Neurodiversity Literature Review

Updated July 27, 2023

Table of Content

Children	4
ADHD	6
Autism	9
Tourette's Syndrome	12
Learning Disabilities	14
Adolescents and Adults	16
Tourette Syndrome	16
Learning Disabilities	17
Autism	19
ADHD	25
Older Adults	
Neurodiversity as a concept	
ADHD	27
Autism	27
Learning Disabilities	31
Neurodiversity as a Concept	
Parents of Neurodiverse Children	37
Gender Differences	
Obsessive Compulsive Disorder	53
Tourette Syndrome	
ADHD	57
ASD	57
Down Syndrome	59
Dyslexia	61
Dysgraphia	61
Dyscalculia	61
Dyspraxia	63
Ataxia	63
Co-occurring Conditions and Experiences	65
Discrimination	65
Physical and Mental Health	
Comorbid Neurodiversity Conditions	79
Victimization and Perpetration	
Poverty and Unemployment	83
Neurodiversity Among LGBTQIA Community	
Interventions	
Neurodiversity and Culture	101
Multidisciplinary Professionals and Neurodiverse Clients	113

Health	
Criminal Justice	
Social Services	
Neurodiversity in Education	
High vs. Low Functioning: Autism isn't Linear	
Real-Life Experiences	
Neurodiversity in the Workplace	
Living With Neurodiverse Conditions	143

Children

Title: *Prevalence and trends of developmental disabilities among children in the United States:* 2009–2017

• https://pubmed.ncbi.nlm.nih.gov/31558576/

Summary: Objectives: To study the national prevalence of 10 developmental disabilities in US children aged 3 to 17 years and explore changes over time by associated demographic and socioeconomic characteristics, using the National Health Interview Survey. Methods: Data come from the 2009 to 2017 National Health Interview Survey, a nationally representative survey of the civilian noninstitutionalized population. Parents reported physician or other health care professional diagnoses of attention-deficit/hyperactivity disorder; autism spectrum disorder; blindness; cerebral palsy; moderate to profound hearing loss; learning disability; intellectual disability; seizures; stuttering or stammering; and other developmental delays. Weighted percentages for each of the selected developmental disabilities and any developmental disability were calculated and stratified by demographic and socioeconomic characteristics. Results: From 2009 to 2011 and 2015 to 2017, there were overall significant increases in the prevalence of any developmental disability (16.2%-17.8%, P < .001), attention-deficit/hyperactivity disorder (8.5%-9.5%, P < .01), autism spectrum disorder (1.1%-2.5%, P < .001), and intellectual disability (0.9%-1.2%, P < .05), but a significant decrease for any other developmental delay (4.7%-4.1%, P < .05). The prevalence of any developmental disability increased among boys, older children, non-Hispanic white and Hispanic children, children with private insurance only, children with birth weight ≥2500 g, and children living in urban areas and with less-educated mothers. Conclusions: The prevalence of developmental disability among US children aged 3 to 17 years increased between 2009 and 2017. Changes by demographic and socioeconomic subgroups may be related to improvements in awareness and access to health care. (Abstract from authors)

Reference:

Zablotsky, B., Black, L., Maenner, M., Schieve, L., Danielson, M., Bitsko, R., Blumberg, S., Kogan, M., Boyle, C. (2017). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics, 144*(4). <u>https://pubmed.ncbi.nlm.nih.gov/31558576/</u>

Title: *Racial/ethnic disparities in the prevalence and trends of autism spectrum disorder in US children and adolescents*

• https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2777029

Summary: Autism spectrum disorder (ASD) is a developmental disability characterized by repetitive behaviors and persistent impairments in social interaction and communication. The prevalence of ASD has been increasing since 2000, with inconsistent findings in racial/ethnic disparities. Over the past decade, the racial/ethnic disparities have persisted but have narrowed

in response to the US Health and Human Services Action Plan to Reduce Racial and Ethnic Health Disparities.⁴ However, it remains unknown how racial/ethnic disparities have changed over time. We used recently released data from the National Health Interview Survey to assess the most recent temporal trends and racial/ethnic disparities in ASD prevalence from 2014 through 2019. (Abstract from authors)

Reference:

Yuan, J., Li, M., Lu, Z. (2021). Racial/ethnic disparities in the prevalence and trends of autism spectrum disorder in US children and adolescents. *JAMA Network Open, 4*(3). https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2777029

Title: Mental health surveillance among children - United States, 2013-2019

<u>https://pubmed.ncbi.nlm.nih.gov/35202359/</u>

Summary: Mental health encompasses a range of mental, emotional, social, and behavioral functioning and occurs along a continuum from good to poor. Previous research has documented that mental health among children and adolescents is associated with immediate and long-term physical health and chronic disease, health risk behaviors, social relationships, education, and employment. Public health surveillance of children's mental health can be used to monitor trends in prevalence across populations, increase knowledge about demographic and geographic differences, and support decision-making about prevention and intervention. Numerous federal data systems collect data on various indicators of children's mental health. particularly mental disorders. The 2013-2019 data from these data systems show that mental disorders begin in early childhood and affect children with a range of sociodemographic characteristics. During this period, the most prevalent disorders diagnosed among U.S. children and adolescents aged 3-17 years were attention-deficit/hyperactivity disorder and anxiety, each affecting approximately one in 11 (9.4%-9.8%) children. Among children and adolescents aged 12-17 years, one fifth (20.9%) had ever experienced a major depressive episode. Among high school students in 2019, 36.7% reported persistently feeling sad or hopeless in the past year, and 18.8% had seriously considered attempting suicide. Approximately seven in 100,000 persons aged 10-19 years died by suicide in 2018 and 2019. Among children and adolescents aged 3-17 years, 9.6%-10.1% had received mental health services, and 7.8% of all children and adolescents aged 3-17 years had taken medication for mental health problems during the past year, based on parent report. Approximately one in four children and adolescents aged 12-17 years reported having received mental health services during the past year. In federal data systems, data on positive indicators of mental health (e.g., resilience) are limited. Although no comprehensive surveillance system for children's mental health exists and no single indicator can be used to define the mental health of children or to identify the overall number of children with mental disorders, these data confirm that mental disorders among children continue to be a substantial public health concern. These findings can be used by public health professionals, health care providers, state health officials, policymakers, and educators to understand the prevalence of specific mental disorders and other indicators of mental health and the challenges related to mental health surveillance. (Abstract from authors)

Reference:

Bitsko, R., Claussen, A., Lichstein, J., Black, L., Jones, S., Danielson, M., Hoenig, J., Davis Jack, S., Brody, D., Gyawali, S., Maenner, M., Warner, M., Holland, K., Perou, R., Crosby, A., Blumberg, S., Avenevoli, S., Kaminski, J., Ghandour, R., Contributor (2022). Mental health surveillance among children - United States, 2013-2019. *The Morbidity and Mortality Weekly*, *71*(2), 1–42. https://pubmed.ncbi.nlm.nih.gov/35202359/

Title: *Preventing school exclusion of students with autism spectrum disorder (ASD) through reducing discrimination: sustainable integration through contact-based education sessions.*

• <u>https://doi.org/10.3390/su13137056</u>

Abstract: Students with autism spectrum disorder (ASD) are discriminated against and stigmatized by the school community. The objective of this study is to analyze the school inclusion process of students with ASD by reducing discrimination and stigmatization through contact-based education sessions. This can be achieved through school projects. In the present study, discrimination and stigmatization toward children with ASD were analyzed in high school students (N = 141) through Haghighat's standardized stigmatization questionnaire (SSQ1). In the active group, a student diagnosed with ASD also participated in the awareness activities of the problems faced by the students with ASD and the contact-based education (CBE) sessions carried out in the classroom. The results showed significant differences in reducing discrimination and stigmatization in high school students, both in the control group and especially in the active group. It was observed that the development of CBE (inclusion of the student with ASD in activities) led to the creation of a supportive school community, demonstrating that the activities carried out within the SucCESS Project achieved their purpose. The SSQ1 can be applied to high school students, and together with CBE activities, it can be used in school inclusion projects for children with ASD or mental disabilities. (Abstract from authors)

Reference:

Nistor, G., & Dumitru, C.-L. (2021). Preventing school exclusion of students with autism spectrum disorder (ASD) through reducing discrimination: sustainable integration through contact-based education sessions. *MDPI*, *13*(13). https://doi.org/10.3390/su13137056

ADHD

Title: ADHD in children and young people: prevalence, care pathways, and service provision

Summary:Attention-deficit hyperactivity disorder (ADHD) is a common childhood behavioural disorder. Systematic reviews indicate that the community prevalence globally is between 2% and 7%, with an average of around 5%. At least a further 5% of children have substantial

difficulties with overactivity, inattention, and impulsivity that are just under the threshold to meet full diagnostic criteria for ADHD. Estimates of the administrative prevalence (clinically diagnosed or recorded) vary worldwide, and have been increasing over time. However, ADHD is still relatively under-recognised and underdiagnosed in most countries, particularly in girls and older children. ADHD often persists into adulthood and is a risk factor for other mental health disorders and negative outcomes, including educational underachievement, difficulties with employment and relationships, and criminality. The timely recognition and treatment of children with ADHD-type difficulties provides an opportunity to improve long-term outcomes. This Review includes a systematic review of the community and administrative prevalence of ADHD in children and adolescents, an overview of barriers to accessing care, a description of associated costs, and a discussion of evidence-based pathways for the delivery of clinical care, including a focus on key issues for two specific age groups-younger children (aged ≤6 years) and adolescents requiring transition of care from child to adult services.(Abstract from authors)

Reference:

Sayal, K., Prasad, V., Daley, D., Ford, T., & Coghill, D. (2018). ADHD in children and young people: Prevalence, care pathways, and service provision. *The Lancet. Psychiatry*, 5(2), 175–186. <u>https://doi.org/10.1016/S2215-0366(17)30167-0</u>

Title: Challenges in ADHD care for ethnic minority children: A review of the current literature

• <u>https://journals.sagepub.com/doi/10.1177/1363461520902885</u>

Summary: While attention deficit hyperactivity disorder (ADHD) has been extensively studied in the past decades, the role of social and cultural practices in its assessment, diagnosis, and treatment has been often overlooked. This selective review provides an overview of research that explores social and cultural influences on help-seeking behavior in ethnic minority children with ADHD. Studies were selected that address cultural diversity in three areas of ADHD help-seeking: problem recognition, access to mental health services, and treatment. Special attention was given to studies of treatment selection and adherence in minority groups. Findings suggested that cultural disparities in ADHD care among ethnic minority children occur in the early stages of problem recognition, through service selection, and in the quality of treatment. Ethnic minority children were less likely than their nonminority counterparts to be diagnosed with ADHD and its comorbid conditions and less likely to be prescribed and adhere to stimulant drug treatment. These differences reflect cultural diversity in norms and attitudes towards mental health issues (e.g., fear of social stigma) as well as limited access to qualified health care. Paradoxically, cultural, racial, and language bias may also lead to the overidentification of ethnic minority children as disabled and to higher ratings of ADHD symptoms. This review highlights the importance of sociocultural factors in understanding developmental psychopathology and help-seeking behavior. In addition, it further supports calls for increasing cultural competence in communications during clinical assessment, diagnosis, and treatment in minority communities. Clinical, theoretical, and methodological considerations for future research are discussed.(Abstract from authors)

Reference:

Slobodin, O., & Masalha, R. (2020). Challenges in ADHD care for ethnic minority children: A review of the current literature. *Transcultural Psychiatry*, *57*(3), 468–483. <u>https://doi.org/10.1177/1363461520902885</u>

Title: A review of factors that promote resilience in youth with ADHD and ADHD symptoms <u>https://pubmed.ncbi.nlm.nih.gov/27747466/</u>

Summary: The vast majority of research on youth with ADHD has focused on risk factors and describing the types of impairment individuals with ADHD experience. However, functional outcomes associated with ADHD are heterogeneous, and although many youth with ADHD experience significant negative outcomes (e.g., school dropout), some are successful in multiple domains of functioning (e.g., pursue and graduate college). There is a growing body of literature supporting the existence of factors that protect youth with ADHD from experiencing negative outcomes, but there is no published synthesis of this literature. Accordingly, the goals of this review are to conceptualize risk-resilience in the context of ADHD using a developmental psychopathology framework and to systematically review and critique evidence for promotive and protective factors in the context of ADHD. The literature search focused specifically on resilience in the context of ADHD symptoms or an ADHD diagnosis and identified 21 studies. including clinic, school, and community samples. Findings of promotive and/or protective factors are summarized across individual, family, and social-community systems. Overall, we know very little of the buffering processes for these youth, given that the study of promotive and protective factors in ADHD is in its infancy. The strongest evidence to date was found for socialand family-level systems. Specifically, multiple longitudinal studies support social acceptance as a protective factor, buffering against negative outcomes such as poor academic performance and comorbid depressive symptoms for youth with ADHD. There was also compelling evidence supporting positive parenting as a promotive factor. In terms of individual-level factors, positive or modest self-perceptions of competence were identified as a promotive factor in multiple studies. Future directions for research that will catalyze the study of resilience with ADHD are provided, and the potential for targeting protective mechanisms with intervention and prevention is discussed. (Abstract from authors)

Reference:

Dvorsky, M. R., & Langberg, J. M. (2016). A review of factors that promote resilience in youth with ADHD and ADHD symptoms. *Clinical Child and Family Psychology Review, 19,* 368–391. https://doi.org/10.1007/s10567-016-0216-z

Title: ADHD in children and young people: Prevalence, care pathways, and service provision

 https://www.clinicalkey.com/#!/content/playContent/1-s2.0-S2215036617301670?returnu rl=https:%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS2215036617301670% 3Fshowall%3Dtrue&referrer=https:%2F%2Fwww.google.com%2F

Summary: ADHD (Attention-deficit hyperactivity disorder) is a common disorder seen in children. Around the world, between 2% and 7% (5% average) of children are diagnosed with ADHD. 5% of children struggle with a level of overactivity, inattention, and impulsivity that is just

shy of the requirements for a diagnosis of ADHD. ADHD is a risk factor for developing other mental disorders, as well as difficulties in education, employment, relationships, and criminality.

Reference:

Sayal, K., Prasad, V., Daley, D., Ford, T., & Coghill, D. (2018). ADHD in children and young people: prevalence, care pathways, and service provision. *Lancet Psychiatry*, 5(2), 175–186. <u>https://doi.org/10.1016/S2215-0366(17)30167-0</u>

Title: Are classrooms meeting the basic psychological needs of children with ADHD symptoms? A self-determination theory perspective

• <u>https://journals.sagepub.com/doi/10.1177/1087054713508926</u>

Summary: ADHD symptoms are not only predictive of underachievement in children but they are also associated with interpersonal and intrapersonal problems in a school environment.

Reference:

Rogers, M., & Tannock, R. (2018). Are classrooms meeting the basic psychological needs of children with ADHD symptoms? A self-determination theory perspective. *Journal of Attention Disorders*, 22(14), 1354–1360. <u>https://doi.org/10.1177/1087054713508926</u>

Title: Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study

• https://link.springer.com/article/10.1007/s00787-014-0606-z

Summary: A lot of children experiencing symptoms of ADHD don't receive healthcare services for their struggles. The most commonly reported barrier for parents of children with ADHD was being unsure of who could help their children. Among children who meet the criteria for ADHD and are receiving healthcare services, 36% are prescribed stimulant medication. The more severe the symptoms were rated by teachers, the more likely a child was to be granted access to services. Clinicians and teachers need to be aware of the association between parental mental health problems and the likelihood that their child will receive ADHD- related healthcare services.

