What Do NCI Data Show About Adults Who Need Support for Self-Injurious Behavior?

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Agenda

• Background
• What is NCI?
• What do the data show?
• Research/policy considerations
Background

• Self-injurious behavior (SIB)
  ▪ Self-inflicted harmful behavior that can result in injury and cumulative physical damage

• For people with ID/DD
  ▪ Affect health, QoL
  ▪ May make it difficult to be in inclusive settings
    • Can lead to social isolation and anxiety
    • Poses caretaking challenges on families
Background (cont.)

• Approaches to supporting people with SIB
  ▪ Aversive and painful interventions
  ▪ Restraints

• Functional Analysis
  ▪ Determining cause of behavior
    • Pain, communication barriers, etc.

• Positive Behavior Supports (PBS)
The National Core Indicators: A quality and outcomes survey

• NASDDDS, HSRI & State DD Directors
  ▪ Multi-state collaboration, launched in 1997 in 6 participating states – now in 46 states (including DC) and 22 sub-state areas

• GOAL: Measure performance of public systems for people with ID/DD by examining outcomes

• Domains:
  • Employment
  • Community inclusion
  • Choice
  • Rights
  • Health
  • Safety
  • Relationships
  • Service satisfaction etc.
NCI Adult Consumer Survey (ACS)

Random sample of adults who receive services regardless of setting

• Background Information Section
  ▪ Data from agency records or information systems
  ▪ Includes info on need for behavior support for SIB

• Section I
  ▪ Individual satisfaction; no proxy allowed

• Section II
  ▪ Fact-based objective questions; proxy allowed
2015-16 ACS Sample

Please identify the level of support the person needs to manage any of the types of behavior listed below.

**BI-55 Self-injurious behavior**

Refers to attempts to cause harm to one’s own body; for example, by hitting or biting self, banging head, scratching or puncturing skin, ingesting inedible substances, or attempting suicide.

- 1 No support needed
- 2 Some support needed; requires only occasional assistance or monitoring
- 3 Extensive support needed; frequent or severe enough to require regular assistance
- 99 Don’t know

Valid responses to this Q for 15,581 individuals in non-institutional settings
What do the 2015-16 NCI Adult Consumer Survey data tell us about people who need support for SIB?

Analysis Notes
• Does not include respondents living in institutional settings
• Averages are not “average of state averages” (as in NCI reporting) but averages of all respondents
• Differences shown are significant at the p<=.001 level
Demographics and Personal Characteristics
Need some or extensive support for SIB (N=15,581)

- Needs some or extensive support for SIB, 23.2%
- Does not need support for SIB, 76.8%
State Variation in Rate of Individuals Needing Support for SIB

Average, 23.2% of respondents need some/extensive support for SIB
Those with SIB support needs... more likely to have severe or profound ID (N=15,301)

<table>
<thead>
<tr>
<th>ID Level</th>
<th>No need for support</th>
<th>Need for some or extensive support</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A- no ID label</td>
<td>6.1%</td>
<td>4.3%</td>
</tr>
<tr>
<td>Mild ID</td>
<td>27.0%</td>
<td>40.3%</td>
</tr>
<tr>
<td>Moderate ID</td>
<td>29.8%</td>
<td>29.7%</td>
</tr>
<tr>
<td>Severe ID</td>
<td>10.5%</td>
<td>18.9%</td>
</tr>
<tr>
<td>Profound ID</td>
<td>6.4%</td>
<td>13.0%</td>
</tr>
<tr>
<td>Unspecified level</td>
<td>6.1%</td>
<td>6.3%</td>
</tr>
<tr>
<td>ID level unknown</td>
<td>0.9%</td>
<td>0.6%</td>
</tr>
</tbody>
</table>
More likely to be diagnosed with mental health diagnoses

- **Mood disorder (N=14,665)**: 27.4% need support
- **Anxiety Disorder (N=14,522)**: 21.5% need support
- **Behavior Challenges (N=14,660)**: 17.9% need support
- **Psychotic Disorder (N=14,503)**: 18.4% need support

Bar chart showing the percentage of individuals needing support for different mental health diagnoses.
More likely to be diagnosed with ASD, seizure disorder/neuro problem; less likely to have diagnosis of Down syndrome

