Emergency Room Visits and Unexpected Hospitalizations Among Adults with IDD and Co-Occurring Mental Health Conditions

Findings from the NCI-IDD In-Person Survey, 2023–24

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Agenda

1 · Why this question — ER visits and unexpected hospitalizations among adults with IDD

2 · Data and methods

3 · Findings — ER visits, unexpected hospitalizations, GERD, and preventive care

4 · Which groups had higher rates

5 · What may explain the patterns — medications and residential settings

6 · What states and provider agencies can do

7 · Limitations and next steps

NCI-IDD In-Person Survey (IPS)



Sampling: States design their samples to be representative of their service population

Inclusion criteria:

IDD: Person receiving at least one service in addition to case management

Consent: Those who are surveyed are informed that their services will not be impacted directly by their responses

Surveyor training: All surveyors complete standardized training. IPS uses peer-surveyors as well.

Survey features: Flexible administration modes/methods

2023–24 sample · NCI-IDD IPS

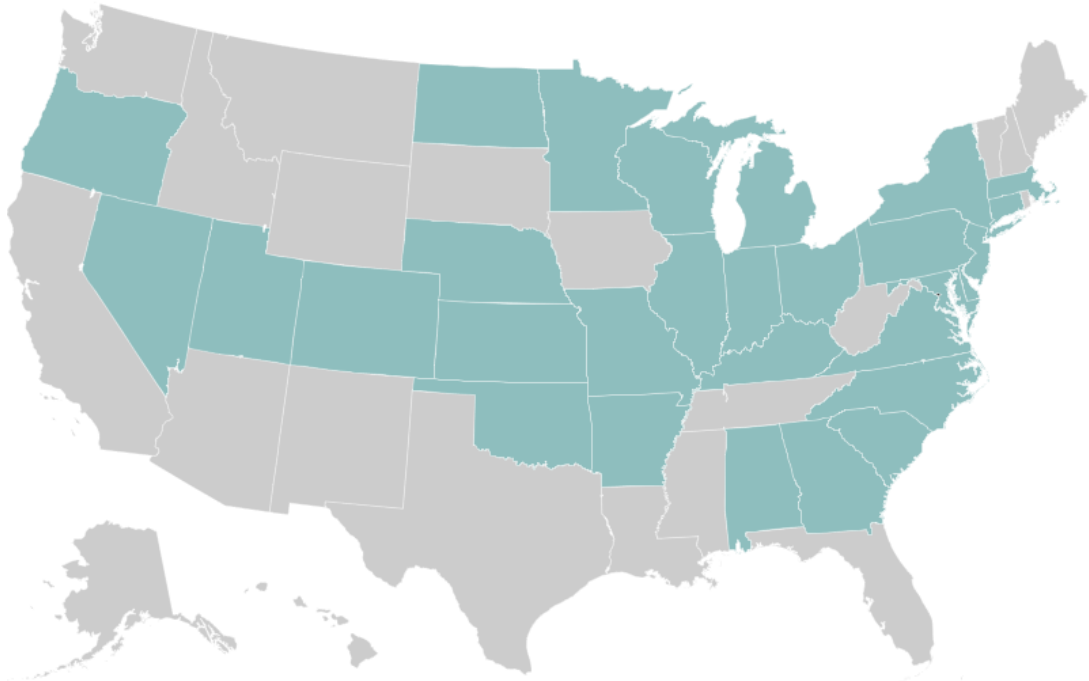
17,585
adults receiving state IDD services

30
participating states

42.5
average age

60%
male

Race/ethnicity: 72% White · 19% Black · 6% Hispanic or Latino
Diagnosis: 86% ID · 30% ASD



Participating states shown in teal

Gaps in coordinated care for adults with IDD and co-occurring mental health conditions

Among adults receiving state IDD services, do those with a reported mental health (MH) condition visit the ER or have unexpected hospitalizations more often than those without — and which groups are most affected?

49%

have a reported mental health (MH) condition

At least one mood, anxiety, psychotic, or other mental health diagnosis appears in the state record.

Prior research

Adults with IDD have higher emergency department use and longer ED stays than the general population (Lunsky et al., 2011; 2012).