Reference:

Sayal, K., Mills, J., White, K., Merrell, C., & Tymms, P. (2014). Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study. *European Child & Adolescent Psychiatry*, 24, 545-552. <u>https://link.springer.com/article/10.1007/s00787-014-0606-z</u>

Autism

Title: Autism and ADHD: A Literature Review Regarding Their Impacts on Parental Divorce

• <u>https://www.mdpi.com/2227-9067/10/3/438</u>

Summary: Introduction: The change in family structure as a consequence of divorce can be a traumatic event for a child that can undermine his or her emotional security. For this reason, it becomes a major health concern. Many divorce-related risk factors have been identified. including attention deficits or autism spectrum disorder (ASD) in children. The aim of this review is to evaluate if and how a diagnosis of ASD or attention deficit hyperactivity disorder (ADHD) in children is associated with an increase in divorce within families. Method: Searches were performed in two databases evaluating studies focusing on articles pertaining to the topic. A total of 20 articles were found, but only 8 were included in the study according to the criteria. Results: The results showed that divorce does not appear to be specifically related to a diagnosed pathology of the child, but rather presents itself as a risk factor in certain situations. In particular, this occurs when the coping strategies required to deal with the diagnosis are dysfunctional. However, it would appear that families in which there are children with ADHD have a greater chance of divorce than families in which there is a child with a diagnosis of ASD. It may be hypothesised that in the latter case, parents receiving a diagnosis early in the child's life have more time to develop adaptive strategies to cope with the condition than parents with children with ADHD who mostly find themselves having to deal with their child's behavioural problems at a school age. Moreover, ASD is a disorder more likely genetic than environment-related, so parents receive more socio-medical support, and they are less likely to blame themselves or be blamed by others. (Abstract from authors)

Refernce:

Anchesi, S. D., Corallo, F., Di Cara, M., Quartarone, A., Catalioto, R., Cucinotta, F., & Cardile, D. (2023). Autism and ADHD: A literature review regarding their impacts on parental divorce. Children (Basel), 10(3), 438. <u>https://doi.org/10.3390/children10030438</u>

Title: Caregivers' perspectives on the sensory environment and participation in daily activities of childrenwith autism spectrum disorder

Summary: The purpose of this phenomenological study was to obtain caregivers' perspectives on the impact of the sensory environment on participation in daily activities of their young children with autism spectrum disorders (ASD). Interviews were completed with 34 caregivers of children with ASD ages 3–7 yr. Results strongly suggest that parents and caregivers were pivotal in enabling participation for their children through the implementation of specific strategies and a parental decision-making process. The decision-making process considered amount of effort necessary to support participation and whether participation in a given activity was perceived as essential or nonessential. Strategies enabled participation and reduced the effort required to support the child's participation. Strategies either directly related to the sensory factors of the environment or focused on reducing behavioral responses associated with sensory factors. In this study, we identified important considerations to enhance participation in the home and community environments for children with ASD. (Abstract from authors)

Reference:

Pfeiffer, B., Coster, W., Snethen, G., Derstine, M., Piller, A., & Tucker, C. (2017). Caregivers' perspectives on the sensory environment and participation in daily activities of

childrenwith autism spectrum disorder. *The American Journal of Occupational Therapy*, 71(4). <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5490458/</u>

Title: *"I'm proud to be a little bit different": The effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem*

• https://link.springer.com/article/10.1007/s10803-020-04575-4

Summary: This study found that there is a positive relationship between the number of positive attributes that participants associated with autism and their collective self-esteem in relation to how they identified with other autistic people.

Reference:

Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. E. (2020). "I'm proud to be a little bit different": The effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*, 51, 704-714. <u>https://link.springer.com/article/10.1007/s10803-020-04575-4</u>

Title: Parent perceptions about autism spectrum disorder influence treatment choices

• <u>https://journals.sagepub.com/doi/10.1177/1088357615610547</u>

Summary: Child age, cognitive functioning, ASD symptoms, family income, parent education, and cultural background, all may influence treatment selection. Treatment category use was found to be influenced by parent perception of control over ASD treatment, behaviors perceived to be related to ASD, and beliefs about the chronicity of the diagnosis.

Reference:

Mire, S. S., Gealy, W., Kubiszyn, T., Burridge, A. B., & Goin- Kochel, R. P. (2015). Parent perceptions about Autism Spectrum Disorder influence treatment choices. *Focus on Autism and Other Developmental Disabilities*, 32(4), 305-318. <u>https://doi.org/10.1177/1088357615610547</u>

Title: The impact of culture on Autism diagnosis and treatment: Considerations for counselors and other professionals

• <u>https://journals.sagepub.com/doi/10.1177/1066480713476834</u>

Summary: Beliefs about the cause of Autism from a specific cultural perspective should be interpreted cautiously because beliefs vary depending on the cultural group. Ethnicity, culture, and socioeconomic status can play a major role in deciding whether a child is diagnosed with and treated for ASD. Technology has played a major role in the development of intervention and treatment of children with ASD. Parents across cultural groups utilize technology to help their children with ASD to communicate, socialize, and observe appropriate behaviors. Counselors must take their own biases towards ASD into consideration and ensure that they are limiting barriers to treatment. Additionally, counselors are encouraged to use the R.E.S.P.E.C.T.F.U.L. model of counseling to ensure effective cultural competency and respect. Finally, counselors

should practice appropriate communication skills and emphasize the importance of family support. Counselors should advocate for the needs of their clients and families affected by ASD, and work to ensure that all available resources are accessible.

Reference:

Ennis-Cole, D., Durodoye, B.A., & Harris, H.L. (2013). The impact of culture on Autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal*, 21(3), 279-287. <u>https://doi.org/10.1177/1066480713476834</u>

Title: National and state estimates of adults with autism spectrum disorder

• https://pubmed.ncbi.nlm.nih.gov/32390121/

Abstract: U.S. national and state population-based estimates of adults living with autism spectrum disorder (ASD) are nonexistent due to the lack of existing surveillance systems funded to address this need. Therefore, we estimated national and state prevalence of adults 18-84 years living with ASD using simulation in conjunction with Bayesian hierarchal models. In 2017, we estimated that approximately 2.21% (95% simulation interval (SI) 1.95%, 2.45%) or 5,437,988 U.S. adults aged 18 and older have ASD, with state prevalence ranging from 1.97% (95% SI 1.55%, 2.45%) in Louisiana to 2.42% (95% SI 1.93%, 2.99%) in Massachusetts. Prevalence and case estimates of adults living with ASD (diagnosed and undiagnosed) can help states estimate the need for diagnosing and providing services to those unidentified. (Abstract from authors)

Reference:

Dietz, P., Rose, C., McArthur, D., & Maenner, M. (2020) National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *50*(12), 4258-4266. <u>https://pubmed.ncbi.nlm.nih.gov/32390121/</u>

Tourette's Syndrome

Title: Tourette's disorder in children and adolescents

• https://tp.amegroups.org/article/view/31560/28325

Summary: Tourette's disorder (TD) is one of the five American Psychiatric Association's 2013 Diagnostic and Statistical Manual of Mental Disorders (DSM-5) classifications of tic disorders. Eponymously linked with the noted 19th century French physician, Gilles de la Tourette [1857–1904], this disorder is identified in 0.3% to 0.7% of the population. It is characterized as a familial neuropsychiatric condition with multiple motor tics and vocal tics (one or more) present for more than 1 year with varying severity. The underlying pathophysiology involves dysfunctional activity of the basal ganglia and circuitry of the frontal cortex as well as dorsolateral striatum deficits. Contributory factors include genetic features interacting with milieu influences. A number of comorbid disorders are seen including obsessive-compulsive disorder (OCD) and attention-deficit/hyperactivity disorder (ADHD). Concepts of management are considered including behavioral therapy and pharmacologic approaches with alpha-adrenoceptor agonists, atypical antipsychotics (AAs), haloperidol, pimozide and others. Other management includes botulinum injections and deep brain stimulation in adults.(Abstract from authors)

Reference:

Greydanus, D. E., & Tullio, J. (2020). Tourette's disorder in children and adolescents. *Translational Pediatrics*, 9(Suppl 1), S94–S103. <u>https://doi.org/10.21037/tp.2019.09.11</u> **Title:** *Tourette's disorder in children and adolescents*

• https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7082238/

Summary: Tic disorders are one of the most common neurodevelopmental disorders in children and adolescents. They may present in combination with other disorders like OCD and ADHD. Provisional tic disorder is found in 4-20% of children/adolescents and may occur from a family history of the disorder; has a 2-3:1 male-to-female ratio. Persistent motor or vocal tic disorder is 1-2% of the general population and is linked to family history. Chronic motor tic disorder can be found in 3-50 per 1,000 school children. Chronic vocal tic disorder can be found in 2.5 to 9.4 per 1,000 school children. Tourette's syndrome is around 5 per 1,000 and ten times more common in children than adults. Tourette's syndrome has a 3-4:1 male-to-female ratio. Tourette's syndrome is around 5 per 1,000 and ten times more common in children than adults. Tourette's syndrome has a 3-4:1 male-to-female ratio. Tourette's syndrome is around 5 per 1,000 and ten times more common in children than adults. Tourette's syndrome has a 3-4:1 male-to-female ratio. Tourette's syndrome is around 5 per 1,000 and ten times more common in children than adults. Tourette's syndrome has a 3-4:1 male-to-female ratio. Tourette's syndrome is around 4-7 years of age with a range of 2 to 15 years. The final age of onset is 21 years.

Reference:

Greydanus, D. E., & Tullio, J. (2020). Tourette's disorder in children and adolescents. *Translational Pediatrics*, 9(Suppl 1), S94–S103. <u>https://doi.org/10.21037/tp.2019.09.11</u>

Title: Treatment of children and adolescents with tics and Tourrette syndrome

• https://journals.sagepub.com/doi/epdf/10.1177/08830738060210080401

Summary: Tics are particularly common in children, particularly those who have developmental and psychiatric disorders. The presence of tics may indicate atypical neurodevelopment or difficulties with cognition and mood. Those with Tourrette syndrome may present with symptoms of inattention, hyperactivity, obsessiveness, or anxiety. Effective treatment is dependent on proper diagnosis and consideration of nonpharmacologic and pharmacologic interventions for symptoms limiting the child's function and quality of life. It's important family members and the general population understand the symptoms of Tourette syndrome, including problems with obsessiveness and impulse control. Important to do collaborative assessments with families and discuss tic-related impairment and realistic expectations of treatment. Be knowledgeable about the side effects of tic treatment interventions. Medical treatments tend to have little effectiveness. Psychological interventions are helpful. Advocacy groups like the Tourette Syndrome Association provide essential resources for patients, families, schools, and health care professionals.

Reference:

Gilbert D. (2006). Treatment of children and adolescents with tics and Tourette syndrome. *Journal of Child Neurology*, 21(8), 690-700. doi:<u>10.1177/08830738060210080401</u>

Learning Disabilities

Title: Evidence-Based Psychotherapies for Children and Adolescents

 <u>https://www.guilford.com/books/Evidence-Based-Psychotherapies-for-Children-and-Adol</u> escents/Weisz-Kazdin/9781462522699

Summary:Widely regarded as the standard reference and text on evidence-based therapies—and now substantially revised—this book has introduced tens of thousands of clinicians and students to exemplary treatments for social, emotional, and behavioral problems in children and youth. Concise chapters focus on specific psychotherapy models. The developers of the respective approaches review their conceptual underpinnings, describe how interventions are delivered on a session-by-session basis, and summarize what the research shows about treatment effectiveness. The book explores important questions and challenges facing the field and identifies best practices for treatment dissemination in real-world clinical contexts.(Abstract from authors)

Reference:

Weisz, J. R., & Kazdin, A. E. (2017). *Evidence-based psychotherapies for children and adolescents* (3rd ed.). The Guilford Press. <u>https://www.guilford.com/books/Evidence-Based-Psychotherapies-for-Children-and-Adolescents</u> /Weisz-Kazdin/9781462522699

Title: Understanding, Educating, and Supporting Children with Specific Learning Disabilities: 50 Years of Science and Practice

<u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6851403/</u>

Summary: Specific learning disabilities (SLD) are highly relevant to the science and practice of psychology, both historically and currently, exemplifying the integration of interdisciplinary approaches to human conditions. They can be manifested as primary conditions—as difficulties in acquiring specific academic skills—or as secondary conditions, comorbid to other developmental disorders such as Attention Deficit Hyperactivity Disorder. In this synthesis of historical and contemporary trends in research and practice, we mark the 50th anniversary of the recognition of SLD as a disability in the US. Specifically, we address the manifestations, occurrence, identification, comorbidity, etiology, and treatment of SLD, emphasizing the integration of information from the interdisciplinary fields of psychology, education, psychiatry, genetics, and cognitive neuroscience. SLD, exemplified here by Specific Word Reading, Reading Comprehension, Mathematics, and Written Expression Disabilities, represent spectrum disorders each occurring in approximately 5–15% of the school-aged population. In addition to risk for academic deficiencies and related functional social, emotional, and behavioral difficulties, those with SLD often have poorer long-term social and vocational outcomes. Given the high rate of occurrence of SLD and their lifelong negative impact on functioning if not

treated, it is important to establish and maintain effective prevention, surveillance, and treatment systems involving professionals from various disciplines trained to minimize the risk and maximize the protective factors for SLD. (Abstract from authors)

Reference:

Grigorenko, E. L., Compton, D., Fuchs, L., Wagner, R., Willcutt, E., Fletcher, J. M. (2020). Understanding, educating, and supporting children with specific learning disabilities: 50 years of science and practice. *American Psychologist, 75*(1), 37-51. doi: <u>10.1037/amp0000452</u>

Title: Domain-general cognitive skills in children with mathematical difficulties and dyscalculia: A systematic review of the literature.

• <u>https://doi.org/10.3390/brainsci12020239</u>

Abstract: Mathematical performance implies a series of numerical and mathematical skills (both innate and derived from formal training) as well as certain general cognitive abilities that, if inadequate, can have a cascading effect on mathematics learning. These latter skills were the focus of the present systematic review. Method: The reviewing process was conducted according to the PRISMA statement. We included 46 studies comparing school-aged children's performance with and without math difficulties in the following cognitive domains: processing speed, phonological awareness, short- and long-term memory, executive functions, and attention. Results: The results showed that some general cognitive domains were compromised in children with mathematical difficulties (i.e., executive functions, attention, and processing speed). Conclusions: These cognitive functions should be evaluated during the diagnostic process in order to better understand the child's profile and propose individually tailored interventions. However, further studies should investigate the role of skills that have been poorly investigated to date (e.g., long-term memory and phonological awareness). (Abstract from authors)

Reference:

Agostini, F., Zoccolotti, P., & Casagrande, M. (2022). Domain-general cognitive skills in children with mathematical difficulties and dyscalculia: A systematic review of the literature. *Brain Sciences, 12*(2), 239. <u>https://doi.org/10.3390/brainsci12020239</u>

Title: Consequences, characteristics, and causes of mathematical learning disabilities and persistent low achievement in mathematics.

