STUDY 2:
COUNT STUDY: NEXT STEPS

THE PREVALENCE STUDY:
DEFINITION OF PREVALENCE [prev·a·lence]: How many? What percentage?

ID + MENTAL HEALTH DISORDERS

RRTC Year 3 Summit

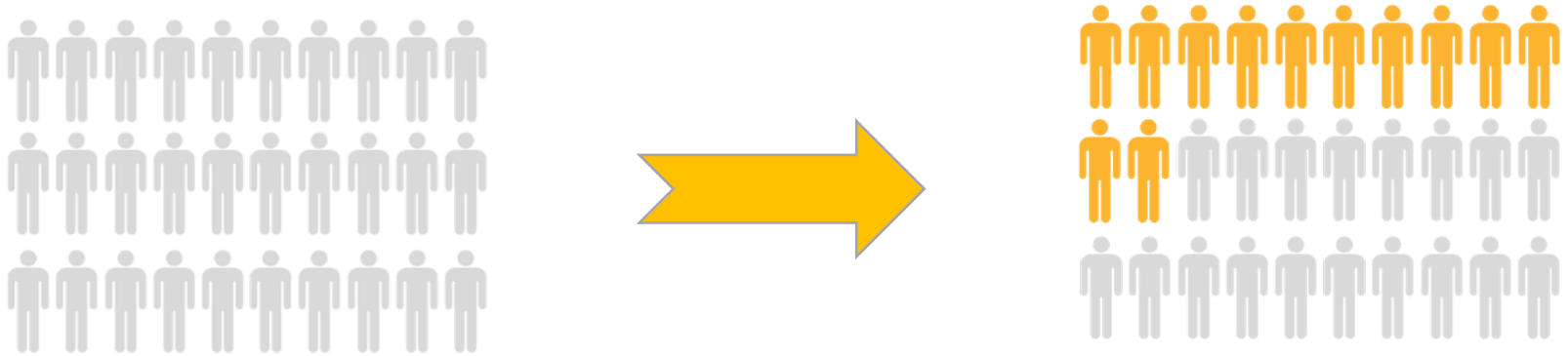
April 10, 2026

NIDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research

http://go.osu.edu/RRTC

RECAP: RESEARCH QUESTION

How many people with **intellectual disability** ALSO have a mental health (**psychiatric**) disorder?

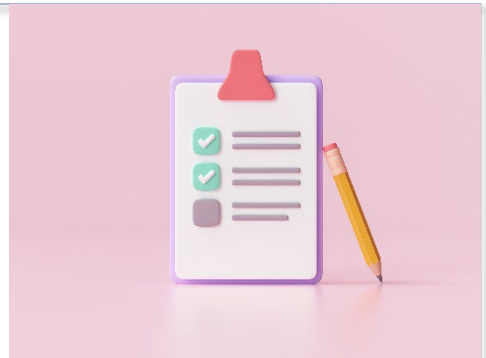


RRTC 1.0: 2018 - 2024

RECAP: STUDY INTERVIEWS/TESTS

N > 490 dyads:

A dyad = 2 people



- Adult with an Intellectual Disability
- Their Study Partner (Caregiver)

RRTC 1.0: 2018 - 2024

RECAP: EARLY FINDINGS

N > 490 dyads:

- ***We ran analyses on RRTC 1.0 data, key highlights:***
  - Prevalence: 3 X what is seen in general population @ 66%
    - Most frequent psychiatric disorders:
      (1) Anxiety Disorders
      (2) ADHD
      (3) Depressive Disorders
    - Gender differences:
      Women => Higher rates of Anxiety Disorders.
      Men => Higher rates of ADHD, Tic Disorder, & Disruptive Impulse Control Disorders.

RRTC 1.0: 2018 - 2024

NEXT STEPS: REVISIT FINDINGS

- These are NOT the final results.
- Statisticians are reanalyzing the data to compare it against the larger National Core Indicators (NCI) sample.
- Why are we doing this? For the sake of good research.
- We want our sample to be similar to (represent) the larger US population in age, race, ethnicity, etc.
- Once we have the final results, we will write up the RRTC 1.0 findings in a paper.

