
Kathleen Jordan, DHA, MEd

How We Will Link with the Massachusetts Health Information Highway

Dr. Jordan is the Senior Vice President/Chief Program Officer of Seven Hills Foundation, a $200 million integrated health and human services agency supporting children and adults in Massachusetts and Rhode Island.
Seven Hills NeuroCare

• Seven Hills has a long history of service to people with ABI in community-integrated residences, a continuum of day services, transitional assistance, recreational, and outpatient psychiatric services.

• Seven Hills currently supports individuals through the ABI/MFP HCBS waiver through our day support, adult family care, and supported employment programs

• 7 ABI ResHab homes in Central, Southeastern and Northeastern Massachusetts, supporting consumers with ABI; four additional ABI homes are currently in development.

• Seven Hills supports an additional 21 individuals with brain injury in other residential programs
SH NeuroCare Home
Key Partnerships: Key To Success

• UMass Medical Neuropsychology Department consults on the clinical supports required.

• Dr. Ricciardi, Clinical Director, has developed intake and assessment tools which are aligned with skill development and quality of life measures.

• Seven Hills’ integrated team includes Certified Brain Injury Specialists, addiction therapists, certified co-occurring treatment specialists, psychiatrists, psychotherapists, medical doctors, neuropsychologists, neurologists, assistive technology specialists and allied health professionals.
TIER: Electronic Medical Record

- People with ABI leaving long-term care settings accumulate a great deal of records (although it doesn't always arrive right away!).

- We have found that our TIER system (EMR) helps us store and retrieve these records quickly and allows accessibility across a range of staff levels and roles.

- We also employ a process for summarizing the record, and storing a print-on-demand summary in our electronic record system; this allows us to quickly train staff, transfer information to other providers; and ensures that multiple care providers are operating on the "same page".

- Additionally, our electronic records system is updated with each provider appointment, medication change, and specialist consult, making information/changes available to program staff as well as medical/clinical specialists.
How Do We Use Data?

• All staff providing services should have rapid access to health information (history, course, current neuropsychological challenges, support strategies)—often this information remains accessible to specialists, but not pushed down to the floor level

• Understanding the details may require specialists to provide "staff friendly" summaries of this information

• Staff are more likely to be coordinated in care when they share an understanding of history and current concerns.
Measuring Outcomes

• Providers’ Council partnered with Netsmart Technologies in 2013 to bring benchmarking to its membership

• Benchmarking is available in four service areas:
  – Intellectual and Developmental Disabilities
  – Children and Families
  – Mental Health
  – Addiction Services

• Valuable metrics relevant to the field of behavioral health and human services: financial, clinical, operational, and organizational climate

• Reports provide subscribers with robust comparisons to other agencies and organizations

• Plus, includes access to Organizational Climate Survey:
  – 25 items, anonymous staff survey with questions about: Relationships among Co-workers, Recognition and Growth, Leadership, Compensation and Benefits, Physical Environment, Quality, Satisfaction
# Category Breakdown

<table>
<thead>
<tr>
<th>Service Level</th>
<th>Description</th>
<th>Intervention Required</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 1</strong></td>
<td>Total Supportive Care and Intensive Staff Oversight</td>
<td>24 hour care to meet the individual’s particular medical, behavioral, and/or safety needs</td>
<td>Medically-directed care 24/7 including community-based group living, Intermediate Care Facilities, Nursing Care, Medical Day Treatment and supports</td>
</tr>
<tr>
<td>Total Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Category 2</strong></td>
<td>Extensive Supportive Care and/or Constant Staff Oversight</td>
<td>6 to 24 hours of care daily to ensure safety and the individual habilitation needs and desires of the individual</td>
<td>Group Community Housing (not medically directed); Community-based day programs; Staffed apartment programs</td>
</tr>
<tr>
<td>Comprehensive Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Category 3</strong></td>
<td>Regular Supports and/or Close Staff Oversight</td>
<td>More than 6 hours/day (and less than 56 hours per week) of supports or intervention required</td>
<td>Shared living supports, Organizational employment, Respite Care; Assistive Technology supports; Behavioral consultation services</td>
</tr>
<tr>
<td>Moderate Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Category 4</strong></td>
<td>Limited Supports and/or staff assistance</td>
<td>More than 1 but Less than 6 hours/day of supports or intervention required</td>
<td>Supported Living (i.e 6 or more hours/weekday of supports); Employment planning services; Community integration services; Personal supports</td>
</tr>
<tr>
<td>Limited Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Category 5</strong></td>
<td>Infrequent staff assistance or supports</td>
<td>Less than 6 hours per week of supports or intervention required</td>
<td>Supported living with less than 6 hours per week of staff support; Independent Living; Self-determined community supports; Service/Care coordination; Self-employment assistance; Benefits planning services</td>
</tr>
<tr>
<td>Infrequent Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