Why it matters

Adults with IDD and co-occurring mental health conditions are served by two systems — IDD services and mental health services — that do not always coordinate well.

Source: NCI-IDD In-Person Survey 2023–24; companion NCI data brief on IDD and co-occurring mental health conditions. Citations: Lunsky Y et al., Am J Emerg Med 2011;29(4):463–5; Lunsky Y et al., Can J Psychiatry 2012;57(10):601–7.

Data and methods

Outcomes come from two sources: the survey (ER visits) and state administrative records (hospitalizations). The MH / no-MH comparison is record-based. Models adjusted for measured differences.

01 **Sample**

17,585 adults receiving state IDD services in the 2023–24 NCI-IDD In-Person Survey.

02 **Co-occurring group**

Any mood, anxiety, psychotic, or other mental health diagnosis in the state record.

03 **Outcomes**

ER visit in the past 12 months (survey) and unexpected hospitalization for five conditions (state records).

04 **Analysis**

Logistic models adjusted for age, gender, race/ethnicity, guardianship, metro residence, residence type, and proxy response for ER; state-clustered standard errors.

Denominator note: percentages use all adults in each group; "No" may mean no diagnosis is on file.

Finding 1 · ER visits were more common in the co-occurring group

ER VISIT IN THE PAST 12 MONTHS

WITH A REPORTED MH CONDITION

32.3%

visited the ER
n = 2,500

WITHOUT A REPORTED MH CONDITION

26.3%

visited the ER
n = 2,428

ADJUSTED RESULT

aOR 1.16

95% CI 1.08–1.25. p < .001

In plain language: compared with peers without a reported MH condition, adults with IDD and a co-occurring MH condition had 16% higher odds of an ER visit in the past 12 months. The association remained after adjustment.

Absolute difference: 6.0 percentage points

Source: NCI-IDD In-Person Survey 2023–24. Denominator: all adults in each group.

Finding 2 · Unexpected hospitalizations were uncommon in both groups

ANY OF FIVE TRACKED CONDITIONS

With MH	Without
6.4%	4.0%

aOR 1.30 · 95% CI 0.89–1.90
Not statistically significant

The overall gap did not remain after demographic and residence-type adjustment.

Five conditions tracked

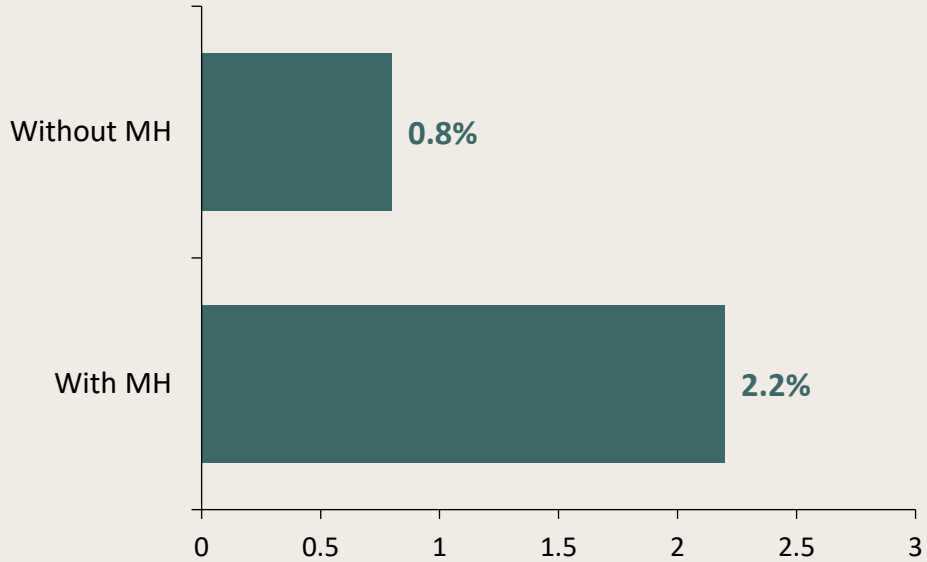
- Dehydration
- Bowel obstruction
- Seizure
- Aspiration
- **GERD**

GERD was the only significant exception.

Source: NCI-IDD In-Person Survey 2023–24. Hospitalization items come from state administrative records.