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>No need for support</th>
<th>Need for some or extensive support</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD Diagnosis (N=14,673)</td>
<td>13.4%</td>
<td>29.8%</td>
</tr>
<tr>
<td>Seizure Disorder/Neurological Problem (N=14,781)</td>
<td>27.2%</td>
<td>34.2%</td>
</tr>
<tr>
<td>Down Syndrome (N=14,750)</td>
<td>11.0%</td>
<td>5.4%</td>
</tr>
</tbody>
</table>

National Core Indicators (NCI)
Less likely to prefer to communicate through spoken word; more likely to use gestures/body language (N=15,457)

- Spoken: 83.3% (68.4% no need for support, 12.9% need for some or extensive support)
- Gestures/body language: 25.1%
- Sign language/ finger spelling: 3.1%
- Communication aid: 0.9%
- Other: 2.5%
Less likely to live in own home or with parent/relatives (N=14,325)

- Group residential setting (e.g., group home): 31.2% need support, 51.4% no need
- Own home or apartment: 22.9% need support, 45.9% no need
- Parents/relatives home: 45.9% need support, 31.4% no need

National Core Indicators (NCI)
Of note...

• No significant differences
  ▪ In level of mobility
  ▪ For those with hearing impairments

• Slightly significant difference in self-perceived health status
  ▪ Those with SIB support needs were slightly more likely to report being in poor health
Outcomes
Those with SIB support needs express lower satisfaction

- Likes where lives (N=10644): 90.2% with no need for support, 87.6% with some or extensive support.
- Want to live somewhere else (N=10349): 24.8% with no need for support, 29.2% with some or extensive support.
- Goes to day program or workshop (N=10464): 57.2% with no need for support, 61.6% with some or extensive support.
- Would like to go to day program/workshop less (N=5622): 14.8% with no need for support, 18.0% with some or extensive support.

No need for support | Need for some or extensive support
---|---
90.2% | 87.6%
24.8% | 29.2%
57.2% | 61.6%
14.8% | 18.0%
Less positive outcomes in the domain of relationships

- Has friends who are not family or staff (N=10430): 78.6% need some or extensive support, 72.9% no need for support
- Need more help to make friends or keep in contact with friends (N=9886): 43.0% need some or extensive support, 47.8% no need for support
- Have other ways of communicating with friends when they cannot see them (N=8987): 81.5% need some or extensive support, 77.1% no need for support
- Can communicate with family when wanted (N=9804): 86.8% need some or extensive support, 80.5% no need for support
- Can date without restrictions, or is married/living with partner (N=8447): 71.0% need some or extensive support, 64.0% no need for support
- Often feel lonely (N=10188): 10.1% need some or extensive support, 13.7% no need for support
... the domain of community inclusion, participation and leisure

![Bar chart showing percentages of individuals with and without support in different domains.](chart.png)

- Can go out and do the things likes to do (N=10274): 86.1% with no need for support, 83.3% need for some or extensive support.
- Has enough things likes to do at home (N=10364): 83.5% with no need for support, 81.1% need for some or extensive support.
- Participates in community groups and/or activities (N=14440): 38.9% with no need for support, 35.9% need for some or extensive support.
Person had at least some input in choosing ...

- Home (N=8386): 64% No need for support, 47% Need for some or extensive support
- Who lives with (N=8251): 53% No need for support, 37% Need for some or extensive support
- Staff (N=13596): 73% No need for support, 67% Need for some or extensive support
- Daily schedule (N=14739): 87% No need for support, 80% Need for some or extensive support
- What to do in free time (N=14741): 94% No need for support, 90% Need for some or extensive support
- Day activity (N=10655): 70% No need for support, 57% Need for some or extensive support
- What to buy with spending money (N=14633): 90% No need for support, 83% Need for some or extensive support
- Case manager (N=14092): 72% No need for support, 68% Need for some or extensive support
- Job (N=2382): 87% No need for support, 79% Need for some or extensive support

Legend: No need for support, Need for some or extensive support.
And were less likely to have a paid, community-based job

Had paid, community-based job in the past two weeks (N=14840):
- No need for support: 20.7%
- Need for some or extensive support: 11.1%