• https://pubmed.ncbi.nlm.nih.gov/21285895/

Abstract: The goals of the review are threefold: (a) to highlight the educational and employment consequences of poorly developed mathematical competencies; (b) overview the characteristics of children with mathematical learning disability (MLD) and with persistently low achievement (LA) in mathematics; and (c) provide a primer on cognitive science research that is aimed at identifying the cognitive mechanisms underlying these learning disabilities and associated cognitive interventions. Literatures on the educational and economic consequences of poor

mathematics achievement were reviewed and integrated with reviews of epidemiological, behavioral genetic, and cognitive science studies of poor mathematics achievement. Poor mathematical competencies are common among adults and result in employment difficulties and difficulties in many common day-to-day activities. Among students, ~ 7% of children and adolescents have MLD and another 10% show persistent LA in mathematics, despite average abilities in most other areas. Children with MLD and their LA peers have deficits in understanding and representing numerical magnitude, difficulties retrieving basic arithmetic facts from long-term memory, and delays in learning mathematical procedures. These deficits and delays cannot be attributed to intelligence but are related to working memory deficits for children with MLD, but not LA children. These individuals have identifiable number and memory delays and deficits that seem to be specific to mathematics learning. Interventions that target these cognitive deficits are in development and preliminary results are promising.(Abstract from authors)

Reference:

Geary D. C. (2011). Consequences, characteristics, and causes of mathematical learning disabilities and persistent low achievement in mathematics. *Journal of Developmental and Behavioral Pediatrics.*, *32*(3), 250–263. https://pubmed.ncbi.nlm.nih.gov/21285895/

Adolescents and Adults

Tourette Syndrome

Title: Meta-analysis: Adulthood prevalence of Tourette syndrome

• https://pubmed.ncbi.nlm.nih.gov/31220521/

Summary: Background: Tourette syndrome (TS) is estimated to have a prevalence of 0.30-0.77% in school aged children. Longitudinal studies suggest that roughly half-to-two-thirds of children with TS experience a substantial improvement in tic symptoms during adolescence. By contrast, few studies have examined adulthood prevalence of TS. Accurate prevalence estimates across the lifespan are needed to support regulatory and public health decisions. Methods: We searched PubMED and EMBASE for studies that examined the prevalence of TS in adults. We conducted a random-effects meta-analysis of logit event rates to estimate prevalence of TS across studies. Too few studies are available to conduct moderator analysis or examine publication bias. We also examined the risk ratio of TS prevalence in adults for males compared to females. Results: Three studies involving 2,356,485 participants were included. There were significant differences in TS adulthood prevalence estimates between studies ranging from 49 to 657 cases of TS per million adults. Overall prevalence of TS in adulthood was estimated to be 118 cases of TS per million adults (95%CI: 19-751 cases per million adults). There was a large amount of heterogeneity between studies (I2 = 99%) that was likely related to differences in their methods of identification of TS cases. By contrast, the male:female ratio of risk of adulthood TS was similar between studies with a Risk Ratio = 2.33 (95% CI: 1.72-3.16). Conclusion: Estimates of adulthood prevalence of TS are sparse and likely highly

affected by differences in method of case identification. Diagnosis and diagnostic estimates of TS could be aided by including a requirement for impairment as well as potential remission criteria similar to other psychiatric conditions. (Abstract from authors)

Reference:

Levine, J., Szejko, N., Bloch, M. (2019). Meta-analysis: Adulthood prevalence of Tourette syndrome. *Progress in Neuro-psychopharmacology & Biological Psychiatry*, 95. https://pubmed.ncbi.nlm.nih.gov/31220521/

Learning Disabilities

Title: *Training Direct Service Personnel in Functional Communication Training with Adults with Disabilities*

• <u>https://link.springer.com/article/10.1007/s10882-020-09766-6</u>

Summary:Adults with intellectual and developmental disabilities (IDD) may engage in challenging behavior. These behaviors present challenges to support staff who often lack training in effective behavior management procedures. Behavioral skills training (BST) is an empirically supported method of staff training and has been used to teach support staff a number of intervention skills. The purpose of this study was to extend the literature on BST and to examine the effects of BST on staff implementation of functional communication training (FCT) for three adults with IDD using a non-concurrent multiple baseline design. Results indicated that with BST, staff fidelity increased over baseline levels. With the addition of individualized coaching, staff implementation reached mastery criteria. Improvements in staff implementation fidelity corresponded with decreases in participant challenging behavior and increases in appropriate communication. Findings suggest that BST with coaching may be an effective method to train staff to implement FCT with adults. (Abstrcat from author)

Reference:

Gregori, E., Rispoli, M., Neely, L., Lory, C., Kim, S. Y., & David, M. (2020). Training direct service personnel in functional communication training with adults with disabilities. *Journal of Developmental and Physical Disabilities*, 33(4), 669–692. <u>https://doi.org/10.1007/s10882-020-09766-6</u>

Title: *'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood*

• <u>https://journals.sagepub.com/doi/10.1177/1362361311405223</u>

Summary: The experiences of individuals in middle adulthood with Asperger syndrome have been the subject of little previous research, especially in terms of their experience of support services. In the present research, 11 adults with Asperger syndrome were interviewed. Interpretative phenomenological analysis (IPA) was used to interpret the interviews. Four themes emerged from the analysis: living with Asperger syndrome; employment issues;

experiences with mainstream support; and future steps towards supporting adults with Asperger syndrome. The findings highlighted the anxiety, depression, and communication difficulties that people with Asperger syndrome may experience. Much of the available support is perceived as unsuitable for individuals with Asperger syndrome. All participants wanted to remain as independent as possible, and believed an individualized approach to support would be greatly beneficial. Recommendations are made for future practice to help support adults with Asperger syndrome. (Abstract from authors)

Reference:

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). "I just don't fit anywhere': Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism: The International Journal of Research and Practice, 16*(5), 532–546. https://doi.org/10.1177/1362361311405223

Title:*Presentation of depression in autism and Asperger syndrome: A review*

• <u>https://journals.sagepub.com/doi/10.1177/1362361306062013</u>

Summary:Depression is common in autism and Asperger syndrome, but despite this, there has been little research into this issue. This review considers the current literature on the prevalence, presentation, treatment and assessment of depression in autism and Asperger syndrome. There are diagnostic difficulties when considering depression in autism and Asperger syndrome, as the characteristics of these disorders, such as social withdrawal and appetite and sleep disturbance, are also core symptoms of depression. Impaired verbal and non-verbal communication can mask the symptoms of depression. Symptoms associated with autism and Asperger syndrome such as obsessionality and self-injury may be increased during an episode of depression. There is a clear need to develop specific tools both for diagnostic purposes and for measurement of depression in autism and Asperger syndrome in order to help alleviate the distress caused by this treatable illness.(Abstract from authors)

Reference:

Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O'Brien, G. (2006). Presentation of depression in autism and Asperger syndrome: A review. *Autism: the International Journal of Research and Practice, 10*(1), 103–116. <u>https://doi.org/10.1177/1362361306062013</u>

Title: External sources promoting resilience in adults with intellectual disabilities: A systematic literature review

Summary: Background: Persons with an intellectual disability are at increased risk of experiencing adversities. The current study aims at providing an overview of the research on how resilience in adults with intellectual disabilities, in the face of adversity, is supported by sources in their social network. Method: A literature review was conducted in the databases Psycinfo and Web of Science. To evaluate the quality of the included studies, the Mixed Method Appraisal Tool (MMAT) was used. Results: The themes: "positive emotions," "network acceptance," "sense of coherence" and "network support," were identified as sources of

resilience in the social network of the adults with intellectual disabilities. Conclusion: The current review showed that research addressing sources of resilience among persons with intellectual disabilities is scarce. In this first overview, four sources of resilience in the social network of people with intellectual disabilities were identified that interact and possibly strengthen each other.(Abstract from authors)

Reference:

Scheffers, F., Moonen, X., & Van Vugt, E. (2022). External sources promoting resilience in adults with intellectual disabilities: A systematic literature review. *Journal of Intellectual Disabilities, 26*(1), 227–243. <u>https://doi.org/10.1177/1744629520961942</u>

Autism

Title: Deficit, Difference, or Both? Autism and Neurodiversity

• https://psycnet.apa.org/fulltext/2012-10810-001.html

Summary:The neurodiversity movement challenges the medical model's interest in causation and cure, celebrating autism as an inseparable aspect of identity. Using an online survey, we examined the perceived opposition between the medical model and the neurodiversity movement by assessing conceptions of autism and neurodiversity among people with different relations to autism. Participants (N = 657) included autistic people, relatives and friends of autistic people, and people with no specified relation to autism. Self-identification as autistic and neurodiversity awareness were associated with viewing autism as a positive identity that needs no cure, suggesting core differences between the medical model and the neurodiversity movement. Nevertheless, results suggested substantial overlap between these approaches to autism. Recognition of the negative aspects of autism and endorsement of parenting practices that celebrate and ameliorate but do not eliminate autism did not differ based on relation to autism or awareness of neurodiversity. These findings suggest a deficit-as-difference conception of autism wherein neurological conditions may represent equally valid pathways within human diversity. Potential areas of common ground in research and practice regarding autism are discussed.(Abstract from author)

Reference:

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & amp; Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59–71. <u>https://doi.org/10.1037/a0028353</u>

Title: Young Adult Outcome of Autism Spectrum Disorders

https://link.springer.com/article/10.1007/s10803-007-0441-x

Summary: To learn about the lives of young adults with ASD, families with children born 1974–1984, diagnosed as preschoolers and followed into adolescence were contacted by mail.

Of 76 eligible, 48 (63%) participated in a telephone interview. Global outcome scores were assigned based on work, friendships and independence. At mean age 24, half had good to fair outcome and 46% poor. Co-morbid conditions, obesity and medication use were common. Families noted unmet needs particularly in social areas. Multilinear regression indicated a combination of IQ and CARS score at age 11 predicted outcome. Earlier studies reported more adults with ASD who had poor to very poor outcomes, however current young people had more opportunities, and thus better results were expected. (Abstract from authors)

Reference:

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(4), 739–747. <u>https://doi.org/10.1007/s10803-007-0441-x</u>

Title: How do adults and teens with self-declared Autism Spectrum Disorder experience eye contact? A qualitative analysis of first-hand accounts

• https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0188446

Summary:A tendency to avoid eye contact is an early indicator of Autism Spectrum Disorder (ASD), and difficulties with eye contact often persist throughout the lifespan. Eye contact difficulties may underlie social cognitive deficits in ASD, and can create significant social and occupational barriers. Thus, this topic has received substantial research and clinical attention. In this study, we used qualitative methods to analyze self-reported experiences with eye contact as described by teens and adults with self-declared ASD. Results suggest people with a self-declared ASD diagnosis experience adverse emotional and physiological reactions, feelings of being invaded, and sensory overload while making eye contact, in addition to difficulties understanding social nuances, and difficulties receiving and sending nonverbal information. Some data support existing mindblindness frameworks, and hyperarousal or hypoarousal theories of eye contact, but we also present novel findings unaccounted for by existing frameworks. Additionally, we highlight innovative strategies people with self-declared ASD have devised to overcome or cope with their eye contact difficulties.

Reference:

Trevisan, D. A., Roberts, N., Lin, C., & Birmingham, E. (2017). How do adults and teens with self-declared Autism Spectrum Disorder experience eye contact? A qualitative analysis of first-hand accounts. *PLOS ONE, 12*(11), e0188446. https://doi.org/10.1371/journal.pone.0188446

Title: Brief Report: Autism Awareness: Views from a Campus Community

• https://link.springer.com/article/10.1007/s10803-013-1893-9

Summary: This paper reports on a college community's views of the diagnostic characteristics and causes associated with autism spectrum disorders. An anonymous on-line survey of autism knowledge was distributed via campus server university-wide to all undergraduates, graduate students, faculty, and staff. Of the 1,057 surveys completed, 76 % of respondents had more

correct answers than neutral and incorrect ones. Respondents who reported that they or someone in their immediate family had autism had significantly more correct responses than other respondents. Demographic variables of respondent sex, age, education, and role at the university independently accounted for significant, though modest, variance in autism knowledge. More accurate and widespread dissemination of information about autism may facilitate a smoother transition for college students who are on the spectrum.(Abstract from authors)

Reference:

Tipton, L. A., & Blacher, J. (2014). Brief report: Autism awareness: Views from a campus community. *Journal of Autism and Developmental Disorders, 44*(2), 477–483. <u>https://doi.org/10.1007/s10803-013-1893-9</u>

Title: *Inflexible daily behaviour is associated with the ability to control an automatic reaction in autism spectrum disorder*

https://www.nature.com/articles/s41598-018-26465-7#Sec2

Summary:Inflexible behaviours in people with autism spectrum disorder (ASD) broadly obstruct social communication. Meanwhile, flexibility implicates cognitive control to resolve socially conflicting situations; however, it remains unclear how people with ASD behave in the face of these conflicts in this respect. We used the ultimatum game (UG) and the implicit-association test (IAT) to examine goal-directed/economic flexibility, both of which involve conflict and cognitive control. In addition, we used the Detail and Flexibility Questionnaire (DFlex) to measure inflexible everyday behaviour with diminished cognitive control and attention shifting. We observed the decreased flexibility in participants with ASD (DFlex and IAT); further, their IAT scores positively correlated with DFlex. However, in the UG, contrary to our prediction, participants with ASD accepted unfair offers more frequently than TD. These results suggest that assessing the automatic/attention processing level with the IAT could be a useful approach to study behavioural flexibility among ASD compared with the UG, which might comprise multiple response strategies besides economic rationality. Overall, the severity of inflexible daily behaviours in people with ASD may be associated with a reduced flexible attitude at an automatic level, altered attention processing and decreased cognitive control.(Abstract from authors)

Reference:

Tei, S., Fujino, J., Hashimoto, R., Itahashi, T., Ohta, H., Kanai, C., Kubota, M., Nakamura, M., Kato, N., & Takahashi, H. (2018). Inflexible daily behaviour is associated with the ability to control an automatic reaction in autism spectrum disorder. *Scientific Reports, 8*(1), 8082–8089. https://doi.org/10.1038/s41598-018-26465-7

Title: Resilience and coping strategies in adults with autism spectrum disorder

Summary: Individuals with Autism spectrum disorder (ASD) are prone to stress and anxiety affecting their mental health. Although developing coping and resilience are key to cope with stressors of life, limited research exists. We aimed to explore stakeholders' experiences related to the coping and resilience of adults with ASD. We interviewed 22 participants, including 13 adults with ASD, five parents, and four service provides of adults with ASD from various Canadian provinces. Using thematic analysis, three themes emerged including: (a) societal expectations and conformity, (b) adjusting daily routines, and (c) learning overtime. This study highlights the importance of coping and informs the development of services to help enhance resilience among adults with ASD. (Abstract from authors)

Reference:

Ghanouni, P., & Quirke, S. (2022). Resilience and coping strategies in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *53*(1), 456–467. <u>https://doi.org/10.1007/s10803-022-05436-y</u>

Title: Transition of individuals with autism to adulthood: A review of qualitative studies

Summary: Many young adults with autism spectrum disorder experience poor transition outcomes in key areas, including postsecondary employment, higher education, health care, social connectedness, and independent living, yet we lack a clear understanding of the specific factors that impact these outcomes. We reviewed qualitative research in which the perspectives of youth and young adults with autism spectrum disorder, parents, services providers, and other stakeholders were gathered to identify barriers and facilitators to optimal outcomes. Findings revealed that poor transition outcomes are influenced by several factors, including poor person-environment fit, uncertainty about the roles of parents, and the lack of comprehensive or integrated services. These findings also revealed the aspects of familial, organizational, and policy contexts that may be targeted for interventions. Finally, stakeholders emphasized that supports should be individualized and focused on the changing aspects of the young adult's social and physical environment rather than behavior change. We discuss implications for policy and practice and provide recommendations for further research. (Abstract from authors)

Reference:

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: A review of qualitative studies. *Pediatrics*, 141(Supplement 4), S318-S327. doi: 10.1542/peds.2016-4300I

Title: How do adults and teens with self-declared autism spectrum disorder experience eye contact? A qualitative analysis of first-hand accounts.

