

The Inclusion of Persons with Down Syndrome in the Health Service Psychology and Mental Health Counseling Research Literature: A 25 Year Scoping Review



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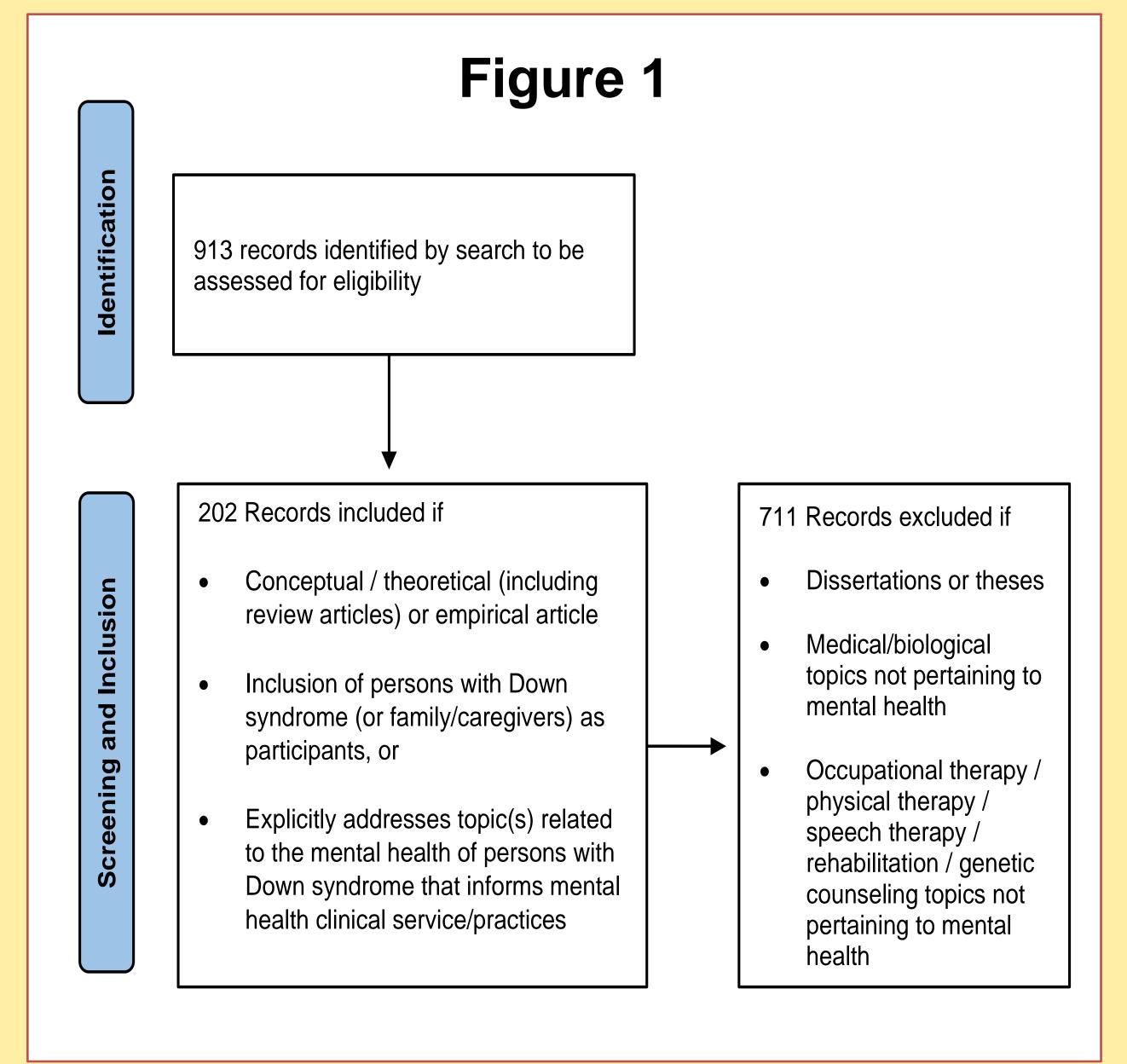


Introduction

- Individuals with Down syndrome (DS) are more likely than their non-DS counterparts to experience numerous mental health conditions (Rivelli et al., 2022)
- Health service (clinical, counseling, and school) psychologists and mental health counselors can play a critical role in addressing the mental health needs of individuals with DS (Brown & Stohlman, 2024).
- We conducted a scoping review to document ways in which health service psychology- and mental health counseling research-specific literature has included the mental health needs of persons with DS since 1999.
- Scoping review explores the question: What information does the literature provide for health service psychologists and mental health counselors about the mental health of people with DS and their families or caregivers?

