Co-Occurring Psychiatric Diagnoses in People with Intellectual Disability

Jason Buckles, MA, LPCC

Clinical Director

DDSD – Bureau of Behavioral Support

505-841-5539

Jason.buckles@state.nm.us

Goals of this session…

- Participants will:
  - Be introduced to current literature on the prevalence of psychiatric diagnoses in people with ID.
  - Understand some of the factors that make accurate estimates of these figures hard to come by.
  - Consider how presentation of psychiatric symptoms may be difficult to ascertain in people with ID.
  - Be introduced to an alternate model of diagnosis for this population.
  - Consider the potential role of trauma as a factor in all persons with ID.

Definition of terms…

- **Intellectual Disability**: Prior to age 18, 2 Standard Deviations below the mean on both scales of intelligence (IQ) and adaptive functioning; A focus on ***SUPPORT NEEDS*** across domains of medical, social, communication

- **Mental Illness/Mental Disorder:** Is it *anything* in the DSM-5 or just certain conditions? What about nicotine dependence? Autism?

- **Point Prevalence:** The total number of cases in a given population at a certain point in time.
  - Different from 'incidence' which is the number of new cases within a certain timeframe.
  - Different from 'lifetime prevalence' which is the total percentage of people with a certain condition(s) at any time in his/her life. Some conditions come and go or may be 'cured'. Therefore, lifetime prevalence is higher than point prevalence.

What does the research tell us about prevalence?

- Whitaker and Read (2006)
  - Reviewed 14 articles regarding prevalence published between 1979 and 2003
  - Findings were so variant they could not arrive at a cumulative estimate – **highest rate found was 74%**
  - Some evidence of increased rate of psych diagnoses in people with "lower IQ"

- Kerker et al. (2004)
  - Reviewed 12 articles published between 1970-1995
  - Prevalence rates varied from **0% - 40% depending on measures, definitions, and nature of sample**

- Buckles, Luckasson, & Keefe (2013) and Buckles (2015, in press)
  - 19 total articles reviewed; published between 2003 – 2014
  - Range of prevalence found to be **13.9% - 74%**

  - Note: In US, prevalence of mental disorder diagnosis for general population estimated at 20%

Why are the numbers so variant?

- Differences in **definition of mental illness…**
- Differences in the **study samples…**
  - Administrative vs. Population
- Differences in **how/who assessed…**
- Consideration of possible contributing **medical condition(s)…**
- **Limited geography…**
  - Almost no studies from the United States