Summary: A tendency to avoid eye contact is an early indicator of Autism Spectrum Disorder (ASD), and difficulties with eye contact often persist throughout the lifespan. Eye contact difficulties may underlie social cognitive deficits in ASD, and can create significant social and occupational barriers. Thus, this topic has received substantial research and clinical attention. In this study, we used qualitative methods to analyze self-reported experiences with eye contact as

described by teens and adults with self-declared ASD. Results suggest people with a selfdeclared ASD diagnosis experience adverse emotional and physiological reactions, feelings of being invaded, and sensory overload while making eye contact, in addition to difficulties understanding social nuances, and difficulties receiving and sending nonverbal information. Some data support existing mindblindness frameworks, and hyperarousal or hypoarousal theories of eye contact, but we also present novel findings unaccounted for by existing frameworks. Additionally, we highlight innovative strategies people with self-declared ASD have devised to overcome or cope with their eye contact difficulties. (Abstract from authors)

Reference:

Trevisan, D. A., Roberts, N., Lin, C., & Birmingham, E. (2017). How do adults and teens with self-declared autism spectrum disorder experience eye contact? A qualitative analysis of first-hand accounts. *PLOS ONE, 12*(11), e0188446. https://doi.org/10.1371/journal.pone.0188446

Title: Youth perceptions of stress and coping when transitioning to adulthood with autism: A photovoice study

Summary: Transitioning into adulthood can be a challenging and stressful process for youth living with an autism spectrum disorder. Adults with ASD struggle with living independently, gaining full-time employment, and achieving post-secondary education. The four common themes of coping include (1) utilizing music, books, and physical exercise; (2) seeking support; (3) spirituality; and (4) building self-esteem and confidence. Many young adults with ASD struggle with hyper-responsiveness to stimulation, feeling overwhelmed, isolated, and experiencing negative attitudes toward themselves. These coping skills serve to lessen the negative symptoms of ASD and increase the quality of life for young adults with ASD. Identifying the coping experiences of youth with autism spectrum disorder is important for the design of future programs, services, and policies supporting transition-aged youth with an autism spectrum disorder. (Abstract from authors)

Reference:

First, J. M., Cheak- Zamora, N. C., Teti, M., Maurer-Batjer, A., & First, N. L. (2018). Youth perceptions of stress and coping when transitioning to adulthood with autism: A photovoice study. *Qualitative Social Work*, 18(4). https://doi.org/10.1177/1473325018757078

Title: Neurodiversity and (Semantic) Space for the Academic Inclusion of People on the Autism Spectrum

• https://doi.org/10.35765//mjse.2021.1020.04

Summary: Universities need to implement inclusive high-quality education that's available at all levels of education. Since there's an increasing number of neurodiverse people (ADHD, autism, dyslexia, and other neurodevelopmental disorders), there needs to be more inclusive education. Research shows a need to include neurodiverse students in educational settings because of the

intellectual potential of young people and their high-self awareness, and to provide conditions to assist with their self-determination in adult life. Some European countries don't monitor the number of students diagnosed with ASD. Studies in Poland showed individuals diagnosed with ASD have higher dropouts during their first year of studies, difficulties with relationships, feelings of loneliness, and lower employment levels after graduation. Many diagnosed with ASD don't study. A possible barrier for neurodiverse individuals is the availability of higher education concerning cultural and economic status.

Reference:

Cierzniewska, R., & Podgórska-Jachnik, D. (2021). Neurodiversity and (semantic) space for the academic inclusion of people on the autism spectrum. *Multidisciplinary Journal of School Education*, *10*(20), 71-88. <u>https://doi.org/10.35765//mjse.2021.1020.04</u>

Title: A Scoping Review of Peer Mentoring Programs for Autistic College Students

• https://doi.org/10.1007/s40489-022-00325-7

Summary: Autistic college students struggle with academics (graduating from college), mental health, and sustained post-secondary employment. The purpose of this review is to describe the peer mentoring programs for autistic college students and determine whether they are effective. There are many peer mentoring programs but very little research and even less published data on the impact of the programs on student outcomes. The peer mentoring programs' structures are highly variable ranging from academic to non-academic (social to mental health). Therefore assessing student outcomes is difficult since the objectives of the papers and measures used were mostly different across programs. Further investigation is needed to understand why few support programs for autistic students describe their programs and report the efficacy of their interventions. It is suggested that it is related to the disconnection of the mission of college student support programs (e.g. providing the most help for the most students) and reporting results in scholarly research. Other potential factors may include low priority and little incentive to conduct research in most offices supporting autistic students; and the lack of funding for research even when staff members are interested in researching the efficacy of their interventions for autistic students. To overcome these potential problems, higher education institutions may benefit from initiating collaborations between researchers and practitioners in student support programs. This report identifies opportunities in understanding what components of mentoring programs work and the potential outcomes to strive for the success of autistic college students.

Reference:

Morris, I. F., Matta, C. & Fung, L. K. (2022). A scoping review of peer mentoring programs for autistic college students. *Review Journal of Autism and Developmental Disorders*. <u>https://doi.org/10.1007/s40489-022-00325-7</u>

ADHD

Title: What predicts a good adolescent to adult transition in ADHD? The role of self-reported resilience

Summary: Objective: ADHD is a disorder associated with impairment and comorbid psychiatric problems in young adulthood; therefore, factors that may imply a more favorable outcome among adolescents with ADHD are of interest. Method: This study used a longitudinal design to assess whether adolescent personal resilience characteristics during adolescence protected against psychosocial impairment, depression, and anxiety 3 years later. Self-reported protective factors were used as baseline measures in the assessment of 190 clinically referred adolescents with ADHD. A semi-structured diagnostic interview was performed at the follow-up. Results: In a group of youth with ADHD, personal resilience characteristics were associated with better psychosocial functioning in young adulthood, and less depression and anxiety. Conclusion: Although further research is needed, these results indicate that personal resilience characteristics may be protective factors in the transitional period from adolescence to early adulthood.(Abstract from authors)

Reference:

Schei, J., Nøvik, T. S., Thomsen, P. H., Lydersen, S., Indredavik, M. S., & Jozefiak, T. (2018).
 What predicts a good adolescent to adult transition in ADHD? The role of self-reported resilience. *Journal of Attention Disorders*, 22(6), 547-560. doi: 10.1177/1087054715604362

Title: Diagnostic issues for adolescents and adults with ADHD

• https://onlinelibrary.wiley.com/doi/10.1002/jclp.20118

Summary: Adult prevalence of ADHD ranges from 1% to 6%. The core childhood symptoms of ADHD can persist as a person gets older, and these symptoms can develop into more overt difficulties in adulthood. In order to make a diagnosis of ADHD as an adult, the symptoms must have been active in childhood. Many core symptoms of ADHD can also be nonspecific symptoms for other disorders, so diagnosing can be complicated. ADHD is also commonly comorbid with other psychiatric conditions. This paper discusses several different case studies regarding clients with ADHD and the various clinical concerns and outcomes of each case study.

Reference:

Wasserstein, J. (2005). Diagnostic issues for adolescents and adults with ADHD. *Journal of Clinical Psychology*, 61(5), 535-547. <u>https://doi.org/10.1002/jclp.20118</u>

Title: The prevalence and correlates of adult ADHD in the United States: results from the national comorbidity survey replication.

https://pubmed.ncbi.nlm.nih.gov/16585449/

Summary: Objective: Despite growing interest in adult attention deficit hyperactivity disorder (ADHD), little is known about its prevalence or correlates. Method: A screen for adult ADHD was included in a probability subsample (N=3,199) of 18-44-year-old respondents in the National Comorbidity Survey Replication, a nationally representative household survey that used a lav-administered diagnostic interview to assess a wide range of DSM-IV disorders. Blinded clinical follow-up interviews of adult ADHD were carried out with 154 respondents, oversampling those with positive screen results. Multiple imputation was used to estimate prevalence and correlates of clinician-assessed adult ADHD. Results: The estimated prevalence of current adult ADHD was 4.4%. Significant correlates included being male, previously married, unemployed, and non-Hispanic white. Adult ADHD was highly comorbid with many other DSM-IV disorders assessed in the survey and was associated with substantial role impairment. The majority of cases were untreated, although many individuals had obtained treatment for other comorbid mental and substance-related disorders. Conclusions: Efforts are needed to increase the detection and treatment of adult ADHD. Research is needed to determine whether effective treatment would reduce the onset, persistence, and severity of disorders that co-occur with adult ADHD.(Abstract from authors)

Reference:

Kessler, R., Adler, L., Barkley, R., Biederman, J., Conners, C., Demler, O., Faraone, S., Greenhill, L., Howes, M., Secnik, K., Spencer, T., Ustun, T., Walters, E., Zaslavsky, A. (2006) The prevalence and correlates of adult ADHD in the United States: results from the national comorbidity survey replication. *The American Journal of Psychiatry*, *163*(4), 716-723. <u>https://pubmed.ncbi.nlm.nih.gov/16585449/</u>

Older Adults

Neurodiversity as a concept

Title: The Crisis Facing Older People Living with Neurodiversity and Their Aging Family Carers: A Social Work Perspective

• https://doi.org/10.1080/01634372.2021.1920537

Summary: Older adults who are neurodivergent and their aging family caregivers experience significant levels of social exclusion and a variety of oppression (ableism, sanism, ageism, racism, sexism). These unequal conditions negatively impact their health and well-being, social inclusion, and agency. During the COVID-19 pandemic, neurodivergent elders were at significant risk because they belong to two groups that experience more rates of hospitalization and death, and they face different and significant forms of social isolation and discrimination that have increased due to the pandemic. The response to the pandemic included focusing on medical issues above social and mental health, which has created more uncertainty and

marginalization by widening pre-existing gaps. Such events have highlighted the needs and concerns of those who are older and neurodivergent and those supporting them. Support and advocacy are necessary to address social exclusion and its impact on older adults who are neurodivergent and their aging family caregivers.

Reference:

Brotman S., Sussman T., Pacheco L., Dickson D., Lach L., Raymond E., Deshaies M., Freitas Z., & Milot E. (2021). The crisis facing older people living with neurodiversity and their aging family carers: A social work perspective. *Journal of Gerontological Social Work*, 64(5), 547-556. DOI: <u>10.1080/01634372.2021.1920537</u>

ADHD

Title: The Burden of ADHD in Older Adults: A Qualitative Study

• <u>https://journals.sagepub.com/doi/10.1177/1087054715610001</u>

Abstract: Objective: To explore how ADHD may have affected the lives of older adults who meet the diagnostic criteria of ADHD, but are unaware of their diagnosis. Our second aim was to examine whether the reported symptoms change over the life span. Method: A qualitative study was conducted. Seventeen Dutch older people (>65 years) diagnosed in this study with ADHD participated in in-depth interviews. Data were analyzed according to techniques of thematic approach. Results: Seven themes emerged from the analyses. Four themes correspond to ADHD symptoms: "being active," "being impulsive," "attention problems," and "mental restlessness." In addition, the themes "low self-esteem," "overstepping boundaries," and "feeling misunderstood" emerged. The impact of ADHD symptoms seems to have declined with age. Conclusion: ADHD has a negative impact on late life, and older adults with the disorder may benefit from treatment. Moreover, this study's findings call for early detection and treatment of ADHD in children and adults. (J. of Att. Dis. 2018; 22(6) 591-600) (Abstract from authors)

Reference:

Michielsen, M., de Kruif, J. Th. C. M., Comijs, H. C., van Mierlo, S., Semeijn, E. J., Beekman, A. T. F., Deeg, D. J. H., & Kooij, J. J. S. (2018). The burden of ADHD in older adults: A qualitative study. *Journal of Attention Disorders*, 22(6), 591–600. <u>https://doi.org/10.1177/1087054715610001</u>

Autism

Title: Coping-resilience profiles and experiences of stress in autistic adults

Summary: Emerging studies allude to high stress in autistic adults. Considering the detrimental impact of stress on health outcomes, examining individual resources which may influence the extent to which stress is experienced (e.g., coping and resilience) is vital. Using a person-focused approach, this study aimed to identify coping-resilience profiles, and examine their relations to general perceived stress and daily hassles in a sample of autistic adults (N =

86; aged 19–74 years). Cluster analysis identified four coping-resilience profiles (i.e., high cope/ low resilience, low cope/ high resilience, engage cope/ high resilience, and disengage cope/ low resilience). The high cope/ low resilience and disengage cope/ low resilience groups had significantly higher general perceived stress than the remaining groups. No significant group differences were noted in relation to daily hassles. Jointly addressing coping and resilience may be beneficial on the perceived stress experienced in autistic adults. The use of coping-resilience profiles may also allow for the personalization of stress management and support options in the autistic adult population. (Abstract from authors)

Reference:

Muniandy, M., Richdale, A. L., & Lawson, L. P. (2022). Coping-resilience profiles and experiences of stress in autistic adults. *Autism Research*, *15*(11), 2149–2166. https://doi.org/10.1002/aur.2817

Title: Older Age Autism Research: A Rapidly Growing Field, but Still a Long Way to Go

• <u>https://doi.org/10.1089/aut.2021.0041</u>

Summary: This article included a large literature review on trends in research on ASD in later life. The researchers found that since 2012, there's been a 392% increase in research with older individuals with ASD, 196% for children/early life, 253% for adolescence, and 264% for adult research. The most common research areas identified were cognition, the brain, and genetics. Older adult research only included 0.4% of published autism studies over the past decade. Such an increase in older result research is a positive change, but research on children continues to lead. Its also been noted that finding papers on older-age autism research is challenging and a new keyword should be created to make the research more accessible and explored. Additional research should be conducted on social isolation and the living arrangements of individuals who are older and have ASD and/or intellectual disabilities.

Reference:

Mason D., Stewart G. R., Capp S. J., & Happe F. (2022). Older age autism research: A rapidly growing field, but still a long way to go. *Autism in Adulthood*, 4(2), 164-172. DOI: <u>https://doi.org/10.1089/aut.2021.0041</u>

Title: Aging and autism: A longitudinal follow-up study of mental health and quality of life in autistic adults

• https://www.frontiersin.org/articles/10.3389/fpsyg.2022.741213/full

Summary: Background: Poor mental health is known to adversely affect functional abilities, social isolation, and quality of life (QoL). It is, therefore, crucial to consider the long-term impacts of mental health conditions as autistic adults grow older. Objectives: To explore, in a group of community-based autistic adults, the extent of: (i) autistic traits, co-occurring physical and mental health conditions; (ii) age-related differences in those conditions, and changes over time; and (iii) their impact on everyday living and QoL. Method: About Sixty-eight autistic adults (aged 19–80 years) participated in the first study (T1); 49 participants from T1 took part in a follow-up

at T2 (mean retest interval 2.4 years). Standardised self-report measures of autistic traits, mental health, and QoL were completed at both time points. Results: Over two-thirds (71%) of autistic adult participants experienced at least one co-occurring condition, and over a third (37%) met the criteria for three or more co-occurring conditions. Mental and physical health difficulties were related to autistic traits and difficulties in everyday life and were consistent predictors of poor QoL at T1 and T2. Conclusion: Mental health difficulties in autism persisted into older age and did not improve over time. These findings have important implications for mental health provision for autistic adults in older age. (Abstract from authors)

Reference:

Roestorf A., Howlin P., & Bowler D. M. (2022). Ageing and autism: A longitudinal follow-up study of mental health and quality of life in autistic adults. *Frontiers in Psychology, 13*(741213). doi: 10.3389/fpsyg.2022.741213

Title: *"Older Adults with ASD: The Consequences of Aging." Insights from a series of special interest group meetings held at the International Society for Autism Research 2016–2017*

