Characteristics and Outcomes of People with ID/DD Who Need Support for Self-Injurious Behavior:

A Research and Policy Agenda

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Agenda

- Background
- What is NCI?
- What do the data show?
- Research/policy considerations
We’re invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up.

Participant – Surgeon General’s Conference on Health Disparities and Mental Retardation 2001
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


Prevalence Estimates

• Estimates of the prevalence of SIB within the population of adults with ID/DD
  ▪ vary widely -- differences in assessment methods, sampling strategies, and specific populations
• Rojahn et al. (2007) meta analysis
  ▪ US and UK
  ▪ in both community settings and institutions
  ▪ found that estimated rates of SIB ranged from 4% to 9%.
• Emerson et al. (2001)
  ▪ UK study found that 4% of the sample of individuals with ID receiving services in a variety of venues were reported to exhibit SIB.
• Population with a diagnosis of autism, estimates range from 33% to 71% (Richards et al. 2012)


Approaches to supporting people with SIB

- Functional Analysis
- Determining cause of behavior
  - Pain, communication barriers, etc.
- Positive Behavior Supports (PBS)
  - Aversive and painful interventions
  - Restraints

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
  - Random sampling at the state level, public reporting of aggregate, state-level findings

- 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

Bradley, V., Hiersteiner, D., Bonardi, A. 2016 A Focus on Systems-Level Outcome Indicators in Cross-Cultural Quality of Life (ed. Schalock, R and Keith, K.)
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
NCI Adult Consumer Survey (ACS)

- Minimum of 400 interviews per year (participating states).
- Random sample of adults who receive services regardless of setting.
- State-to-state comparison of results possible within a 95% statistical confidence level (5% margin of error).
- States may oversample in order to secure valid stratified intrastate results (e.g., for inter-regional comparisons).
- Statistical methods are employed to control for differences in consumer characteristics across the states.
- National and state level data reports are publicly available.
NCI Adult Consumer Survey (ACS)

- **Standard survey/interview instrument.** States may not modify the basic project instrument and administration protocols. A state may add questions to address additional topics.

- **Face-to-face structured conversation** with individuals plus the collection of **background information** (health conditions) from records.

- Obtains information directly from adults with developmental disabilities
  - Assesses whether the services they receive result in valued outcomes in support of **system-wide quality improvement activities**.

- Proxy allowed for portion.
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-injuruous 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 public reports) 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)
More likely to be diagnosed with mental health diagnoses

- Mood disorder (N=14,665): 27.4% with no need for support, 45.9% with need for some or extensive support
- Anxiety Disorder (N=14,522): 21.5% with no need for support, 38.6% with need for some or extensive support
- Behavior Challenges (N=14,660): 17.9% with no need for support, 67.2% with need for some or extensive support
- Psychotic Disorder (N=14,503): 10.1% with no need for support, 18.4% with need for some or extensive support
More likely to be diagnosed with ASD, seizure disorder/neuro problem; less likely to have diagnosis of Down syndrome.
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, 25.1% need for some or extensive support)
- Gestures/body language: 12.9% (1.6% no need for support, 2.5% need for some or extensive support)
- Sign language/finger spelling: 1.3% (3.1% no need for support, 0.9% need for some or extensive support)
- Communication aid: 0.9% (0.9% no need for support, 0.9% need for some or extensive support)
- Other: 1.6% (2.5% no need for support, 0.9% need for some or extensive support)

National Core Indicators (NCI)
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, 17.2% no need.
- Parents/relatives home: 45.9% need support, 31.4% no need.
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% No need for support, 87.6% Need for some or extensive support
- Want to live somewhere else (N=10349): 24.8% No need for support, 29.2% Need for some or extensive support
- Would like to go to day program/workshop less (N=5622): 14.8% No need for support, 18.0% Need for some or extensive support
Less positive outcomes in the domain of relationships

- Has friends who are not family or staff (N=10430): 78.6% (No need for support) vs. 72.9% (Need for some or extensive support)
- Need more help to make friends or keep in contact with friends (N=9886): 43.0% (No need for support) vs. 47.8% (Need for some or extensive support)
- Have other ways of communicating with friends when they cannot see them (N=8987): 81.5% (No need for support) vs. 77.1% (Need for some or extensive support)
- Can communicate with family when wanted (N=9804): 86.8% (No need for support) vs. 80.5% (Need for some or extensive support)
- Often feel lonely (N=10188): 10.1% (No need for support) vs. 13.7% (Need for some or extensive support)
... the domain of community inclusion, participation and leisure

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

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

Categories:
- 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%
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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