RRTC 2.0: 2023 - 2028

RECAP: RECRUITMENT

- In the new RRTC grant, we said we would keep the study going to recruit more dyads. 100/year starting in 2024.

PY2 (2024-2025): N=100 dyads *(Actual: 82)*
PY3 (2025-2026): N=100 dyads *(Current: 31)*
PY4 (2026-2027): N=100 dyads
PY5 (2027-2028): N=100 dyads

- So far in RRTC 2.0 we recruited **113 dyads to date.**

- What this means: We need your help to get the word out. **Now more than ever.**

RRTC 2.0: 2023 - 2028

NEXT STEPS: RECRUITMENT

- We will continue to work with Special Olympics (SO) and their state partners. They will recruit SO athletes through ongoing programs and upcoming events.
- We thank the good people at SO for their work and partnership.
- We will continue to work with REEP and DEEP to get the word out. Please keep sending the study flier to old and new contacts. Doing this more than once (repetition) is key.
- We will make an action plan where we will touch base with REEP members in between monthly REEP meetings.

RECAP: SPANISH DIAAID

- We need more Hispanics/Latinos in the Count Study. One way to do this is to translate our surveys (measures) into Spanish.
- The DIAAID is an important measure in our study. We use it to ask about mental health in an interview.
- The DIAAID Study Partner (SP) modules were translated into Spanish. This process took many steps.
- We thank Eduardo Ortiz and his amazing team at Utah State University (USU) for their great work.
- They are now testing the Spanish DIAAID SP with Spanish speaking families in Utah.

RRTC 2.0: 2023 - 2028

NEXT STEPS: SPANISH DIAAID

- We will hire a Spanish speaking interviewer.
- We will train this interviewer on the study methods.
- We will get the Spanish DIAAID into REDCap (our online data collection system).
- We will ask Utah and others to focus on recruiting Spanish speaking dyads (state SO program and USU).
- We will do study interviews using the translated DIAAID measure with Spanish speaking participants.

RRTC 2.0: 2023 - 2028

NEXT STEPS: SPANISH DIAAID

- USU may translate the DIAAID modules for Adults with Intellectual Disability (AID).
- They may also translate other Count Study surveys.
- They may also translate recruitment materials (e.g., consents, flier, scripts).
- The above activities will depend on resources (money + time). They are not guaranteed.

RRTC 2.0: 2023 - 2028

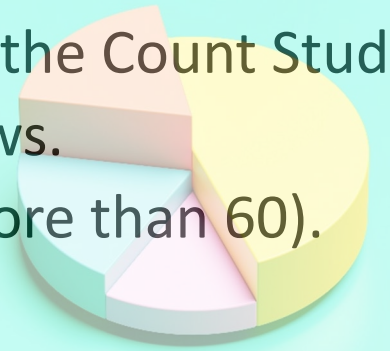
RECAP: VALIDATION STUDY

- As an add-on smaller study (substudy), some Count Study participants agree to do a separate interview.
- Purpose is to ask mental health questions to see how on point (accurate, valid) the DIAAID is (i.e., “we built the car and now we want to see how well it drives”).
- Clinicians are the interviewers. They do not know how people responded on the DIAAID. That prevents bias.
- Since RRTC 1.0, we did 103 interviews.

RRTC 2.0: 2023 - 2028

NEXT STEPS: VALIDATION STUDY

- We will keep doing these substudy interviews.
- Goal is to do as many interviews as we can.
- We would like to recruit at least 10% of our larger Count Study sample by the time this project is done in 2028.
- So far, we are going beyond that goal.
  - Since RRTC 1.0, we recruited about 600 dyads in the Count Study.
  - 10% of 600 is 60 dyads/validation study interviews.
  - As stated, we did 103 substudy interviews (43 more than 60).



QUESTIONS?

STUDY 2:
COUNT STUDY

THE PREVALENCE STUDY:
DEFINITION OF PREVALENCE [prev·a·lence]: How many? What percentage?

CO-OCCURRENCE OF
INTELLECTUAL DISABILITY + PSYCHIATRIC DISORDERS

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