Summary: A special interest group (SIG) entitled "Older Adults with ASD: The Consequences of Aging" was held at the International Society for Autism Research (INSAR) annual meetings in 2016 and 2017. The SIG and subsequent meetings brought together, for the first time, international delegates who were members of the autistic community, researchers, practitioners and service providers. Based on aging autism research that is already underway in the UK, Europe, Australia and North America, discussions focused on conceptualizing the parameters of aging when referring to autism, and the measures that are appropriate to use with older adults when considering diagnostic assessment, cognitive factors and quality of life in older age. Thus, the aim of this SIG was to progress the research agenda on current and future directions for autism research in the context of aging. A global issue on how to define 'aging' when referring to ASD was at the forefront of discussions. The 'aging' concept can in principle refer to all developmental transitions. However, in this paper we focus on the cognitive and physical changes that take place from mid-life onwards. Accordingly, it was agreed that aging and ASD research should focus on adults over the age of 50 years, given the high rates of co-occurring physical and mental health concerns and increased risk of premature death in some individuals. Moreover, very little is known about the cognitive change, care needs and outcomes of autistic adults beyond this age. Discussions on the topics of diagnostic and cognitive assessments, and of quality of life and well-being were explored through shared knowledge about which measures are currently being used and which background guestions should be asked to obtain comprehensive and informative developmental and medical histories. Accordingly, a survey was completed by SIG delegates who were representatives of international research groups across four continents, and who are currently conducting studies with older autistic adults. Considerable overlap was identified across different research groups in measures of both autism and quality of life, which pointed to combining data and shared learnings as the logical next step. Regarding the background questions that were asked, the different research groups covered similar topics but the groups differed in the way these questions were formulated when

working with autistic adults across a range of cognitive abilities. It became clear that continued input from individuals on the autism spectrum is important to ensure that questionnaires used in the future are accessible and understandable for people across the whole autistic spectrum, including those with limited verbal abilities. (Abstract from authors)

Reference:

Roestorf, A., Bowler, D. M., Deserno, M. K., Howlin, P., Klinger, L., McConachie, H., Parr, J. R., Powell, P., Van Heijst, B. F. C., Geurts, H. M. (2019). "Older adults with ASD: The consequences of aging." Insights from a series of special interest group meetings held at the international society for autism research 2016–2017. *Research in Autism Spectrum Disorders, 63*, 3–12. doi: 10.1016/j.rasd.2018.08.007

Title: Aging well on the autism spectrum: The perspectives of autistic adults and carers

 <u>https://www.cambridge.org/core/journals/international-psychogeriatrics/article/aging-well-on-the-autism-spectrum-the-perspectives-of-autistic-adults-and-carers/CD9BC6E6766C 0FD92C820E27C2A479C3
</u>

Summary: Background: "Aging well" is an increasingly popular concept in gerontology. Adults with disabilities such as autism spectrum disorder represent a demographically substantial population, yet remain excluded from existing conceptualizations of aging well. This gualitative study aimed to explore what it means for autistic adults to "age well" from the perspectives of autistic adults and carers. Methods: Twenty-four semi-structured interviews were conducted with 15 autistic adults (mean age 50.3 years) and 9 carers of autistic adults. Interviews were offered in four formats: email, telephone, Skype, and face-to-face and included three questions exploring what it means for autistic adults to age well as well as what might help or hinder them from aging well. Results: Aging well was found to be a multifaceted concept that encompassed the autistic individual, others, the world they live in, and relational issues connecting these domains. Thematic analysis revealed eight themes to be common across participants' responses: "myself," "being autistic," "others," "lifestyle and living well," "being supported," "relating to others," "life environment," and "societal attitudes and acceptance." Conclusions: In line with previous studies, a more diverse range of personal and environmental factors should be included in conceptualizing aging well. In contrast to dominant perspectives, being autistic was not considered a hindrance to aging well. Rather, social and relational issues were central and unique to aging well for autistic adults. Implications include the need to address societal attitudes towards autism and building capacity and understanding in those who are both formally and informally involved in the lives of autistic adults. (Abstract from authors)

Reference:

Hwang, Y., Foley, K., & Trollor, J. (2017). Aging well on the autism spectrum: The perspectives of autistic adults and carers. *International Psychogeriatrics*, 29(12), 2033-2046. doi: 10.1017/S1041610217001521

Learning Disabilities

Title: *Transitions for older people with learning disabilities and behaviours that challenge others, and their family carers: A merged protocol for two rapid scoping reviews of evidence.*

• <u>https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-021-01883-3#citeas</u>

Summary: There are over 1 million adults with a learning disability in the UK, of whom approximately 20% displaying behaviours that challenge others. Two thirds of people with learning disabilities live in the family home. As they and their family carers age, both are likely to face particular difficulties and stresses, but there is little understanding of their experiences and needs. To address this evidence gap, our main objective is to undertake two rapid scoping reviews that will collectively focus on the health and social care needs, experiences, service interventions and resources of older people with learning disabilities and behaviours that challenge others, and their family carers. Both reviews will focus on issues relating to forward planning and transitions to different care contexts. The study is part of a research project funded by the National Institute for Health Research No.129491.(Abstract from authors)

Reference:

Vseteckova, J., Jordan, J., Tilley, E., Larkin, M., Ryan, S., Wallace, L. M. (2022). Transitions for older people with learning disabilities and behaviours that challenge others, and their family carers: A merged protocol for two rapid scoping reviews of evidence. *Systematic Reviews*, *11*(14). <u>https://doi.org/10.1186/s13643-021-01883-3</u>

Title: A qualitative study of the needs of older adults with intellectual disabilities.

• https://onlinelibrary.wiley.com/doi/epdf/10.1111/jar.12900

Summary: Background: Research indicates that adults with intellectual disabilities are living longer. However, there is limited research on how this affects health and care needs.Objective: The present study aimed to examine the health and social care needs of older adults with intellectual disabilities in Ireland using multiple informants.Methods: Data were gathered from a sample of 20 adults aged 50 years or older (Mean = 59.1, SD = 5.9, range = 50-72; 11 female). The sample included individuals with mild (n = 7), moderate (n = 10) and severe/profound (n = 3) intellectual disabilities. Additional data from key workers (n = 19) and family carers (n = 15) provided a more complete understanding of needs. Results: Results revealed some areas of agreement and difference between adults with intellectual disability and their carers regarding the social care, employment, retirement, physical and mental health needs of this population. Conclusions: The findings of this study have potential implications for the provision of high-quality services for older adults with intellectual disabilities. (Abstract from authors)

Reference:

McCausland D., Guerin S., Tyrrell J., Donohoe C., O'Donoghue .I, Dodd P. (2021). A qualitative study of the needs of older adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 34*(6), 1560–1568. <u>https://doi.org/10.1111/jar.12900</u>

Neurodiversity as a Concept

Title:Compassionate pedagogy for neurodiversity in higher education: A conceptual analysis

https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1093290/full

Summary:The neurodiversity paradigm challenges pathologizing accounts of neurodevelopmental differences, including autism, attention deficit disorder (ADHD), dyslexia, developmental language disorder (DLD) and others. From a neurodiversity perspective, these differences in the way people perceive, learn about and interact with the world are conceptualised as naturally occurring cognitive variation, akin to biodiversity in the natural environment, which may bring unique strengths and challenges for individuals. An implication of this approach is that interventions designed to create contexts in which neurodivergent people can thrive are needed, in addition to those that seek to ameliorate individual-level difficulties. In this conceptual review, we consider how higher education can offer a context in which cognitive diversity can be noticed, welcomed and accepted with warmth. In universities, neurodiversity is one dimension of difference within an increasingly diverse student population, which overlaps but is not synonymous – with disability. We argue that improving experience and outcomes for neurodivergent students should be a priority for universities aiming to produce graduates equipped to tackle the complex problems of contemporary society. Drawing on the foundational principles of compassion-focused psychological therapies, we consider how compassion can be enacted within interpersonal interaction, curriculum design, and leadership culture in universities. We apply the insights of double empathy theory to the problem of overcoming barriers of difference in the classroom. Finally, we make recommendations for Universal Design for Learning (UDL) and strengths-based pedagogical approaches, which create a fit-for-purpose educational environment for the widest possible range of learners. This realignment with the neurodiversity paradigm offers an antidote to bolt-on provisions for students who differ from the neuro-normative, and might enable neurodivergent thinkers to flourish within and beyond higher education.(Abstract from author)

Reference:

Hamilton, L. G., & Petty, S. (2023). Compassionate pedagogy for neurodiversity in higher education: A conceptual analysis. *Frontiers in Psychology*, 14(1093290). <u>https://doi.org/10.3389/fpsyg.2023.1093290</u>

Title: Principles of instructional design, 5th edition

Summary: This pioneering text describes a rationally consistent basis for instructional design, based in cognitive psychology and information-processing theory. The authors prepare teachers to design and develop a course, unit, and module of instruction, outline the nine stages of instructional design procedure, and integrate current research and practice in the movement toward performance systems technology. The Fifth Edition of PRINCIPLES OF

INSTRUCTIONAL DESIGN emphasizes the social and cultural context of learning, learner-centered principles, and the affordances of new technologies and learning environments.(Abstract from author)

Reference:

Gagne, R. M., Wager, W. W., Golas, K. C., Keller, J. M., & Russell, J. D. (2005). Principles of instructional design, 5th edition [Review of Principles of instructional design, 5th edition]. *Performance Improvement, 44*(2), 44–46. <u>https://doi.org/10.1002/pfi.4140440211</u>

Title: *The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers?*

• <u>https://karger.com/hde/article/66/2/73/828432/The-Neurodiversity-Approach-es-What-Ar</u> <u>e-They-and</u>

Summary: This paper presents the concepts of "neurodiversity" and the "neurodiversity approaches" towards disability and discusses how confusion regarding the meaning of these concepts exacerbates debate and conflict surrounding the neurodiversity approaches. For example, some claim the neurodiversity approaches focus solely on society and deny contributions of individual characteristics to disability (a controversial stance), whereas this paper joins other literature in acknowledging the contributions of both individual and society to disability. This paper also addresses other controversies related to neurodiversity, such as uncertainty regarding the scope of the approaches – to whom do they apply? – and their implications for diagnostic categories. Finally, it provides recommendations for developmental researchers who wish to carry out neurodiversity-aligned research: scholars are urged to study both individual neurodivergent people and the contexts around them; to consider both strengths and weaknesses; to recognize their own biases; and to listen to and learn from neurodivergent people.(Abstract from authors)

Reference:

Dwyer, P. (2022). The neurodiversity approach(es): What are they and what do they mean for researchers? *Human Development*, 66(2), 73–92. <u>https://doi.org/10.1159/000523723</u>

Title:*Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement*

• https://link.springer.com/article/10.1007/s10728-011-0169-9

Summary:Neurodiversity has remained a controversial concept over the last decade. In its broadest sense the concept of neurodiversity regards atypical neurological development as a normal human difference. The neurodiversity claim contains at least two different aspects. The first aspect is that autism, among other neurological conditions, is first and foremost a natural variation. The other aspect is about conferring rights and in particular value to the neurodiversity condition, demanding recognition and acceptance. Autism can be seen as a natural variation on par with for example homosexuality. The broad version of the neurodiversity claim, covering low-functioning as well as high-functioning autism, is problematic. Only a narrow conception of

neurodiversity, referring exclusively to high-functioning autists, is reasonable. We will discuss the effects of DSM categorization and the medical model for high functioning autists. After a discussion of autism as a culture we will analyze various possible strategies for the neurodiversity movement to claim extra resources for autists as members of an underprivileged culture without being labelled disabled or as having a disorder. We will discuss their vulnerable status as a group and what obligation that confers on the majority of neurotypicals.(Abstract from authors)

Reference:

Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis, 20*(1), 20-30. https://doi.org/10.1007/s10728-011-0169-9

Title:*Clinical Practice Guidelines for Psychoeducation in Psychiatric Disorders General Principles of Psychoeducation*

 <u>https://journals.lww.com/indianjpsychiatry/Fulltext/2020/62002/Clinical_Practice_Guidelin</u> es_for_Psychoeducation.19.aspx

Summary: In the last few decades, psychoeducation has come up as a useful and effective mode of psychotherapy for persons with mental illness. It has been found to be fruitful in both clinical and community settings.Psychoeducation has its roots in the "Mental Hygiene Movement" of the early 20th century and "Deinstitutionalization Movement" of the 1950s and 1960s. Subsequently, studies on the role of "Expressed Emotions" in schizophrenia provided further impetus to the growth of psychoeducation.Psychoeducation combines the elements of cognitive-behavior therapy, group therapy, and education. The basic aim is to provide the patient and families knowledge about various facets of the illness and its treatment so that they can work together with mental health professionals for a better overall outcome.(Abstract from authors)

Reference:

Sarkhel, S., Singh, O., & Arora, M. (2020). Clinical practice guidelines for psychoeducation in psychiatric disorders general principles of psychoeducation. *Indian Journal of Psychiatry*, 62(8), 319. <u>https://doi.org/10.4103/psychiatry.indianjpsychiatry</u> 780_19

Title: Autism as a natural human variation: Reflections on the claims of the neurodiversity movement

Summary: Neurodiversity has remained a controversial concept over the last decade. In its broadest sense the concept of neurodiversity regards atypical neurological development as a normal human difference. The neurodiversity claim contains at least two different aspects. The first aspect is that autism, among other neurological conditions, is first and foremost a natural variation. The other aspect is about conferring rights and in particular value to the neurodiversity condition, demanding recognition and acceptance. Autism can be seen as a natural variation on par with for example homosexuality. The broad version of the neurodiversity claim, covering

low-functioning as well as high-functioning autism, is problematic. Only a narrow conception of neurodiversity, referring exclusively to high-functioning autists, is reasonable. We will discuss the effects of DSM categorization and the medical model for high functioning autists. After a discussion of autism as a culture we will analyze various possible strategies for the neurodiversity movement to claim extra resources for autists as members of an underprivileged culture without being labelled disabled or as having a disorder. We will discuss their vulnerable status as a group and what obligation that confers on the majority of neurotypicals.(Abstract from authors)

Reference:

Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis, 20*(1), 20-30. doi: 10.1007/s10728-011-0169-9.

Title: Trends in the prevalence and incidence of attention-deficit/hyperactivity disorder among adults and children of different racial and ethnic groups

• https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2753787

Summary: Question: What are recent trends in adult attention-deficit/hyperactivity disorder (ADHD) prevalence and incidence among racial and ethnic groups in the United States? Findings: In this cohort study of 5 282 877 patients who identified as African American or black, Native American, Pacific Islander, Latino or Hispanic, non-Hispanic white, Asian American, or other and were cared for at Kaiser Permanente Northern California, the annual adult ADHD prevalence and incidence rates significantly increased over a 10-year period for every race/ethnicity except Native American; rates remained highest among white patients throughout. The presence of other psychiatric diagnoses was found to be a major factor associated with likelihood of adult ADHD diagnosis. Meaning: The prevalence and incidence of adults diagnosed with ADHD are increasing, although pronounced racial/ethnic inequalities in rates of diagnosis remain. (Abstract from authors)

Reference:

Chung, W., Jiang, S., Paksarian, D., Nikolaidis, A., Castellanos, X., Merikangas, K., Milham, M. (2019). Trends in the prevalence and incidence of attention-deficit/hyperactivity disorder among adults and children of different racial and ethnic groups. *JAMA Network Open*, 2(11). https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2753787

Title: Neurodiversity: An Insider's Perspective

• https://doi.org/10.1177/1362361318820762

Summary: This article discusses the diverse nature of the growing neurodiversity movement, as well as misinformation regarding the concept of neurodiversity from the perspective of an autism researcher that is on the autism spectrum. The first piece of misinformation is the claim that neurodiversity frames autism as a difference and a cultural identity and not as a disability. The author states that it is clearly a disability, and arguments that state otherwise are misinformed.

The second piece of misinformation addressed is the idea that the neurodiversity paradigm can only be applied to "high-functioning" people with autism. The argument discounts those that are not "high-functioning" as being too disabled to be included in the movement. The author disagrees and insists that the functioning of someone with autism fluctuates too much from topic to topic, skill to skill, to reliably label someone as "low-functioning." The final piece of misinformation that the author addresses is the idea that autism is "just a natural variation," as she puts it, and that people with autism do not require support. This ties into the idea that autism is not a disability when it is and people with autism do require support. The author discusses these criticisms and misinformation about the neurodiversity movement and seeks to address these criticisms using scientific references.