Finding 3 · GERD hospitalizations were more than twice as common

GERD hospitalization, % of all adults in group



173 adults with MH vs **78 adults** without

ADJUSTED ODDS RATIO

1.94

95% CI 1.15–3.27 · p < .05

The only one of the five tracked conditions where the adjusted difference remained significant.

Small absolute numbers; interpret with caution.

Source: NCI-IDD In-Person Survey 2023–24

Finding 4 · Across the full sample, higher ER use despite similar or higher preventive care

Adults with and without a reported co-occurring condition received preventive care at similar rates.

ROUTINE PREVENTIVE-CARE MEASURES

Physical exams	Dental visits	Vision exams	Hearing tests
Similar or slightly higher	Similar or slightly higher	Similar or slightly higher	Similar or slightly higher

No preventive-care difference was statistically significant after adjustment; utilization was similar or slightly higher in the co-occurring group.

Source: NCI-IDD In-Person Survey 2023–24

Which groups had higher rates?

Three adjusted patterns stood out — two for ER visits, one for unexpected hospitalizations.

Where people live mattered most

Residence type was the strongest predictor of ER visits — higher in ICF/IIDs, group settings, and own homes than with family.

STRONGEST SIGNAL

Age drove hospitalizations

Adults aged 55 and older had the highest rates of unexpected hospitalization for any of the five tracked conditions.

Gender and race differed modestly

For ER visits, women had higher rates than men (aOR 1.14), and White respondents higher than respondents of other races (aOR 1.19).

Source: NCI-IDD In-Person Survey 2023–24. Adjusted models; all adults in the sample.

Looking more closely at GERD: what may explain the signal?

What may explain the GERD signal?

•Published studies link GERD with antidepressants, antipsychotics, and sedatives.
•NCI research documents high psychotropic use in ICF/IID and group residential settings.
•Medication and residence patterns warrant closer state-level review.

These data do not establish why GERD hospitalizations were higher.

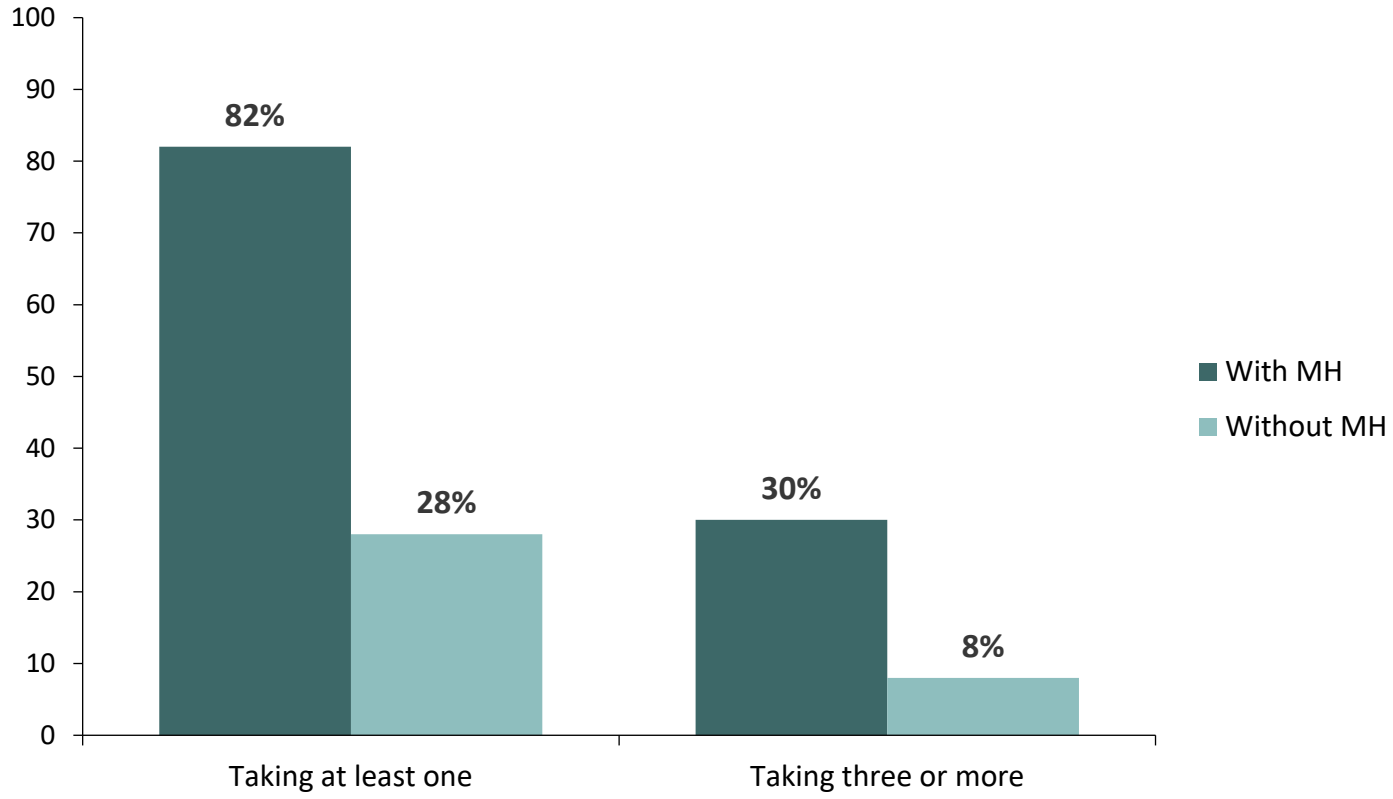
A possible contributor: high psychotropic medication use