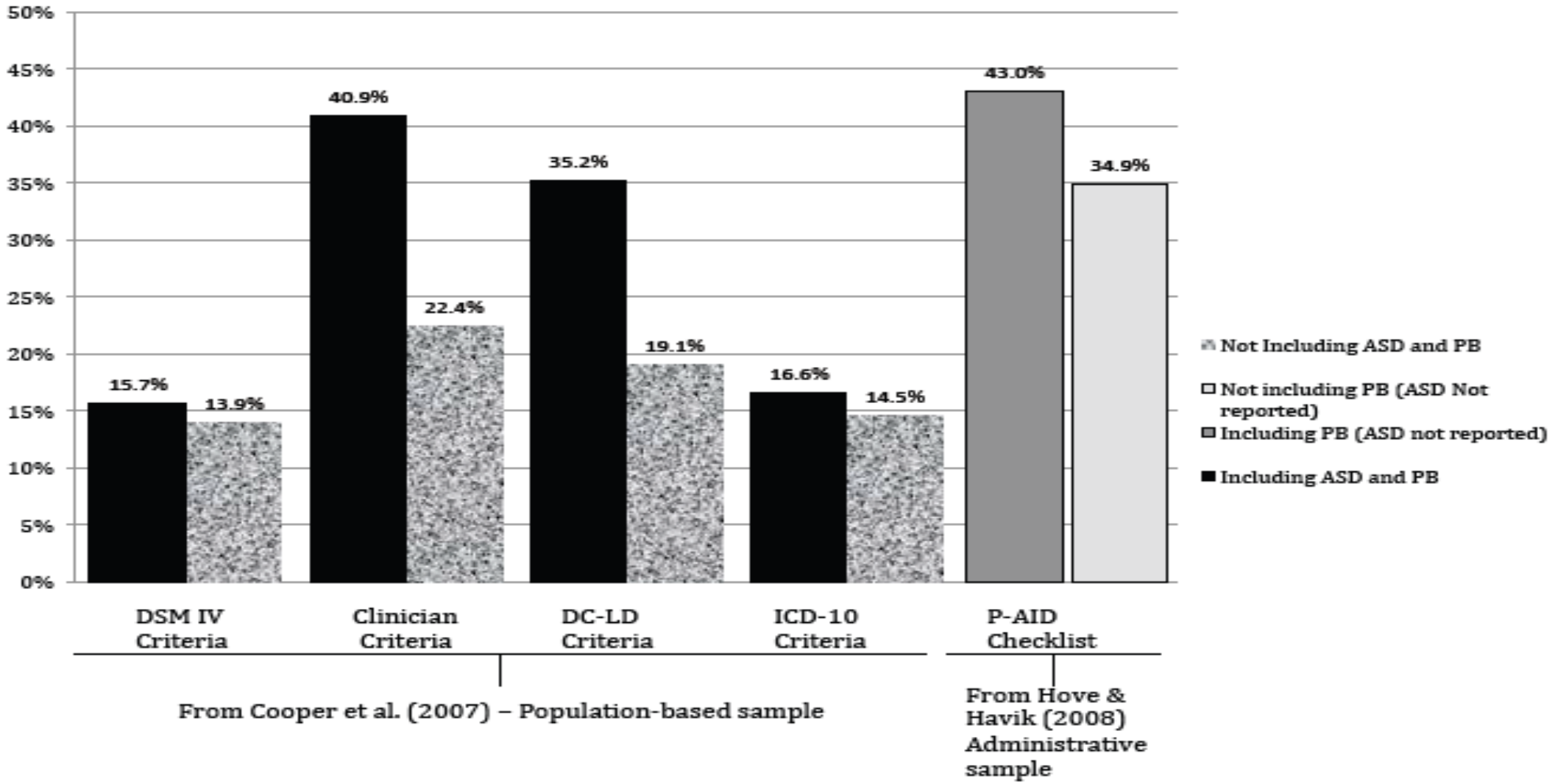

Figure 1: Variation of point prevalence of mental disorder in adults with ID: Effect of diagnostic criteria, inclusion/exclusion of ASD and/or problem behavior (PB), and sampling method. Originally published in Buckles, Luckasson, and Keefe (2013). Used with permission.

Difficulties in psychiatric diagnosis for people with ID…

- 1) Our current model in the U.S. (DSM-5) is **heavily dependent on <u>self report</u> of <u>internal experiences</u>.**
  - Differences/deficits in expressive language for some people with ID;
  - Many practitioners may be less familiar with assessment in these circumstances.

- 2) **DIAGNOSTIC OVERSHADOWING** (Reiss et al., 1982)
  - The presence of ID overshadows other possible conditions;
    - ID seen as the 'go-to' explanation – "Well, s/he has ID so…"
  - Some psychiatric symptoms classified as 'behavioral' and thus not eligible for inpatient/outpatient services/supports.

Why is this a potential problem?

- Inadequate consideration of possible underlying psychiatric conditions may prevent/limit access to:
  - **Treatment** (psychotherapy, medication, etc.);
    - Providers can only justify services if there is a diagnosis attached
  - **Comprehensive understanding**;
    - When we recognize and understand a person's behavior in the context of possible psychiatric conditions ~ our whole support of/reaction to the person and his or her patterns can change drastically…
      - Think about seizures…
  - **Longitudinal/lifelong planning**
    - From both individual and systems perspectives.

An alternate model of identifying psychiatric conditions in people with ID:

- *The Diagnostic Manual – Intellectual Disability* (DM-ID; National Association for the Dually Diagnosed, 2007)
  - Modified criteria sets based on DSM-IV definitions
  - If it's based on the DSM, then why isn't it the D***S***M-ID?
    - What does the 'S' stand for?
  - Provides guidance for how certain 'classic' symptoms may present differently (i.e., behaviorally) for people with varying 'severity' of ID;
  - Anecdote…
    - Young man with Autsim and ID with significant support needs;
    - Psych Diagnoses: Intermittent Explosive Disorder, ADHD, Psychosis, Oppositional Defiant Disorder;
    - Had been on meds for all of these with little positive effect;
    - Psychiatrist and neuropsychologist reassessed using the DM-ID – Post Traumatic Stress was able to be confirmed;
    - New perspective, availability of different interventions = much improved life.