Reference:

den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, 23(2), 271–273. https://doi.org/10.1177/1362361318820762

Title: The neurodiversity approach(es): What are they and what do they mean for researchers?

• <u>https://doi.org/10.1159/000523723</u>

Abstract: This paper presents the concepts of "neurodiversity" and the "neurodiversity approaches" towards disability and discusses how confusion regarding the meaning of these concepts exacerbates debate and conflict surrounding the neurodiversity approaches. For example, some claim the neurodiversity approaches focus solely on society and deny contributions of individual characteristics to disability (a controversial stance), whereas this paper joins other literature in acknowledging the contributions of both individual and society to disability. This paper also addresses other controversies related to neurodiversity, such as uncertainty regarding the scope of the approaches – to whom do they apply? – and their implications for diagnostic categories. Finally, it provides recommendations for developmental researchers who wish to carry out neurodiversity-aligned research: scholars are urged to study both individual neurodivergent people and the contexts around them; to consider both strengths and weaknesses; to recognize their own biases; and to listen to and learn from neurodivergent people.(Abstract from authors)

Reference:

Dwyer, P. (2022). The neurodiversity approach(es): What are they and what do they mean for researchers? *Human Development*, 66(2), 73–92. <u>https://doi.org/10.1159/000523723</u>

Title: Is our legal, health care and social support infrastructure neurodiverse enough? How far are the aims of the neurodiversity movement fulfilled for those diagnosed with cognitive disability and learn

• https://www.emerald.com/insight/content/doi/10.5042/tldr.2011.0005/full/html

Summary:Should those of us who are neurologically atypical be diagnosed as ill, so in need of treatment or cure, or accepted as embodying a different way of being, as called for by the neurodiversity movement? We consider what legal structures and health and social care

systems would be appropriate to promote neurodiversity, and how far this infrastructure in the United Kingdom today meets these criteria for those diagnosed with cognitive disability and learning disability.(Abstract from authors)

Reference: Mackenzie, R., & Watts, J. (2011). Is our legal, health care and social support infrastructure neurodiverse enough? How far are the aims of the neurodiversity movement fulfilled for those diagnosed with cognitive disability and learning disability? *Tizard Learning Disability Review, 16*(1), 30–37. <u>https://doi.org/10.5042/tldr.2011.0005</u>

Title: Shifting the discourse on disability: Moving to an inclusive, intersectional focus

• https://psycnet.apa.org/fulltext/2023-11160-001.html

Summary: Individuals with disabilities comprise one of the largest marginalized groups in the United States and experience systemic barriers in health care. In Westernized communities, disability has historically been conceptualized via the medical model, which considers disability an individual-level deficit in need of correction. Although other models of disability (e.g., social model) have been developed to address the medical model's ableist shortcomings, these fail to consistently acknowledge intersectionality. Specifically, these models fail to consider that (a) a disabled individual may hold other marginalized or oppressed identities and (b) these intersecting oppressions may exacerbate health inequities. Intersectionality, which originates from Black feminist literature, describes the ways that systems of power and oppression (e.g., racism, sexism) interact to form an individual's unique experience. To date, the intersection of disability and other marginalized identities has been neglected in psychology and related fields, leaving little guidance for how scholars, clinicians, and other stakeholders can address disability via an intersectional lens. The present article discusses how a disability-affirmative, intersectional approach can serve as a strategy for challenging and reforming oppressive systems across the field of psychology. We assert that, ultimately, this approach has the potential to optimize and expand access to equitable, inclusive mental health care, and we propose actionable steps psychologists can take in research, practice, training, and policy in pursuit of this aim.(Abstract from authors)

Reference:

Brinkman, A. H., Rea-Sandin, G., Lund, E. M., Fitzpatrick, O. M., Gusman, M. S., Boness, C. L., & Scholars for Elevating Equity and Diversity. (2022). Shifting the discourse on disability: Moving to an inclusive, intersectional focus. *American Journal of Orthopsychiatry*. <u>https://doi.org/10.1037/ort0000653</u>

Parents of Neurodiverse Children

Title: Autism spectrum disorder: family quality of life while waiting for intervention services

Summary: Purpose: Families of children with autism spectrum disorder (ASD) often experience high levels of stress; it is important to investigate the family quality of life (FQOL) to understand how to serve the entire family, not just the child. The purpose of this investigation was to determine: (a) how families with a child with ASD view their overall FQOL and (b) what aspects of everyday life have the greatest influence on the FQOL?MethodsA survey designed to asses FQOL was mailed to all families (n = 454) of children with ASD (0-18 years) waiting for government-funded services. Results from 151 surveys were examined (31 % response rate). Descriptive on all variables, ordinal logistic regression, and t tests were used to analyze the data.ResultsThe most influential factors on FQOL were whether the child with ASD had a major health concern, whether the family's needs were met by disability-related services, and whether there were opportunities to engage in leisure and recreation activities. Conclusions Families on waitlists experience challenges in FQOL influenced by the health of the family members; this is implicitly important for service agencies and providers. Future research should continue to explore how access to disability-related services impacts FQOL; and how these associations may be moderated by contextual factors such as socioeconomic status, health of child and family members, access and engagement in recreation, and severity of the child's needs.(Abstract from author)

Reference:

Jones, S., Bremer, E., & Lloyd, M. (2017). Autism spectrum disorder: family quality of life while waiting for intervention services. *Quality of Life Research, 26*(2), 331–342. <u>https://doi.org/10.1007/s11136-016-1382-7</u>

Title:Challenges and Coping among Parents having Children with Autism Spectrum Disorder **Summary:** Autism Spectrum Disorder (ASD) is a complex neurological disorder that affects an individual's brain function and causes impairments in multiple areas of development. Parents of these children face difficulties in dealing with challenging behaviours, communication pattern, and basic life skills. Parents appear to carry the larger burden of care and experience stress related to coping with the heavy load of care giving. The present paper aims to highlight the major challenges and difficulties faced by parents having children with autism and their coping strategies in dealing with their children with ASD.(Abstract from author)

Reference:

Kakkar, J., & Srivastava, P. (2017). Challenges and coping among parents having children with autism spectrum disorder. *Journal of Psychosocial Research*, *12*(2), 363-371. <u>https://www.proquest.com/scholarly-journals/challenges-coping-among-parents-having-c hildren/docview/2015378870/se-2</u>

Title: Understanding Parental Gatekeeping in Families with a Special Needs Child

• <u>https://onlinelibrary.wiley.com/doi/10.1111/fcre.12273</u>

Summary:Supporting the positive development of a special needs child is especially challenging when parents have separated or divorced. Invariably, there is an increased need for collaborative co-parenting wherein information is shared and intervention plans can be

implemented effectively. In this article, the evolving literature on parental gatekeeping is applied to families with special needs children, as it offers a useful model for understanding the strengths and liabilities of co-parenting relationships. We describe some of the typical and unique gatekeeping dynamics that occur when children suffer from developmental, physical, and/or psychiatric syndromes that require specific treatment and specialized parenting skills. Examples of both restrictive and facilitative gatekeeping are described as they manifest in these families. Implications for decision making are also discussed.(Abstract from authors)

Reference:

Kaufman, R. L., & Pickar, D. B. (2017). Understanding parental gatekeeping in families with a special needs child. *Family Court Review, 55*(2), 195–212. <u>https://doi.org/10.1111/fcre.12273</u>

Title:Caring for Autism: Practical Advice from a Parent and Physician

• https://academic.oup.com/book/40752

Summary:When a professional states, "Your child has Autism Spectrum Disorder (ASD)", it is enough to make your whole world fall apart. What does it mean to be on the autism spectrum? How will this affect your child's life, your life, the life of your family, and others you interact with? What sorts of medications, therapies, and alternative methods are used to help manage the disorder? What are the financial and legal ramifications? How will this affect schooling, your spiritual growth, and everyday life? These are just a few of the questions that will rapidly cross your mind. Caring for Autism: Practical Advice from a Parent and Physician delves into all these questions and more. As the father of a daughter with ASD and as a trained psychiatrist who specializes in ASD, Dr. Michael A. Ellis provides a holistic view of what comes after diagnosis. In user-friendly tones, he answers the most commonly asked questions about what it's actually like to live with ASD, what medications and therapies are available, and the global impact it has on the child's environment. With the help of his wife, Lori Layton Ellis, to provide a mother's perspective, Dr. Ellis shares personal stories of their 10-year journey in order to provide insight and support for anyone - patient, parent, caregiver - traversing the difficulties of autism.(Abstract from authors)

Reference:

Ellis, M. A. (2018). *Caring for autism: Practical advice from a parent and physician*. Oxford University Press. <u>https://doi.org/10.1093/oso/9780190259358.001.0001</u>

Title: Structural Family Therapy and Autism Spectrum Disorder: Bridging the Disciplinary Divide

• https://www.tandfonline.com/doi/full/10.1080/01926187.2017.1303653

Summary: Applied Behavior Analysis (ABA) is an evidence-based practice approach for the treatment of individuals with autism. The systemic effects of autism suggest that family therapy would considerably enhance the treatment of individuals with autism. Marriage and family therapy (MFT) training does not routinely include exposure to autism beyond the associated diagnostic criteria. Structural Family Therapy (SFT) is a systemic model that is familiar to those trained in family therapy and appropriate for the needs of families affected by autism. Therefore,

the authors have used SFT as a foundation for supervising MFT trainees working in an autism treatment setting.(Abstract from authors)

Reference:

Parker, & Molteni, J. (2017). Structural family therapy and autism spectrum disorder: Bridging the disciplinary divide. *The American Journal of Family Therapy, 45*(3), 135–148. <u>https://doi.org/10.1080/01926187.2017.1303653</u>

Title:Parenting stress in US families: implications for paediatric healthcare utilization

• <u>https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2214.2009.01052.x</u>

Summary: Objective According to family stress models, parental responses to stress disrupt interactions between parent and child and may lead to parental inability to seek timely medical care for their child. The objective of this study was to quantitatively assess the relationship between high parenting stress and child healthcare utilization. Methods We used the 2003-2004 National Survey of Children's Health to determine the prevalence of parenting stress in US families and associated socio-demographic variables. We used weighted logistic regression to investigate associations between parenting stress and healthcare utilization, controlling for other parental psychosocial and socio-demographic variables. The primary independent variables were parenting stress, parental mental health, parental coping and social support. The main dependent variables were emergency care, sick visits to primary care and preventive care in the past 12 months. Results Nationally, 13% of children lived in households with at least one parent experiencing high parenting stress. Socio-demographic variables associated with the highest odds of parenting stress included Black race, special needs status and non-English primary language. Parents with high parenting stress had a higher odds (adjusted odds ratio 1.24, 95% confidence interval 1.10–1.41) of seeking emergency care for their children compared with parents with low parenting stress, controlling for other parental psychosocial factors and socio-demographic variables. Conclusions Having a parent who is experiencing high parenting stress is associated with greater utilization of paediatric emergency care. Interventions targeted at parenting stress may provide families with needed support and reduce unnecessary emergency care utilization. (Abstarct from author)

Reference:

Raphael, J. L., Zhang, Y., Liu, H., & Giardino, A. P. (2010). Parenting stress in US families: implications for pediatric healthcare utilization. *Child: Care, Health & Development, 36*(2), 216–224. <u>https://doi.org/10.1111/j.1365-2214.2009.01052.x</u>

Title:Autism and Systemic Family Therapy

• <u>https://onlinelibrary.wiley.com/doi/10.1002/9781119438519.ch98</u>

Summary:Family therapy improves communication between autistic people and their families. It introduces a relational perspective to the individualizing discourse of autism. Accounts of people diagnosed as having an Autism Spectrum Condition are exchanged for descriptions of interacting social systems. Family therapy shifts the focus from diagnostic activity to relational

curiosity and encourages collaborative, curiosity-generating ways of conversing between autistic people and their networks. The concept of "mind" is relocated from the physical structure of a cognitive brain to the social, neurodiverse relational activities between people. The professional narratives of autism are expanded to demonstrate how the bias of the neurotypical, those considered normal by the general population, is restrictive and oppressive for autistic people and their families, resulting in what we call "oughtism." We discuss trends in autism theory, diagnosis, research, and treatment methods, explore how autism impacts on people's lives, and introduce new systemic practice theory on autism such as the Eco-Chaotic Conversational Approach, deconstructing "oughtism," and identifying communicating systems in areas of special interest. The chapter identifies areas for developing systemic family therapy training, practice, and research on autism.(Abstract from authors)

Reference:

Simon, G., Evans, M., Cano, F. U., Helps, S. L., & Vlam, I. (2020). Autism and systemic family therapy. In The Handbook of Systemic Family Therapy (pp. 407–432). John Wiley & Sons, Ltd. <u>https://doi.org/10.1002/9781119438519.ch98</u>

Title:*Understanding Autism: How Family Therapists Can Support Parents of Children with Autism Spectrum Disorders*

• https://onlinelibrary.wiley.com/doi/10.1111/j.1545-5300.2012.01399.x

Summary: The number of children diagnosed with an Autism Spectrum Disorder has increased dramatically in the last 20 years. Parents of children with autism experience a variety of chronic and acute stressors that can erode marital satisfaction and family functioning. Family therapists are well-suited to help parents stay connected to each other as they create a "new normal." However, family therapists need updated information about autism, and they need to understand how family therapy can help parents of children with autism. Because having a child with autism affects multiple domains of family life, this paper explores how family therapists can utilize an integrative approach with parents, enabling them to flexibly work with the domains of action, meaning, and emotion.(Abstract from authors)

Reference:

Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process*, *51*(2), 250–264. <u>https://doi.org/10.1111/j.1545-5300.2012.01399.x</u>

Title: Family therapy for autism spectrum disorders

Summary:Autism spectrum disorders (ASDs) are characterised by impairments in communication and reciprocal social interaction. These impairments can impact on relationships with family members, augment stress and frustration, and contribute to behaviours that can be described as challenging. Family members of individuals with ASD can experience high rates of carer stress and burden, and poor parental efficacy. While there is evidence to suggest that individuals with ASD and family members derive benefit from psychological interventions

designed to reduce stress and mental health morbidity, and enhance coping, most studies to date have targeted the needs of either individuals with ASD, or family members. We wanted to examine whether family (systemic) therapy, aimed at enhancing communication, relationships or coping, is effective for individuals with ASD and their wider family network.(Abstract from authors)

Reference:

Spain, D., Sin, J., Paliokosta, E., Furuta, M., Prunty, J. E., Chalder, T., Murphy, D. G., & Happe, F. G. (2017). Family therapy for autism spectrum disorders. *Cochrane Database of Systematic Reviews, 5*(5), CD011894–CD011894. https://doi.org/10.1002/14651858.CD011894

Title: Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience

Summary: The aim of this study was to test whether the effect of the pile-up of demands associated with a disability on quality of life, was mediated by resilience, quantity and quality of social support for adolescents with a disability and their parents. One hundred and thirty two parents, 90 mothers and 42 fathers and 111 adolescents, aged between 16 and 24 years completed measures of the pile-up of demands, social support, resilience and quality of life. Structural equation modeling with the bootstrap resampling method showed that the impact of the disability of their son/daughter on the quality of life of the parents was fully mediated through the parents' resilience and the quantity of social support and that resilience, however only partly, mediates the effect of adaptive skills on the quality of life of the adolescents with a disability. Limitations of the study and clinical implications are discussed. (Abstract with author)

Reference:

Migerode, F., Maes, B., Buysse, A., & Brondeel, R. (2012). Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience. *Journal* of Developmental and Physical Disabilities, 24(5), 487–503. doi: 10.1007/s10882-012-9285-1.

