The Importance of Measuring Outcomes in PBIS Organizations Serving Individuals with I/DD

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Goals

• To understand how effective and efficient data collection can lead to more achievable goals and improved outcomes.
• To analyze incident data to assess program-wide progress, identify problem areas and action plan for improvement.
• To identify and use data collection tools to assess individual progress and quality of life indicators.
MEASURING OUTCOMES AT THE MAY INSTITUTE

Bob Putnam
Erin McDermott
Kevin Donohue
• Large behavior analytical organization with a sixty-five year history serving individuals with autism/IDD
  – Serving 330 individuals in five private schools
  – Serving 542 adult individuals in day and residential services across 120 homes and 5 day habilitation programs
  – Providing center-based services to young children with ASD
  – Providing PBIS consultation to schools and agencies
• Serving primarily individuals with moderate to severe IDD with challenging behavior
• Many who are limited communicators
• Built an **electronic** incident reporting system focusing on protective holds (PH) and physical escorts (PE) in 2014 called May Institute Data Analysis System (MIDAS) to answer the following queries
  – How many PHs and PEs per month?
  – Where do they occur?
  – When do they occur?
  – Which individual?
  – What time?
Total Physical Management

Year of Incidence

Number of Incidents

Month

2019

Number of Incidents:

- January: 14
- February: 24
- March: 19
- April: 19
- May: 16
- June: 33
- July: 47
- August: 33
- September: 20
- October: 33
- November: 10
- December: 32

2020

Number of Incidents:

- January: 7
- February: 4
- March: 1
- April: 1
- May: 1
- June: 1
- July: 1
- August: 1
- September: 1
- October: 1
- November: 1
- December: 1

May Institute
By Individual

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<thead>
<tr>
<th>Quarter</th>
<th>January</th>
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Tier 3 Outcomes

- 21 individuals
- 7 females, 14 males
- Diagnoses of ASD and other developmental disabilities
  - Some have mental health and psychiatric diagnoses
- All attend and/or live in May Institute day and residential programs
Percent of Individuals Responding to Tier 3 Intervention

- **Aug-13**
  - Non-Responder: 24%
  - Partial Responder: 48%
  - Responder: 29%

- **Sep-15**
  - Non-Responder: 10%
  - Partial Responder: 40%
  - Responder: 50%

Legend:
- Red: Non-Responder
- Yellow: Partial Responder
- Green: Responder
Percent of Tier 3 Target Behaviors Improving

- 13-Aug: 45%
- 15-Sep: 65%
Total Protective Holds

Year 1: 40
Year 2: 6

85%
There are four major health issues that are common among individuals with intellectual and developmental disabilities (IDD) residing in congregate care settings or in community based residential settings. These health issues, commonly referred to as “The Fatal Four”, include aspiration, dehydration, constipation, and seizures.
Fatal Four – Aspiration

• Tier 1
  – Screening & Assessments
  – General training for direct care and select admin employees on:
    • Signs and symptoms of swallowing issues, aspiration and choking (which can lead to aspiration)
    • 911 protocol
    • First Aid training
  – Provision of standardized tools/blenders (Vitamix) with related-training at all programs which must process foods into specific textures. (Per organization practice, any blender present on-site must be a specific Vitamix model which is designed for commercial use and is known to be very durable.)
Fatal Four – Aspiration

- Tier 2
  - Modified Diets & Dining Protocols
  - Implementation of dining protocols at Day Habilitation Programs (now being extended/rolled out to residences and schools)

- Tier 3
  - Evaluation by Specialist for Specific Issues
  - Individual-specific dining protocols obtained and followed when necessary
  - Detailed training on individual-specific needs and diets for direct care employees
  - 911 Protocol
Aspiration Events

Total Incidents by Month

<table>
<thead>
<tr>
<th>Month</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
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<tr>
<td>Jan</td>
<td>1</td>
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Average Incidents:
- 2018: 1.5
- 2019: 1.5
- 2020: 1.5

Fatal Risk:
- Aspiration/Choking
Quality of Life – Assessment

- Essential for Living – A communication, behavior and functional living skills curriculum and assessment.
- Screening for all individuals served to determine communication and behavioral functioning
National Core Indicators (NCI) is used across states to assess the quality and outcomes of Developmental Disability (DD) services provided to individuals with IDD and their families.

NCI offers valid, reliable, person-centered measures that states use to demonstrate how publicly funded supports are impacting people’s lives and to determine where they can improve the quality of those supports.

A total of 46 states and the District of Columbia participated in NCI in 2016-17.
<table>
<thead>
<tr>
<th>Survey Type</th>
<th>May Survey Question</th>
<th>May</th>
<th>NCI</th>
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<tbody>
<tr>
<td>Individual</td>
<td>Do you get to spend time alone?</td>
<td>94.0%</td>
<td>95.0%</td>
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<td>Do staff treat you with respect?</td>
<td>92.1%</td>
<td>91.0%</td>
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<td>Are you given choices?</td>
<td>90.8%</td>
<td>88.0%</td>
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<td>Do you get to spend time in the community with other people?</td>
<td>86.2%</td>
<td>81.0%</td>
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<td>Overall are you happy with your home/program?</td>
<td>97.0%</td>
<td>86.0%</td>
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<td>Parent/Guardian</td>
<td>Do you feel that your family member/dependent is receiving the services as planned?</td>
<td>92.9%</td>
<td>89.0%</td>
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<td>Are you satisfied that your family member/dependent gets the services he/she needs?</td>
<td>85.7%</td>
<td>79.0%</td>
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<td>Are you satisfied with the opportunities you are given to provide input into your family member/dependent's treatment/service plan?</td>
<td>92.9%</td>
<td>84.0%</td>
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<td>Do you have a clear understanding of what the May Center provides for your family member/dependent?</td>
<td>92.9%</td>
<td>79.0%</td>
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<td>Are you satisfied that services/supports are available when needed, even in a crisis?</td>
<td>85.2%</td>
<td>60.0%</td>
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THANK YOU!

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