RESEARCH PROGRAMS
### Sample Report

#### IDD Dashboard - Example Organization

**Time Frame: 2014 Q1 - 2015 Q1**

<table>
<thead>
<tr>
<th>Metric</th>
<th>Rct Qtr Value</th>
<th>Overall Rank</th>
<th>Rct Qtr Rank</th>
<th>Overall</th>
<th>Same Qtr - Prev Year</th>
<th>Compare to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Physician Identified</td>
<td>100.0%</td>
<td>1 (of 8)</td>
<td></td>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Physical Health Exam</td>
<td>100.0%</td>
<td></td>
<td>1 (of 9)</td>
<td>9.7%</td>
<td>0.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Dental Health Exam</td>
<td>100.0%</td>
<td></td>
<td>1 (of 9)</td>
<td>9.2%</td>
<td>0.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Participation in Wellness Program</td>
<td>55.0%</td>
<td>2 (of 5)</td>
<td></td>
<td>9.6%</td>
<td>-45.0%</td>
<td>50.0%</td>
</tr>
</tbody>
</table>

**OSHA Incident Rate**

- Number of Weeks Employed (Provider Paid): 100.0
- Average Hourly Rate of (Provider Paid): 8.0
- Average Number of Hours Worked (Provider Paid): 100.0
- Average Number of Weeks Employed (Community Paid): 8.0
- Average Hourly Rate of (Community Paid): 8.0
- Average Number of Hours Worked (Community Paid): 8.0

**Financial Metrics**

<table>
<thead>
<tr>
<th>Metric</th>
<th>Value</th>
<th>Rct Qtr Rank</th>
<th>Overall</th>
<th>Same Qtr - Prev Year</th>
<th>Compare to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Ratio</td>
<td>4.5</td>
<td>1 (of 6)</td>
<td></td>
<td>4.0%</td>
<td>4.5</td>
</tr>
<tr>
<td>Days Cash on Hand</td>
<td>71.3</td>
<td>1 (of 8)</td>
<td></td>
<td>13.5%</td>
<td>71.3</td>
</tr>
<tr>
<td>Net Margin Percent</td>
<td>4.7%</td>
<td>2 (of 6)</td>
<td></td>
<td>-26%</td>
<td>8.0%</td>
</tr>
<tr>
<td>Payer Mix % Medicaid</td>
<td>40.0%</td>
<td>4 (of 5)</td>
<td></td>
<td>-20%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Payer Mix % Commercial/Private</td>
<td>3.0%</td>
<td>4 (of 5)</td>
<td></td>
<td>-28%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Payer Mix % Government Grants/Contracts</td>
<td>0%</td>
<td>2 (of 6)</td>
<td></td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Payer Mix % Foundation/Private Grants</td>
<td>100%</td>
<td>4 (of 5)</td>
<td></td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Payer Mix % Other</td>
<td>1.0%</td>
<td>4 (of 5)</td>
<td></td>
<td>-5.5%</td>
<td>1.0%</td>
</tr>
</tbody>
</table>