Title: Stress, coping, and resiliency among families of individuals with autism: A systematic review

Summary: Introduction: The rate of diagnosis for autism spectrum disorder (ASD) is on the rise. Families of individuals with ASD usually face challenges in raising their children. The coping strategies that allow for caregivers to prevail and be resilient in this situation need to be better understood. Thus, this review aimed to compile evidences related to resiliency and coping strategies among families of individuals with ASD. Methods: We searched several online databases including CINAHL, EBSCO, Embase, and Medline, which yielded 1613 articles. After applying the inclusion/exclusion criteria, 25 studies remained for review. Results: We found that caregivers use different coping strategies and report different stressors that are influenced by their partners support and resiliency. Positive cognitions can mediate the effects of raising a child with ASD, and the severity of the child's symptoms is one of the greatest influences on maternal well-being. Conclusion: The majority of previous studies are cross sectional or descriptive. It is crucial that empirical, longitudinal research establish a cogent picture of parental resiliency. A clearer picture of resiliency will help outline the ways in which parents can increase their well-being and quality of life, and this will support advancing the child resiliency and interventions that might be adopted. (Abstract with author)

Reference:

Ghanouni, P., & Hood, G. (2021). Stress, coping, and resiliency among families of individuals with autism: A systematic review. *Review Journal of Autism and Developmental Disorder, 8*, 389–402. doi: 10.1007/s40489-021-00245-y.

Title: Factors associated with resilience in families of children with autism spectrum disorder.

Summary: Objectives: Families of children with autism spectrum disorder (ASD) report high levels of stress and poor psychological functioning. Resilience serves to buffer these challenges. Little is known about the factors associated with resilience in these families. Methods: Data from the National Survey of Children's Health (NSCH) 2016 were used to investigate independent child, parent, and health care factors associated with resilience in families of children with ASD. We used the NSCH's family resilience composite derived from 4 survey questions focused on (1) communication, (2) working together to solve problems, (3) drawing on strengths, and (4) staying hopeful during difficult times. We defined family resilience as high or low based on the number of questions answered "all of the time" or "most of the time" versus "some of the time" or "none," respectively. Using survey weights, univariate and multivariate logistic regression analyses identified associations of child, parent, and health care factors with low family resilience. Results: We analyzed data representing 1151 children with ASD. Low resilience was reported in 32% of families. Low family resilience was significantly associated with parent factors such as not having someone to turn to for support, cutting work hours, and feeling "child hard to care for"; child ASD-related factors such as moderate ASD severity; and health care factors such as lack of satisfaction in communications with providers. Conclusion: The findings highlight specific vulnerabilities in families of children with ASD that are associated with low family resilience. Intervention approaches that have the ability to improve overall family resilience should be carefully considered. (Abstract from authors)

Reference:

Al-Jadiri, A., Tybor, DJ., Mulé, C., & Sakai, C. (2021). Factors associated with resilience in families of children with autism spectrum disorder. *Journal of Developmental & Behavioral Pediatrics, 42*(1), 16–22. doi: 10.1097/DBP.00000000000867.

Title: Supporting the supporter: Social support and physiological stress among caregivers of children with severe disabilities

Summary: The social, economic, and physical costs associated with providing long-term care for a child with disabilities can be overwhelming, and it is not uncommon for caregivers to experience burnout, emotional distress, and significant health ailments as a result of their

commitment to their child. Social support can be a key resource to combat these negative effects, as ample research has shown that social support can act as a buffer to the negative effects of stress. The current study explored whether short-term supportive interactions between parents of children with disabilities and members of their supportive network (n = 40 dyads) influenced the physiological stress responses (as measured by salivary cortisol) of both interactants. Results indicated that receiving support in a short interaction resulted in parents experiencing decreases to their physiological stress, though the quality of the support played a key role in determining how beneficial the interaction was in this context. These results suggest the importance of considering support quality when examining the influence of social support on physical outcomes for support recipients.(Abstract from authors)

Reference:

Faw, M. H. (2018). Supporting the supporter: Social support and physiological stress among caregivers of children with severe disabilities. *Journal of Social and Personal Relationships*, 35(2), 202–223. <u>https://doi.org/10.1177/0265407516680500</u>

Title: Stress among parents of children with and without Autism Spectrum Disorder: A comparison involving physiological Indicators and parent self-reports

<u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5502228/</u>

Summary: This study compared parent-reported stress, anxiety, depression, and some physiological measures of stress (cortisol, alpha-amylase, ambulatory blood pressure, heart rate) between parents of children with and without ASD. Results showed that parents whose children have ASD reported higher levels of parental distress, anxiety, and depression than parents of neurotypical children. Parents of children with ASD had significantly lower cortisol levels a half hour after walking and reported significantly higher utilization of multiple adaptive coping strategies (emotional support, positive reframing, planning, humor, acceptance, religion). Recommendations included meeting the individual needs of parents of children with ASD through health screening, stress-reduction interventions, and assistance with developing adaptive coping strategies.

Reference:

Padden, C., & James, J. E. (2017). Stress among parents of children with and without Autism Spectrum Disorder: A comparison involving physiological Indicators and parent self-reports. *Journal of Developmental and Physical Disabilities*, 29(4), 567–586. <u>https://doi.org/10.1007/s10882-017-9547-z</u>

Title: *Perceptions, experiences, and needs of parents of culturally and linguistically diverse children with autism: A scoping review*

• https://link.springer.com/article/10.1007/s40489-020-00210-1#citeas

Summary: This article contains a review of studies conducted in the U.K. and U.S. to examine perceptions, experiences, and needs of culturally diverse families of children with ASD. They found four themes: knowledge and beliefs about autism and their impact on the family; autism

and family life; family experiences of accessing services and support, parents' needs; and multilanguage. The results indicated that family perceptions of autism are influenced by a lack of knowledge, they experienced social stigma and difficulties in accessing services. The study found neurodivergent individuals and their families need culturally sensitive interventions, information available in multiple languages, and parent-professional collaboration.

Reference:

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2020). Perceptions, Experiences, and Needs of Parents of Culturally and Linguistically Diverse Children with Autism: a Scoping Review. *Review Journal of Autism Developmental Disorders*, 8, 195–212. https://doi.org/10.1007/s40489-020-00210-1

Title: Understanding disability in healthcare: Exploring the perceptions of parents of young people with autism spectrum disorder.

• https://www.tandfonline.com/doi/full/10.1080/09638288.2021.1948114

Summary: Purpose: How autism spectrum disorder (ASD) is understood (i.e., as a medical problem or natural human variation) has profound implications for how healthcare services are designed and delivered. As the recipients of these services, children and families are highly invested in these debates, yet little research has sought to investigate their views. The purpose of this study was to explore parents' conceptualizations of ASD in relation to disability, and how they align with, or diverge from, conceptualizations they encounter within healthcare. Materials and methods: Nine semi-structured qualitative interviews were conducted with parents of children with ASD and thematically analyzed. Results: The accounts suggested that participants integrated multiple and sometimes contradictory conceptualizations of disability that reflected both "medical" and "social" models and sources of disablement. While the participants often advocated for acceptance and inclusion of their child, the label of "neurodiversity" was commonly rejected due to the concern for potential loss of funding for services. Conclusions: Study findings highlight the relationship between how parents conceptualize ASD and their experiences accessing supportive services within current delivery structures. Implications for ASD service providers emphasize accommodating parents' unique and evolving values and priorities for healthcare and their relation to current service systems. Implications for Rehabilitation: Parents' conceptualizations of ASD both inform and are influenced by their experiences of accessing supportive services. This study highlights that parents' perspectives are fluid, context-dependent, and do not exclusively represent a single model or perspective of disability. To meet family needs, service providers including healthcare professionals must recognize parents' unique understandings of their child's ASD and appreciate how healthcare shapes these perceptions.(Abstract from authors)

Reference:

Stein, S. W., Alexander, R., Mann, J., Schneider, C., Zhang, S., Gibson, B. E., Gabison, S., Jachyra, P., & Mosleh, D. (2022). Understanding disability in healthcare: Exploring the perceptions of parents of young people with autism spectrum disorder. *Disability and Rehabilitation*, 44(19), 5623-5630, DOI: <u>10.1080/09638288.2021.1948114</u> **Title:** Early adversity and positive parenting: Association with cognitive outcomes in children with autism spectrum disorder

• https://onlinelibrary.wiley.com/doi/epdf/10.1002/aur.2613

Summary: Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and repetitive behaviors. Children with ASD are statistically more likely to experience early adversity; however, little is known about the types of early adversity that place these children at risk, the role of parenting as a protective factor, and how this early life stress impacts cognitive outcomes. We assessed early adversity in 302 children (ASD=98) aged 6–16 years old, using the parent-based report. To identify protective factors, we assessed parenting styles using parent surveys. Executive functions were assessed in the children using the WISC-V. Children with ASD had an increased incidence of familial stressors compared to the typically developing (TD) group. Positive parenting was associated with a significant decrease in the incidence of familial adverse events for both children with ASD and TD children. Examining the relationship between adversity and cognitive outcomes, in young children (6–11 years) with ASD, environmental stressors were associated with cognitive impairments. Findings suggest children with ASD may be at higher risk for familial adversity than their TD peers. However, all children benefit from positive parenting styles, which may mitigate the adverse effects of family-based early life stress.(Abstract from authors)

Reference:

Kuenzel, E., Seguin, D., Nicolson, R., Duerden, E. G. (2021). Early adversity and positive parenting: Association with cognitive outcomes in children with autism spectrum disorder. *Autism Research*, *14*(12), 2654-2662. <u>https://doi.org/10.1002/aur.2613</u>

Title: The spectrum of attitudes towards the spectrum of autism and its relationship to psychological distress in mothers of children with autism.

• https://journals.sagepub.com/doi/full/10.1177/13623613221081185

Summary: Attitude of mothers towards their children's autism may play a role in mothers' psychological well-being. We investigated the predictive value of how mothers understand autism (as a neurodivergence or a developmental disorder) on their psychological distress. A group of 371 mothers of children on the autism spectrum participated in this study. We found that understanding autism as a neurodivergence was related to lower psychological distress in mothers, even after controlling for the level of autism symptoms. However, when controlling for caregiver burden, their attitude towards autism was no longer significant in explaining their psychological distress. These findings suggest that the way mothers understand autism may be important for their psychological adjustment. However, it also suggests that mothers of children on the autism spectrum may adopt different attitudes towards autism, depending on their child's level of autism symptoms and the caregiver burden. (Abstract from author)

Reference:

Ferenc, K., Byrka, K., & Król, M. E. (2022). The spectrum of attitudes towards the spectrum of autism and its relationship to psychological distress in mothers of children with autism. *Autism*, 0(0). <u>https://doi.org/10.1177/13623613221081185</u>

Title: Custodial Homes, Therapeutic homes, and parental acceptance: Parental experiences of autism in Kerala, India and Atlanta, GA USA.

https://link.springer.com/article/10.1007/s11013-015-9441-z#citeas

Summary: The home is a critical place to learn about cultural values of childhood disability, including autism and intellectual disabilities. The current article describes how the introduction of autism into a home and the availability of intervention options change the structure and meaning of a home and reflect parental acceptance of a child's autistic traits. Using ethnographic data from Kerala, India and Atlanta, GA USA, a description of two types of homes are developed: the custodial home, which is primarily focused on caring for basic needs, and the therapeutic home, which is focused on changing a child's autistic traits. The type of home environment is respondent to cultural practices of child rearing in the home and influences daily activities, management, and care in the home. Further, these homes differ in parental acceptance of their autistic children's disabilities, which is critical to understand when engaging in international work related to autism and intellectual disability. It is proposed that parental acceptance can be fostered through the use of neurodiverse notions that encourage autism acceptance. (Abstract from authors)

Reference:

Sarrett, J. C. (2015). Custodial Homes, Therapeutic homes, and parental acceptance: Parental experiences of autism in Kerala, India and Atlanta, GA USA. *Culture, Medicine, and Psychiatry* 39, 254–276. <u>https://doi.org/10.1007/s11013-015-9441-z</u>

Gender Differences

Title: The female autism phenotype and camouflaging: a narrative review.

Summary: Autism is more commonly diagnosed in males than females. One explanation is the 'female protective effect': there is something inherent in being female which reduces the likelihood of developing autism. However, evidence suggests that the condition is underdiagnosed in females, perhaps because females express their autism in ways which do not meet current diagnostic criteria. This review explores evidence for a female-typical autism presentation, the Female Autism Phenotype (FAP) and the component of camouflaging (compensating for and masking autistic characteristics) in particular. The evidence so far supports the existence of a female-typical autism presentation, although further examination of the characteristics and their impact across all genders and ages is needed.(Abstract from authors)

Reference:

Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: a narrative review. *Review Journal of Autism and Developmental Disorders*, 7, 306–317. <u>https://doi.org/10.1007/s40489-020-00197-9</u>

Title: Epidemiological and clinical gender differences in OCD

• https://link.springer.com/article/10.1007/s11920-019-1015-2#citeas

Summary: Purpose of Review: This review highlights recent research regarding gender differences in OCD, with a focus on prevalence, course of illness, symptom presentation, comorbidity, and treatment response. Recent Findings: Overall, findings remain mixed. OCD may be more common among males in childhood, but is more common among females in adolescence and adulthood. Males tend to report an earlier age of onset and present with symptoms related to blasphemous thoughts. Females often describe symptom onset as occurring during or after puberty or pregnancy and present with symptoms related to contamination and/or aggressive obsessions. Females also tend to report significantly higher depression and anxiety. There are no reported gender differences in treatment outcome. Summary: Gender may play a role in the onset, presentation, and impact of OCD symptoms. However, more work is needed to account for differences across studies, with one promising future direction being the study of reproductive hormones.(Abstract from author)

Reference:

Mathes, B. M., Morabito, D. M., & Schmidt, N. B. (2019). Epidemiological and clinical gender differences in OCD. *Current Psychiatry Reports*, 21(5), 36. https://doi.org/10.1007/s11920-019-1015-2

Title: Explaining the Sex Difference in Dyslexia

• https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5438271/

Summary: Background: Males are diagnosed with dyslexia more frequently than females, even in epidemiological samples. This may be explained by greater variance in males' reading performance. Methods: We expand on previous research by rigorously testing the variance difference theory, and testing for mediation of the sex difference by cognitive correlates. We developed an analytic framework that can be applied to group differences in any psychiatric disorder. Results: Males' overrepresentation in the low performance tail of the reading distribution was accounted for by mean and variance differences across sex. There was no sex difference at the high performance tail. Processing speed and inhibitory control partially mediated the sex difference. Verbal reasoning emerged as a strength in males. Conclusions: Our results complement a previous finding that processing speed partially mediates the sex difference in symptoms of attention deficit/hyperactivity disorder (ADHD), and helps explain the sex difference in both dyslexia and ADHD and their comorbidity.(Abstract from authors)

Reference:

Arnett, A. B., Pennington, B. F., Peterson, R. L., Willcutt, E. G., DeFries, J. C., & Olson, R. K. (2017). Explaining the sex difference in dyslexia. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 58*(6), 719–727. <u>https://doi.org/10.1111/jcpp.12691</u>

Title: The prevalence and correlates of adult ADHD in the United States: results from the national comorbidity survey replication.