82% of adults with a reported MH condition take at least one mental health medication, and 30% take three or more — compared with 28% and 8% of adults without a reported MH condition.

High psychotropic use is one plausible pathway to GERD — detailed on the next slide.

Jansson 2007; Martín-Merino 2010; Crouse 2018; Lagergren 2000; Houseworth 2024; Erickson 2022; Houseworth 2023.

Mental health medication use



Why it matters for GERD

Published studies link GERD with antidepressants, antipsychotics, and sedatives.

NCI research documents high psychotropic use in ICF/IID and group residential settings.

Medication and residence patterns warrant closer state-level review.

Source: NCI-IDD In-Person Survey 2023–24. Jansson 2007; Martín-Merino 2010; Crouse 2018; Lagergren 2000; Houseworth 2024; Erickson 2022; Houseworth 2023.

Using NCI data for advocacy: the exit ramp

NCI data can show where a pattern exists. They cannot, on their own, identify the root cause or prescribe the solution.

1. **Reveal the pattern**
   Use consistent indicators across states and years.

2. **Ask what may explain it**
   Bring together state data, providers, people with lived experience, and families.

3. **Consider more than one response**
   Match the response to the local system and setting.

4. **Track whether things change**
   Use the same indicators over time.



National pattern → state conversation → local action

Four questions states can ask with their own NCI data

1

How do ER-visit rates compare across residence types?

Nationally, residence type was the strongest predictor.

2

What are our GERD hospitalization rates—and how is psychotropic medication reviewed?

Include PRN (as needed) medications and review frequency.

3

Do direct support professionals have what they need when a change occurs?

Consider staffing levels and after-hours clinical guidance.

4

How are the IDD and mental health systems coordinating?

The ACL Link Center offers technical assistance, training, and resources.

Every NCI-IDD state collects the ER-visit and hospitalization items.

What these data can—and cannot—tell us

These are descriptive associations—not causal explanations.

Limitations

Mental health status comes from state records — “No” may mean not on file.

The ER item is yes/no — it does not capture frequency or reason.

Hospitalization items cover five conditions only.

GERD admissions are rare — small-number caution applies.

Next steps

Share the NCI-IDD data brief with state partners.

Examine ER and GERD rates by residence type within states.

Link psychotropic medication counts to acute-care outcomes.

Use Medicaid claims to confirm patterns and capture additional events.

Track both indicators across survey years.

Key takeaways

32.3% vs 26.3%

ER visit in the past 12 months

aOR 1.94

GERD hospitalization

Residence type

Strongest predictor of ER visits

Adults with IDD and a reported mental health condition visit the ER more often and have more GERD-related admissions, while receiving preventive care at similar rates.

Thank you · Questions?

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