#### RESEARCH PROGRAMS
# Sample Report

## Addiction Benchmarking Report

### Overall Organization

<table>
<thead>
<tr>
<th>Sample Size</th>
<th>Standard Deviation</th>
<th>Mean</th>
<th>Median</th>
<th>Current Score</th>
<th>Overall Percentile</th>
<th>Setting: Drug and Alcohol Provider</th>
<th>Geographic: Rural</th>
<th>Budget: Over $10M</th>
<th>Previous 08/30/2012 Score</th>
<th>Overall Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>OPERATIONAL BENCHMARKS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

1) Access - Days Between Date of First Contact and Initial Assessment | 08/30/2012
82 | 7.19 | 7.59 | 5.54 | 2.99 | 19.22 ▲ | 19.15 ▲ | 18.29 ▲ | 18.75 ▲ | 2.30 | 15.39 |

2) Subsequent Access - Days Between Initial Assessment and First Scheduled Treatment Session | 08/30/2012
49 | 8.38 | 8.40 | 7.00 | 8.18 | 79.17 ▼ | 82.27 ▼ | 70.67 ▼ | 96.17 ▼ | 8.47 | 79.17 |

### Length of Stay Residential Short-Term

3) Residential Short-Term Length of Stay - Adult | 08/30/2012
93 | 13.90 | 25.22 | 23.45 | 20.44 | 57.14 | 59.73 | 52.25 | 59.04 | 18.04 | 23.81 |

4) Residential Short-Term Length of Stay - Youth | 08/30/2012
48 | 13.27 | 33.39 | 32.74 | 34.86 | 33.33 | 32.86 | 32.75 | 34.37 | 30.68 | 16.67 |

5) Residential Short-Term Length of Stay - Adult/Youth | 08/30/2012
93 | 13.97 | 25.81 | 23.51 | 18.55 | 22.73 | 18.04 | 21.81 | 22.23 | 23.76 | 59.09 |
Why Does This Matter??

• MANAGED CARE!
• Benchmarking is one of the most potent and under-utilized management tools available
• New demands being placed on providers. Be part of the discussion instead of having outcomes forced on you!
• Vital external context to identify your organization’s areas of strength and areas for improvement and drive efficiencies
• Connect with organizations to identify and share best practices
• Provides objective data to justify agency initiatives and supports culture of data-driven solutions
Hebatallah Naim, MD, MS/IHPPM

Collecting and analyzing costs and return on investment

‘Heba’ is a Ph.D. Student at the Heller School for Social Policy and Management, Brandeis University. Her research focuses on policies aiming to mainstream people with disability into the community and support their caregivers.
Supportive Living’s Program

We all want to live with independence, relationships, and meaningful things to do...

With high-quality community services & supports we all can...

Image source: http://www.supportivelivinginc.org/
Supportive Living, Inc.

• Supportive Living provides housing and collaborates with Advocates to provide standardized supported independent living services for adults with chronic moderate-to-severe ABI.

• Supportive Living aims to provide person-centered care that fosters opportunities for residents to:
  o be independent
  o interact with each other, other people, and the community
  o participate in meaningful activities.
Research Tracks at Supportive Living

- Physical Fitness
- Cognitive Fitness
- Social Fitness
- Policy & Management
Partnerships: Key To Success

Heller graduate students, advised by Dr. Donald Shepard and Dr. Lorenz, are conducting a comparative cost-effectiveness analysis of different interventions and their impact on Health-Related Quality of Life (HR-QoL) outcomes for Supportive Living residents.

Hyosin Kim, MA
Mayada Saadoun, MS

Advocates

House Managers & Direct Care Staff!

BRANDEIS UNIVERSITY

The Heller School
FOR SOCIAL POLICY AND MANAGEMENT

RESEARCH PROGRAMS
Cost-Effectiveness Analysis

- **Costs**: both direct and indirect for each intervention. Comparison groups are assigned based on their participation in the studied intervention.

- **Self-Reported HR-QoL**, using EuroQOL with a sample of Supportive Living and Waiver residents (N=37).

- **Mayo-Portland brain injury outcomes data** – MPAI-4 (baseline and post-intervention).