Method

- Scoping review was conducted using the PRISMA guidelines (Moher et al., 2009) in May 2025.
- Limited to conceptual or empirical articles in English published between 1/1999 and 5/2025.
- Utilized the "Anywhere in the record" option to find words related to "Down syndrome" AND "Mental health" OR "Counseling" OR "Psychotherapy"
- Used APA PsycArticles and PsycInfo search engines as they are specific to health service psychology and mental health counseling.
- Figure 1 shows the study selection process according to the PRISMA guidelines



Discussion

- Large amount of literature describing (1) prevalent mental health disorders and problems of persons with Down syndrome and (2) caregiver/family functioning.
- A smaller amount of literature on assessment/screening (e.g., dementia) and intervention development & adaptation
- Less attention given to improving access to and quality of — mental health practice to eliminate mental health disparities among persons with Down syndrome
- Based on APA Guidelines for Assessment & Intervention With Persons With Disabilities (2023), scholarship is needed in areas of (1) Practitioner Training, Awareness,, & Access; [e.g., Teach knowledge base; Increase self-awareness/ableism; Learn, consult, & advocate for well-being and access to care], (2) Accurate Assessment [e.g., importance of context & validity]; and (3) Disability-Affirmative Interventions [e.g., working alliance; appropriate adaptation of interventions; multisystemic approaches].

Results		
CATEGORIES	# of RECORDS (%)	AREAS OF STUDY (# of articles)
Information about Potential Clients with Down syndrome: Articles that describe common mental health concerns, disorders & related factors	73 (36.14%)	1. Common mental health disorder/problems (17) 2. Dementia/cognitive decline (9) 3. Medical/Behavioral comorbidities (7) 4. Aggression and other behavioral problems (5) 5. Depression and/or mania (4) 6. Adaptive behavior (e.g., at school, work) (3) 7. Anxiety (3) 8. Autism spectrum disorder (3) 9. Obsessive compulsive disorder (3) 10. Regression/Disintegrative disorder and stress (3) 11. Self-injurious/harm behaviors (2) 12. Social determinants of health inequities (2) 13. Social support/connectedness (2) 14. Stigma (2) 15. Attention deficit / hyperactivity disorder (1) 16. Bereavement (1) 17. Physical activity (1) 18. Psychotic symptoms (1) 19. Quality of Life (1) 20. Self-perception (1) 21. Sleep problems (1) 22. Life events, stress, & trauma (1)
Information about Family Members and Caregivers: Articles that describe the well-being, problems, functioning of family/caregivers of persons with Down syndrome	70 (34.65%)	 Mental/physical health or well-being of caregivers or siblings (23) Challenges, burdens, experiences, & needs (8) Family functioning/cohesion/conflict (6) Grief, regret, and loss (4) Perinatal and postnatal parental support programs (4) Father involvement/experiences (3) Marital/couples functioning (3) Stigma (3) "Down syndrome advantage" (2) Maternal-child attachment (2) Hope and uncertainty (2) Quality of parent-child (including adult child) relationship (2) Compound caregiving (1) Coping humor and family functioning (1) Early educational/psychological intervention for fathers (1) Grandmother support (1) Help-seeking (1) Maternal hopelessness (1) Parental burnout (1) Positive parenting (1)
Mental Health Treatment Information: Articles that describe mental health treatment approaches such as theories and interventions (counseling, prevention, medications) to address mental disorders/problems among persons with Down syndrome	30 (14.85)	 Psychotropic medication use (4) Reviewing treatments for problem behaviors (3) Adapting interventions (e.g., cognitive behavioral therapy) to treat depression (4. Exercise programs (cycling, running) & mental health of adolescents (2) Parent driven interventions (sexuality & behavioral/emotional difficulties) (2) Applying Jungian based sandplay therapy among children (1) Case summaries of treatments (e.g., maintenance electroconvulsive therapy) for depression & catatonia (1) Considering disability via an intersectional approach in psychotherapy (1) Developing a therapeutic relationship (1) Dobhsa-hou: an effective therapeutic approach for adults (1) Interpersonal model of depression among adults (1) Interpersonal model of depression among adults (1) Parenting programs for families of a child with a disability (1) Peer-delivered social skills intervention (1) Positive psychology concepts to promote mental health (1) Preventing depression (1) Promoting affirmative attitudes toward disability: school inclusion program (1) Reviewing psychosocial interventions for persons with dementia and ID (1) Reviewing school-based interventions for youth (1) Social-emotional intervention (1) Treating OCD in adolescents and adults (1)
Mental Health Assessment Information: Articles that develop and evaluate psychological measures for persons with Down syndrome (e.g., dementia, anxiety, depression).	21 (10.40)	 Assessing dementia and cognitive decline (12) Assessing anxiety (2) Assessing autism spectrum disorder (2) Adaptation of self-report measures (1) Assessing adaptive functioning in adolescents (1) Assessing depression in adolescents and young adults (1) Use of the Strengths and Difficulties Questionnaire with adults (1) Assessing psychopathology in adults (1)
Mental Health Services-Related Information: Articles that describe issues related to accessing and providing mental health services	8 (3.96)	 APA's Guidelines for Assessment & Intervention (2) Assessing comprehensive model programs serving adults (1) Disease burden, access to care, and family impact (1) Family-provider relationship and well-being (1) Impact of medical care coordination and social support (1) Parental perceived service effectiveness (1) Recommendations for working with American Indian families (1)