The Periodic Risk Evaluation: 
A Tool for Identifying Risk and Service Needs among Adults with Autism

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Pennsylvania’s Office of Developmental Programs
Pennsylvania leads the nation: first to map out models of service for adults with autism
System Opening Up

Services for individuals with autism who also have ID

Services for adults with autism with or without ID

Services for individuals of all ages who have autism, with or without ID

pennsylvania DEPARTMENT OF HUMAN SERVICES
Peer-reviewed research conceptualizes autism risk in a different way...
SIS and its use for people with Autism Spectrum Disorders

The Supports Intensity Scale may be a useful tool for planning teams interested in identifying support needs of people with Autism Spectrum Disorders (ASD). The same support needs assessment and planning process outlined in the SIS User’s Manual, that is, using the SIS in conjunction with person-centered planning, is recommended. It is important to understand that the norm-referenced SIS Support Needs Index (i.e., the overall score) is based on a population of people with intellectual disabilities and related developmental disabilities. This population overlaps, but does not consume the population of persons with ASD. Please note that there are no separate norms for people with ASD. Also, for those people with autism whose intellectual functioning is higher and therefore whose social communication abilities are higher, SIS would not be as appropriate a tool to determine support needs.
Periodic Risk Evaluation (PRE): Why?

- Need to systematically identify risk and need for additional services and supports
- Informs planning and operational processes
- Shortage of available tools to identify risk and mitigation strategies
- Few options predict risk
- Fewer options for adults with autism
Clinician-identified domains:

1. Law enforcement
2. Risk of harm to self and others
3. Stressful life events
4. Unstable living environment
5. Natural supports
6. Substance abuse
7. Co-occurring mental health diagnoses
8. Chronic medical conditions
Structural Priorities

Maximize mutual exclusivity to optimize analytics

- Chronic medical conditions do not include mental health conditions
- Risk of harm to self or others not related or leading to law enforcement contact

Validate and qualify elected responses for analysis and service planning

- Type of law enforcement contact (police called, arrested, probation/parole)
- Specific mental health/physical diagnoses (ADHD, diabetes)
PRE: The Tool
PRE Creation: Scoring/Weighting

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PRE Testing

- BAS programs with ~850 enrollees
- PRE administered at intake, annually, and at change of risk

**Step 1.**
BAS Clinical Expert blind rates individuals based on 'complex' status at regular intervals

**Step 2.**
Establish testing groups

**Step 3.**
Identify scoring cut point for implementation

**Group A:**
- 80% of sample
  - Establish scoring optimization

**Group B:**
- 20% of sample
  - Test scoring optimization
## Initial Results

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity</td>
<td>64%</td>
</tr>
<tr>
<td>Specificity</td>
<td>91%</td>
</tr>
<tr>
<td>Positive Predictive Value</td>
<td>72%</td>
</tr>
<tr>
<td>Negative Predictive Value</td>
<td>88%</td>
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</table>
PRE Dissemination

Periodic Risk Evaluation (PRE)
Training Manual

Periodic Risk Evaluation (PRE):
INDIVIDUAL SUPPORT PLAN (ISP)

FREQUENTLY ASKED QUESTIONS

Question: Is there a specific timeframe to complete the PRE?
Answer: Yes, the PRE should be completed within 15 business days of the date the ISP is signed.

Question: Who is responsible for completing the PRE?
Answer: The PRE should be completed by the Supports Coordinator or the person providing the services to the individual. If no one is available, a member of the treatment team may complete it.

Risk Domain: Law Enforcement
Risk Domain: Risk of Harm to Self or Others
Risk Domain: Unstable Living Environment
Risk Domain: Natural Supports
Risk Domain: Substance Use
Risk Domain: Chronic Medical Conditions
Risk Domain: Stressful Life Events

ISP Section: General Health
ISP Section: Crisis Support
ISP Section: Physical Assessment

PERIODIC RISK EVALUATION (PRE):
FULL RISK MITIGATION CYCLE

Recognize:
The PRE is one of several components used to recognize risk. It is used in conjunction with ISP assessments, risk monitoring, incident report analysis, and participant/family member and provider feedback.