- **Demographic data** for the sample

- **Interventions**: Participation in Physical Fitness Training, Day Programs, Recreation activities, and Support Groups.
Challenges

1. Data Collection:
   - IRB: Brandeis and DDS approval
   - Primary data: EQ survey
   - Secondary data: Residents’ records
   - Cost data: Revenues & expenditures per group home and per resident

2. Data Inference:
   - Adjust the demographic (age, etc), physical and psychological limitations for each resident.
   - Acknowledge the role of the background story
   - Account for confounders: transportation, motivation, volunteers
Support

• **Existing research/data infrastructure:**
  ✓ Database of demographic info and BI-specific outcomes (MPAI-4) for several years – and approval of cross-organizational access
  ✓ Motivated teams, administration
  ✓ Research Council at Supportive Living

• **Technical and methods support**
  ✓ Heller School professors, faculty advisors

• **Grants**
  ✓ Open Society Foundation
  ✓ Other philanthropic donors
Best Practices/Recommendations

➢ Use standardized measures: NINDS CDE, COMBI
➢ Record Demographic, Costs, Participation data
➢ Regular recording
➢ Share and compare
Sindi Samayoa, MS

Brain injury outcomes and translating evidence to practice: MPAI-4

Sindi is Senior Director of Quality Management for Brain Injury Services at Advocates. Sindi became involved in Supportive Living’s research program in 2011 as an intern on the Pilot Transition Study while pursuing a Master’s in Rehabilitation Counseling at UMASS Boston.
Advocates- Brain Injury Services

• Advocates strives to assist individuals with chronic acquired brain injury (ABI) to become members of the communities they live in and to participate in these communities.

• The Brain Injury Services division currently supports 59 individuals in its community-based homes located in Woburn, North Reading, Lexington, Framingham, Rockport, and Paxton.

• Projected growth for 2016 includes opening four new Waiver-funded group homes.
CARF International Recommended...

• Administering an outcomes tool specific to brain injury. Advocates first administered MPAI-4 in 2011.

• Using findings to evaluate and re-evaluate an individuals’ function over time.

(CARF International = Commission on Accreditation of Rehabilitation Facilities)
What Is MPAI-4?

- A standardized tool used to understand long-term outcomes of ABI. Advocates administers annually.
- The tool has 29 items in 5 domains: physical, cognitive, emotional, behavioral, and social.
- The tool has 3 indices: Ability, participation, and adjustment. Each generates a “t score” based on a consensus evaluation of resident function by 2 staff.
- Higher t scores indicate deterioration of function; lower t scores indicate improvement in any given year.
- Scores of 50-60 on any index indicates moderate to severe limitations compared with other people with ABI; scores between 30-40 suggest mild limitations.
# Use of MPAI-4 Data – Then and Now

<table>
<thead>
<tr>
<th>Past Use</th>
<th>Current Use</th>
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<tbody>
<tr>
<td>Compared the level of community participation among residents in different group homes.</td>
<td>Staff are using MPAI-4 data in annual PCSP and ISP meetings to discuss and refine residents’ goals for the coming year.</td>
</tr>
<tr>
<td></td>
<td>MPAI-4 data are providing vital outcomes data for studies investigating the impact of different programs and policies.</td>
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</table>
MPAI-4 Data and Research Initiatives

• Used to measure efficacy and cost-effectiveness of the fitness program started at the BI Wellness Center in Lexington.

• Used to compare efficacy and cost effectiveness of different service models funded by public sources. (Analysis is ongoing – stay tuned!)
Challenges and Recommendations

• MPAI-4 is used by Advocates as a staff rating of observed function.

• Measures that gauge residents’ perspectives are also needed. Advocates has initiated an annual “experience” survey and report.

• Advocates administers MPAI-4 annually based on admission and PCSP evaluation date. Staggered administration can pose challenges to analysis.

• MPAI-4 requires organizational investments in tool administration and analysis of findings.

• Identifying ways to utilize the data and findings is ongoing.
Wrap Up and Q&A