Had unpaid, facility-based activity in the past two weeks (N=14603):
- No need for support: 35.6%
- Need for some or extensive support: 40.9%

Community employment is goal in service plan (N=14891):
- No need for support: 31.1%
- Need for some or extensive support: 22.9%

National Core Indicators (NCI)
Considerations for future research

• Identify system components that are related to better outcomes
  • Person-centered planning, Employment First policies, positive behavior supports
• What is the impact of other demographic/personal characteristics on outcomes for people with SIB support needs?
  ▪ Do the presence of other factors have influence on outcomes for individuals with SIB support needs?
Considerations for public policy

- Standardized construct to facilitate accurate assessment of SIB
- Policy can reinforce the importance of functional assessment of adults with SIB; these assessments are critical to identifying potential causes and consequences of the behavior
- States can look at adoption of evidence-based practices such as positive behavior supports
- Necessitates training and education of those who implement the support
Considerations for public policy (continued)

• States can review state policy regarding behavior plans
• Public managers can look at their policies regarding aversive treatments
• States can also work to develop and maintain high standards regarding qualification, training, and quality assurance of those who provide support for SIB
• States can work to expand family supports (e.g., quality crisis and respite care)
What did she say?

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Positive Behavior Support: South Carolina Department of Disabilities and Special Needs

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Why Did South Carolina DDSN Decide to Implement PBS?

• Focus Group Results
  ▪ What training do you need to do your job better?

• Frequent Requests for Assistance
  ▪ Requests for alternative residential placement based on behavioral needs

• Complaints about quality of behavioral services and some behavioral providers
Why Did South Carolina DDSN Decide to Implement PBS Cont’d

- Advancements in Professional Practices (PBS)

- The motivation was “How Can We Improve the Quality of Behavior Supports in the South Carolina DDSN System?”

- There was (and is) no involvement from the Department of Justice and no lawsuit related to behavior supports.
How Was the Plan Developed?

• Collaboration between DDSN and the USC Center for Disability Resources (UCEDD/Rotholz).

• Task Force on How to Improve the Quality of Behavior Supports
  - Behavior Analyst, family member, community behavioral provider, clinical supervisor, community residential coordinator, DDSN training coordinator, pharmacy director (DDSN), psychology director for residential center, program director, direct support professional supervisor.
What Did the Plan Propose?

- Coordinated effort across the areas of:
  - Paradigm Shift to PBS
  - Capacity related to behavioral and psychiatric services
  - Training
  - Provider Qualifications
  - Quality Review specific to behavior supports
Quote from Rotholz & Ford (2003)

• It is a simple task to provide examples of existing literature on behavior support. It is considerably more difficult to point to widespread implementation of these methods at the local level or systems that promote and support them (p. 355).
A Lesson Learned . . .

- “There is a considerable difference between recommendations and the actual implementation of efforts . . . The recommendation that training be provided differs considerably from the process of securing funding, developing a request for proposals, selecting a contractor, collaboratively developing a curriculum, and implementing competency-based training for hundreds of staff persons throughout South Carolina” (p. 356).
How Was the Plan Operationalized?

- Implementation Workgroup
  - Training
  - Qualifications
  - Provider Applicant Approval/Enrollment
  - Quality Assurance
Training

• For Supervisors of DSPs
  - AAIDD PBS Training Curriculum
    • Editions 1 - 3
    • Follow up course to train local trainers

• For Behavior Support Plan Authors
  - University Based
  - Began as 3-course sequence, evolved into full BACB approved 6-course sequence
    • 2 years before QA process implemented
Qualifications & Approval Process

• Revision of Medicaid Waiver, creation of Behavior Support Service

• Interview and Work Sample required
  ▪ 2 year approval status
  ▪ CEU requirement
Quality Assurance

- Originally based on 13 criteria (from Medicaid Waiver service) and conducted by DDSN and CDR faculty/staff
- Revised to 6 standards with operationalized guidance and weighted scoring
  - Conducted by contracted BCBA-Ds trained to inter-rater reliability on standards and guidance
Challenges and Adaptations

• Legal
  ▪ 2 lawsuits – none lost
  ▪ Medicaid administrative appeals on removal from provider list – none lost

• Political
  ▪ Legislative Audit Council review focused on DDSN included a few items on Behavior Supports approval process
Changes Over Time

- Added skills check for local PBS trainers
- Interviews as part of qualification process
- Screening of applications
- Revision of criteria --> standards (2014)
- Discontinuation of interviews
- New QA process based on 2014 standards
Outcomes

• Process and Provider Outcomes
  ▪ Process (partial examples)

  • QA reviews show that required components are part of the service provided.
  