Evaluate:
Evaluate the effectiveness of the risk mitigation plan and continue to monitor risk factors during quarterly treatment meetings or more frequently at provider meetings. The PRE can be completed again if a new risk is present and again annually at the

Assess:
The PRE informs assessment based on whether concerns were identified as mild, moderate, or severe in the different domains. Risk factors are verified as present and severity of risk is determined.
PRE Refinement

- Opportunities for item reduction
- Scoring modifications
- Continued development of resources
- New groups for adaptation

Bayesian Additive Regression Tree (BART)
Preliminary Outcome Data
PRE Submissions Across Role

- Behavioral Specialist
- Supports Coordinator
- Other
Occurrences Across Domains

- Law Enforcement
- Harm Self/Others
- Unstable Living
- Natural Supports
- Substance Use
- Chronic Medical
- Stressful Life
- Mental Health

Baseline vs. Annual
<table>
<thead>
<tr>
<th>Variable</th>
<th>Importance Rank</th>
<th>Highest Score Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk of harm to self/others history/frequency</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Chronic medical history/frequency</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Family supports are harmful</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Unstable living environment history/frequency</td>
<td>4</td>
<td>2.5</td>
</tr>
<tr>
<td>Law enforcement engagement history/frequency</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Stressful life events history/frequency</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Risk of harm to self/others level of concern</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Stressful life events concern</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Unstable living environment level of concern</td>
<td>9</td>
<td>2.5</td>
</tr>
<tr>
<td>Sexual abuse or exploitation</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Seizures present</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Ongoing law enforcement interaction</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Co-occurring mental health condition concern</td>
<td>13</td>
<td>0</td>
</tr>
</tbody>
</table>
Risk of Harm to Self/Others: History/Frequency

- No history of behaviors
- Recent high intensity (3 or more incidents in the last 2 years)
- Recent lower intensity (2 or fewer incidents in the last 2 years)
- Remote (2 or more years ago)

Baseline vs. Annual
Individual Case Presentation
Meet Brandon

• Enrolled: October 2013
• 30 years old
• Works part-time at 2 jobs
• Lives independently
• Excellent musical talent, attended a film camp, contributes to local magazine, loves sports,
• Currently receives Behavioral Support Services, Systematic Skill Building, Community Supports, Counseling,
• 7th SC in 5 years
Before PRE was first administered

- Took 6 months to get initial plan approved
  - Paranoia for who would see plan, resistant to completing assessments
- 5 SCs, at least 2-3 Behavioral Specialists, and multiple Community Support staff
  - Some he fired, others left on their own
- Reactive approach
  - Survival mode, no consistency
- No clear understanding of critical needs
  - Poor communication among team members
- No contact with family (Brandon’s choice)
- BAS pulled in occasionally (usually for crisis management)
PRE Administration

- **Baseline**: February 2017
- **Annual**: August 2017 and August 2018
Brandon

Domain Presence

<table>
<thead>
<tr>
<th>Domain</th>
<th>Evident During Baseline</th>
<th>Evident During Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Law Enforcement</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Harm Self/Others</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Unstable Living</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Natural Supports</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Substance Use</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Chronic Medical</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Stressful Life</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Mental Health</td>
<td>yes</td>
<td>no</td>
</tr>
</tbody>
</table>
Brandon- History/Frequency

- Law Enforcement
- Harm Self/Others
- Unstable Living
- Natural Supports
- Substance Use
- Stressful Life

Comparison of recent, high intensity, recent, low intensity, remote, and none across different conditions.

Baseline History/Frequency and Annual History/Frequency.
Brandon - Severity

Baseline Severity | Annual Severity

- Severe persistent
- Moderate persistent
- Mild persistent
- Mild intermittent

Chronic Medical | Mental Health
Brandon- Maintenance

- Baseline- Maintenance
- Annual- Maintenance

- No tx or therapy
- Inconsistent tx or therapy
- Consistent tx or therapy

Chronic Medical
Mental Health
Brandon - Ongoing?

- Law Enforcement
- Harm Self/Others
- Unstable Living
- Natural Supports
- Substance Use
- Stressful Life

Baseline - Ongoing: yes
Annual - Ongoing: yes

Baseline - Ongoing: no
Annual - Ongoing: no
What changed for Brandon?

- PRE served as an objective point of context
- Team Communication more effective
  - regular meetings, SC took the lead, strong Behavioral Specialist, BAS oversight, defining roles and responsibilities
- Team began prioritizing needs- low hanging fruit before more complex
- Mindfully worked with Brandon to build skills
Adaptations & Limitations
Adaptations

Need to **pilot** to account for population and intent beyond the current model/tool

Recommendations:

- Determine clinical relevance of domains
- Solicit feedback
- Review with statistician
- Collect pilot data
- Design process for use of the data/score/information
- Continuous analysis for optimal scoring/tool
Limitations

• Monitoring outcomes:
  Providers identify domains in participants plans, but lack mitigation plans

• Change to processes:
  Original intent to assign administrative leads changed due to lack of global buy in

• Technology:
  We are using a platform not typically designed for a tool like this, which has made parts of the analysis tedious

• Only applies to a certain population:
  This was implemented for two programs for adults with Autism in PA

• No other risk tool like this exists:
  We are providing technical assistance while also trying to update resources and processes