One diagnosis – perhaps, the most important and most overlooked…

- **POST TRAUMATIC STRESS (*Disorder?*...)**
  - In the 'pure' DSM definition:
    - Only specific types of 'traumatic experiences/events' are allowable;
    - There are a significant amount of symptoms that may require the person to report thoughts, feelings, and internal experiences (e.g. flashbacks, memories)

One important diagnosis – perhaps, the most important and most overlooked…PTS

- **BUT…we know that people with ID are at heightened risk of experiencing all kinds of events that involve abuse/neglect/exploitation**
  - "[B]etween 39 and 68% of female children and 16 and 30% of male children with a disability will be sexually abused before they are 18 years old" (Mahoney & Poling, 2011).
  - Perpetrators are more likely to be in a position of providing care/education.
- **AND**…events that may not be considered 'traumatic' per DSM definitions can be **intensely traumatic for people with ID –** examples?
- **ADD TO THIS**…the fact that stress can be expressed in an exceedingly wide array of behaviors, emotions etc. that often may look like 'problems' or other diagnoses to us but can be a form of 'solutions' to that person

Some general pointers…

- **The approach of trauma-informed care**
  - Assume that trauma has occurred and, at least partly, informs the patterns of the person
  - You cannot treat trauma with trauma
  - Our job – REDUCE STRESS

- The label of a psychiatric disorder may help us conceptualize from a wide angle view but often **does not tell us much about the person.**
  - "Once a diagnostic label is attached there is the risk that all the [individual's] characteristics are filtered through this diagnosis or explanatory mechanism resulting in a tendency to view the [individual's] behavior as symptoms, rather than as expressions of his or her unique personality. Furthermore, by ascribing to this perspective the source of the 'disability' is firmly located within the individual and not as a result of the expectations of the social contexts in which the individual exists" (Malloy & Vasil, 2001, p. 661).
  - E.g., Institutional Pathology – and note: 'institutions' are not made of brick and mortar – they are made from thoughts and actions…

- For treatment - **focus on specific symptoms not on global diagnoses**

Resources in New Mexico

- **Customizable training** available from the Bureau of Behavioral Support – call us, we are nerds…
  - Positive Behavior Support/Positive Approaches; Dignity of Risk/Duty of Care; Sexuality and ID; Suicide and Intellectual Disability; Trauma Informed Care; and more thorough aspects of co-occurring conditions in people with ID;
- **The DD/MI project** – through UNM Continuum of Care (Molly Faulkner, PhD, LISW – Chair)
  - Interactive telehealth with interdisciplinary teams on the DD Waiver including physician to physician consults;
- **The Transdisciplinary Evaluation and Support Clinic (TEASC)**
  - Through Continuum of Care/UNM – multimodal, onsite evaluations by physicians of different specialties.
- **Certain practitioners** (MDs, Counselors/Social Workers) with extensive experience
  - We can refer you to some
  - Remember – no one can be denied services due to the presence of a disability

References

Buckles, J. (2015, in press). The epidemiology of psychiatric disorders in adults with intellectual disabilities: A critical review of the research 2004-2014. In C. Hemmings & N. Bouras (Eds.), *Psychiatric and Behavioral Disorders in Intellectual and Developmental Disabilities*, pp. 34-44. Cambridge, UK: Cambridge University Press.

Buckles, J., Luckasson, R., & Keefe, L. (2013). A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003-2010. *Journal of Mental Health Research in Intellectual Disabilities, 6*, 181-207.

Fletcher, R., Loschen, E., Stavrakaki, C, et al. (Eds.). (2007). *Diagnostic Manual - Intellectual Disability: A textbook of diagnosis of mental disorders in persons with intellectual disability.* Kingston, NY: NADD Press.

Kerker, B. D., Owens, P. L., Zigler, P. I., & Horwitz, S. M. (2004). Mental health disorders among individuals with mental retardation: Challenges to accurate prevalence estimates. Public Health Reports, 119, 409–417.

Mahoney, A., & Poling, A. (2011). Sexual abuse prevention for people with severe developmental disabilities. *Journal of Developmental and Physical Disabilities, 23*(4), 369-376.

Molloy, H., & Vasil, L. (2002). The social construction of Asperger syndrome: The pathologising of difference. *Disability and Society, 17*(6), 659-669.

Reiss, S. (1994). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency, 86*(6), 567-574.

Whitaker, S., & Read, S. (2006). The prevalence of psychiatric disorders among peoples with intellectual disabilities: An analysis of the literature. Journal of Applied Research in Intellectual Disabilities, 19, 330–345.