  • Functional Assessment (with competing behavior pathways diagram)
  
  • Replacement Behavior (objective & graph)
  
  • Observation-based fidelity checks
Other States Models

Minnesota

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Missouri

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Implementing Multi-Tiered Systems of Support - Minnesota

Positive Behavior Support

**Tertiary Stage**
- Individualized PBS Plans
- Integrated with Other Positive Supports (PCP, Trauma-Informed Care, DBT, Etc.)
- Plans Are Monitored - Data-Based Decision Making
- Teams Monitor Progress of Each Person

**Secondary Stage**
- Early Intervention and Data Monitoring
- Additional Supports for Key Social Skills
- Function-Based Decisions
- Simple Interventions
- Mental Health and Wellness Interventions

**Universal Stage**
- Teach and Encourage Communication
- Predictable and Proactive Settings
- Encourage and Reinforce Social Skills
- Consensus-Based Team Focus
- Emphasis on Using Data For Decisions

**Positive Behavior Support**

**Person-Centered Practices & Planning**

**Organizational Workforce**
Implementing Multi-Tiered Systems of Support
Minnesota

Person-Centered Practices & Planning

**Tertiary Stage**
- In Depth Person-Centered Plans
- Integrated Plans (PCP, PBS, Trauma-informed Therapy)
- Teams Monitor Plan Progress

**Secondary Stage**
- Monitor PCT Action Plans
- Additional Quality of Life Strategies
- Increase Strategies for Supporting Independence and Community Involvement
- Mental Health and Wellness Interventions

**Primary Stage**
- Universal Person-Centered Strategies
- Encourage Self Expression
- Self-Determination and Choice Making
- Meaningful Participation in the Community
Implementing Multi-Tiered Systems of Support - Minnesota

Organizational Workforce Development

Tertiary Stage
• Tailor Problem Solving for Specific Problematic Situations
• Individualize Training and Mentoring to Address Unique Settings Where Problems Occur
• Improve Supervision and Mentoring for Locations Experiencing Challenges
• Establish Matching/Hiring Tailored to Individualized Plans

Secondary Stage
• Monitoring and Early Intervention
• Training Targeted for Groups
• Targeted Strategies to Improve Specific Settings
• Simple Problem Solving for Challenging Situations That Occur in More Than One Situation

Universal Stage
• Align Policies to Person-Centered Practices
• Revise Job Descriptions, and Performance Evaluations
• Integrate Person-Centered Practices and PBS With New Orientation and Ongoing Instruction
• Use Data for Decision Making
Missouri’s Tiered Supports Vision is strategy implementation at the level of the service provider of each of the levels of prevention.
MO-DD Tiered Supports state-level implementation mirrors the PBS School-wide model at Tier 1 Level of Prevention

**Mo DDD Tiered Organization-wide Model**
- State wide Coordinator
- Regional Resource Teams
- Organization-wide teams (Agency teams)
- Unit of implementation = Agency
- System of Recognition of implementation
- Trainings designed for Implementation phases
- Agency systems and support evaluation tools (ASSET)
- Incident reports
- Organization-wide Improvement data, e.g. Positive-Negative Interaction ratios

**Mo School-wide Model**
- State-wide Coordinator
- Regional Consultants
- School-wide teams
- Unit of Implementation = School Building
- System of Recognition (Bronze, Silver Gold)
- Training designed for implementation phases
- School systems and supports evaluation tool (SET)
- Office referrals
- School-wide Improvement Data

**Practices**
- Agency team – designs and implements Universal Strategies including Staff Interactions skills (Tools of Choice), and teaching and recognizing Life Values

**Data**
- School Team designs implementation of school wide Tier 1 and 2 strategies
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