• https://pubmed.ncbi.nlm.nih.gov/16585449/

Summary: Objective: Despite growing interest in adult attention deficit hyperactivity disorder (ADHD), little is known about its prevalence or correlates. Method: A screen for adult ADHD was included in a probability subsample (N=3,199) of 18-44-year-old respondents in the National Comorbidity Survey Replication, a nationally representative household survey that used a lay-administered diagnostic interview to assess a wide range of DSM-IV disorders. Blinded clinical follow-up interviews of adult ADHD were carried out with 154 respondents, oversampling those with positive screen results. Multiple imputation was used to estimate prevalence and correlates of clinician-assessed adult ADHD. Results: The estimated prevalence of current adult ADHD was 4.4%. Significant correlates included being male, previously married, unemployed, and non-Hispanic white. Adult ADHD was highly comorbid with many other DSM-IV disorders assessed in the survey and was associated with substantial role impairment. The majority of cases were untreated, although many individuals had obtained treatment for other comorbid mental and substance-related disorders. Conclusions: Efforts are needed to increase the detection and treatment of adult ADHD. Research is needed to determine whether effective treatment would reduce the onset, persistence, and severity of disorders that co-occur with adult ADHD.(Abstract from authors)

Reference:

Kessler, R. C., Adler, L., Barkley, R., Biederman, J., Conners, C. K., Demler, O., Faraone, S. V., Greenhill, L. L., Howes, M. J., Secnik, K., Spencer, T., Ustun, T. B., Walters, E. E., & Zaslavsky, A. M. (2006). The prevalence and correlates of adult ADHD in the United States: results from the National Comorbidity Survey Replication. *The American journal* of psychiatry, 163(4), 716–723. https://doi.org/10.1176/ajp.2006.163.4.716

Title: Sex differences in autism spectrum disorder based on DSM-5 criteria: Evidence from clinician and teacher reporting

• <u>https://link.springer.com/article/10.1007/s10802-014-9881-x</u>

Abstract: In the absence of intellectual impairment autism spectrum disorder (ASD) is diagnosed both less and later in females. This study used clinician and teacher report to explore sex differences in the behavioural presentation of 69 girls and 69 boys all diagnosed with high-functioning ASD. Evidence from DSM-IV-TR and DSM-5 are presented. Sex differences in teacher concerns were also explored. While no sex differences were found in the broad social criteria presented in the DSM-IV-TR or DSM-5, numerous differences were evident in how boys and girls came to meet each criterion. For example, girls were more likely to show an ability to integrate non-verbal and verbal behaviours, maintain a reciprocal conversation, and be able to

initiate, but not maintain friendships. Moreover, girls presented with both less and different restricted interests. Teachers also reported substantially fewer concerns for girls than boys, including for externalising behaviours and social skills. Results suggest girls with ASD may present with a surface-level 'look' different from the 'classic' presentation of ASD, and present as less impaired when in a school setting. Consequently, results provide insight into why the disorder may be more difficult to detect in cognitively-able girls.(Abstract from author)

Reference:

Hiller, R.M., Young, R.L. & Weber, N. Sex differences in autism spectrum disorder based on DSM-5 criteria: Evidence from clinician and teacher reporting. Journal of Abnormal Child Psychology 42, 1381–1393 (2014). <u>https://doi.org/10.1007/s10802-014-9881-x</u>

Title: Specific learning disorder: Prevalence and gender differences

• <u>https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0103537</u>

Summary: Comprehensive models of learning disorders have to consider both isolated learning disorders that affect one learning domain only, as well as comorbidity between learning disorders. However, empirical evidence on comorbidity rates including all three learning disorders as defined by DSM-5 (deficits in reading, writing, and mathematics) is scarce. The current study assessed prevalence rates and gender ratios for isolated as well as comorbid learning disorders in a representative sample of 1633 German speaking children in 3rd and 4th Grade. Prevalence rates were analysed for isolated as well as combined learning disorders and for different deficit criteria, including a criterion for normal performance. Comorbid learning disorders occurred as frequently as isolated learning disorders, even when stricter cutoff criteria were applied. The relative proportion of isolated and combined disorders did not change when including a criterion for normal performance. Reading and spelling deficits differed with respect to their association with arithmetic problems: Deficits in arithmetic co-occurred more often with deficits in spelling than with deficits in reading. In addition, comorbidity rates for arithmetic and reading decreased when applying stricter deficit criteria, but stayed high for arithmetic and spelling irrespective of the chosen deficit criterion. These findings suggest that the processes underlying the relationship between arithmetic and reading might differ from those underlying the relationship between arithmetic and spelling. With respect to gender ratios, more boys than girls showed spelling deficits, while more girls were impaired in arithmetic. No gender differences were observed for isolated reading problems and for the combination of all three learning disorders. Implications of these findings for assessment and intervention of learning disorders are discussed.(Abstract from authors)

Reference:

Moll, K., Kunze, S., Neuhoff, N., Bruder, J., Schulte-Körne, G. (2014). Specific learning disorder: Prevalence and gender differences. *PLoS ONE*, *9*(7), e103537. <u>https://doi.org/10.1371/journal.pone.0103537</u>

Title: Influence of gender on Tourette syndrome beyond adolescence

• https://pubmed.ncbi.nlm.nih.gov/25193042/

Summary: Although boys are disproportionately affected by tics in Tourette syndrome (TS), this gender bias is attenuated in adulthood and a recent study has suggested that women may experience greater functional interference from tics than men. The authors assessed the gender distribution of adults in a tertiary University-based TS clinic population and the relative influence of gender and other variables on adult tic severity (YGTSS score) and psychosocial functioning (GAF score). We also determined retrospectively the influence of gender on change in global tic severity and overall TS impairment (YGTSS) since adolescence. Females were over-represented in relation to previously published epidemiologic surveys of both TS children and adults. Female gender was associated with a greater likelihood of tic worsening as opposed to tic improvement in adulthood; a greater likelihood of expansion as opposed to contraction of motor tic distribution; and with increased current motor tic severity and tic-related impairment. However, gender explained only a small percentage of the variance of the YGTSS global severity score and none of the variance of the GAF scale score. Psychosocial functioning was influenced most strongly by tic severity but also by a variety of comorbid neuropsychiatric disorders.(Abstract from authors)

Reference:

Lichter, D., Finnegan, G. (2015). Influence of gender on Tourette syndrome beyond adolescence. *European Psychiatry: The Journal of the Association of European Psychiatrists*, *30*(2), 334–340. <u>https://pubmed.ncbi.nlm.nih.gov/25193042/</u>

Title: ASD in females: Are we overstating the gender difference in diagnosis?

• https://link.springer.com/article/10.1007/s10567-013-0148-9

Summary: ASD can present differently between genders. ASD is diagnosed more in males. ASD may be underdiagnosed in females if they don't present with intellectual impairment and because they tend to internalize their problems. Females have less unusual stereotyped and repetitive behaviors. Biases, clinician expectations, measurement tools, different symptom expressions, and sociocognitive/developmental processes may explain the gender discrepancy. Culture-influenced interpretation of ASD causes females to experience delays in diagnosis, misdiagnosis, or lack of diagnosis. Recommendations include widespread screening and comparing females with previously unidentified ASD to males with previously unidentified ASD allowing for the examination of under-identification of ASD females. Inform school employees of signs and symptoms of ASD in females since they have a critical role in referrals.

Reference:

Kreiser, N. L., White, S. W. (2013). ASD in females: Are we overstating the gender difference in diagnosis? *Clinical Child and Family Psychology Review*, 17, 67–84. <u>https://doi.org/10.1007/s10567-013-0148-9</u>

Title: Gender bias, female resilience, and the sex ratio in autism

<u>https://www.clinicalkey.com/service/content/pdf/watermarked/1-s2.0-S089085671200411</u>
 X.pdf?locale=en_US&searchIndex=

Summary: A study found that when using the Development and Wellbeing Assessment (DAWBA) 56% of boys and 38% of girls met the criteria for ASD. Boys exhibit more social deficits, girls exhibit more communication deficits. The girls who received a diagnosis exhibited more intellectual and behavioral deficits than their male counterparts. The results suggest that females need to experience more symptoms and burdens to meet the threshold for diagnosis. Either current diagnostic approaches are flawed or girls may have a better adaptation to the same levels of ASD that would normally result in a diagnosis in boys. Genetic studies have shown that resilience and protective factors in females may explain the 4:1 male-to-female ratio for most familial autistic syndromes. Suggestions include possibly developing gender-specific thresholds for ASD screening and diagnosis.

Reference:

Constantino, J. N., & Charman, T. (2012). Gender bias, female resilience, and the sex ratio in autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(8), 756-758. <u>https://www.clinicalkey.com/service/content/pdf/watermarked/1-s2.0-S089085671200411</u> X.pdf?locale=en_US&searchIndex=

Title: Sex differences in predicting ADHD clinical diagnosis and pharmacological treatment

https://link.springer.com/article/10.1007/s00787-018-1211-3#citeas

Summary: In youth, ADHD is more commonly diagnosed in males than females, but higher male-to-female ratios are found in clinical versus population-based samples, suggesting a sex bias in the process of receiving a clinical diagnosis of ADHD. This study investigated sex differences in the severity and presentation of ADHD symptoms, conduct problems, and learning problems in males and females with and without clinically diagnosed ADHD. We then investigated whether the predictive associations of these symptom domains on being diagnosed and treated for ADHD differed in males and females. Parents of 19.804 twins (50.64% male) from the Swedish population completed dimensional assessments of ADHD symptoms and co-occurring traits (conduct and learning problems) when children were aged 9 years. Children from this population sample were linked to Patient Register data on clinical ADHD diagnosis and medication prescriptions. At the population level, males had higher scores for all symptom domains (inattention, hyperactivity/impulsivity, conduct, and learning problems) compared to females, but similar severity was seen in clinically diagnosed males and females. Symptom severity for all domains increased the likelihood of receiving an ADHD diagnosis in both males and females. Prediction analyses revealed significant sex-by-symptom interactions on diagnostic and treatment status for hyperactivity/impulsivity and conduct problems. In females, these behaviours were stronger predictors of clinical diagnosis (hyperactivity/impulsivity: OR 1.08, 95% CI 1.01, 1.15; conduct: OR 1.43, 95% CI 1.09, 1.87), and prescription of pharmacological treatment (hyperactivity/impulsivity: OR 1.24, 95% CI 1.02, 1.50; conduct: OR 2.20, 95% CI 1.05, 4.63). Females with ADHD may be more easily missed in the ADHD diagnostic process and less likely to be prescribed medication unless they have prominent externalising problems.(Abstract from authors)

Reference:

Mowlem, F. D., Rosenqvist, M. A., Martin, J., et al. (2019). Sex differences in predicting ADHD clinical diagnosis and pharmacological treatment. *European Child & Adolescent Psychiatry, 28*, 481–489. <u>https://doi.org/10.1007/s00787-018-1211-3</u>

Title: Differential Identification of Females and Males with Reading Difficulties: A Meta-Analysis

• https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6023418/

Summary: Males are more likely than females to be identified as having reading difficulties, but it is unclear if this is a result of sample ascertainment or identification bias. The purpose of this meta-analysis was to determine the magnitude of gender differences in reading difficulties using available studies in which researchers investigated this difference and an additional dataset with a representative U.S. sample. After conducting a literature search, sixteen studies and a restricted use dataset were included in the present analysis (N = 552,729). A random-effects odds ratio (OR) model indicated that males are 1.83 times more likely than females to have reading difficulties. Moderator analyses revealed that the gender ratio is greater when the identified reading difficulties were more severe. Further, this difference in identification rates across males and females was found without evidence of publication bias. Implications for the identification of students with reading difficulties are discussed.(Abstract from authors)

Reference:

Quinn, J. M. (2018). Differential identification of females and males with reading difficulties: A meta-analysis. Reading and Writing, 31(5), 1039-1061. doi: <u>10.1007/s11145-018-9827-8</u>

Obsessive Compulsive Disorder

Title: Obsessive-compulsive disorder in children and adolescents

• https://pubmed.ncbi.nlm.nih.gov/21475565/

Summary: Background: Early-onset obsessive-compulsive disorder (OCD) is one of the more common mental illnesses of children and adolescents, with prevalence of 1% to 3%. Its manifestations often lead to severe impairment and to conflict in the family. In this review, we summarize the manifestations, comorbidity, pathophysiology, and course of this disease as well as current modes of diagnosis and treatment. Methods: We selectively review the relevant literature and the German-language guidelines for the diagnosis and treatment of mental illnesses in children and adolescents. Results: Obsessive-compulsive manifestations are of many types and cause severe impairment. Comorbid mental disturbances are present in as many as 70% of patients. The disease takes a chronic course in more than 40% of patients. Cognitive behavioral therapy is the treatment of first choice, followed by combination pharmacotherapy including selective serotonin reuptake inhibitors (SSRI) and then by SSRI alone. Conclusion: OCD often begins in childhood or adolescence. There are empirically based

neurobiological and cognitive-behavioral models of its pathophysiology. Multiaxial diagnostic evaluation permits early diagnosis. Behavioral therapy and medications are highly effective treatments, but the disorder nonetheless takes a chronic course in a large percentage of patients.(Abstract from authors)

Reference:

 Walitza, S., Melfsen, S., Jans, T., Zellmann, H., Wewetzer, C., & Warnke, A. (2011).
 Obsessive-compulsive disorder in children and adolescents. *Deutsches Arzteblatt international*, *108*(11), 173–179. <u>https://doi.org/10.3238/arztebl.2011.0173</u>

Title: The effects of the COVID-19 pandemic on patients with obsessive-compulsive disorder

• https://www.tandfonline.com/doi/full/10.1080/13651501.2022.2082984

Summary: The main goal of the study was to examine how the pandemic has affected patients with obsessive compulsive disorder. 30 patients with OCD and 30 neurotypical controls were included in the cross-sectional study. The findings state that symptom severity worsened in 60% of OCD patients during the pandemic compared to the pre-pandemic stage. The results found that the levels of COVID19 related obsession and fear are not linked to the severity of OCD, but the anxiety levels.(Abstract from authors)

Reference:

Tükel, R., Başaran, O., Ergün, S., Chousein, M. G., Keskin, M., & Ertekin, E. (2022). The effects of the COVID-19 pandemic on patients with obsessive-compulsive disorder. *International Journal of Psychiatry in Clinical Practice.* <u>https://doi.org/10.1080/13651501.2022.2082984</u>

Title: A qualitative study exploring neurodiversity conference themes, representations, and evidence-based justifications for the explicit inclusion and valuing of OCD

https://www.jstor.org/stable/pdf/48645276.pdf?refreqid=excelsior%3A420c9150c8697cd3
 342a6f54f54dc586&ab_segments=&origin=&acceptTC=1

Summary: In this study, the inclusivity of neurodivergent conferences are evaluated. Viewing obsessive compulsive disorder, this study critically examines the inclusivity in the flyers that advertise these conferences. 22 conference flyers are inspected along with 14 scholarly articles. These articles offer evidence-based justifications for the greater inclusion of OCD content in neurodiversity conferences. The study warns that the lack of OCD as a topic at these conferences can lead to harm to the people who identify with this disorder.

Reference:

Mellifont, D. (2021). A qualitative study exploring neurodiversity conference themes, representations, and evidence-based justifications for the explicit inclusion and valuing of OCD. *The International Journal of Information, Diversity, & Inclusion*, *5*(2), 111–138. <u>https://www.jstor.org/stable/48645276</u> **Title:** *Is juvenile obsessive-compulsive disorder a developmental subtype of the disorder? A review of the pediatric literature.*

• https://pubmed.ncbi.nlm.nih.gov/9549963/

Abstract: Objective: To examine the clinical correlates of obsessive-compulsive disorder (OCD) in children and adolescents.Method: A systematic review of the extant literature on juvenile OCD was conducted examining age at onset, gender distribution, symptom phenomenology, psychiatric comorbidity, neurological and perinatal history, family psychiatric history, cognitive and neuropsychological profiles, and treatment and outcome in juvenile OCD subjects.Results: Juvenile OCD was associated with a unique peak of age at onset indicating a bimodal incidence of the disorder, male preponderance, a distinct pattern of comorbidity with attention-deficit/hyperactivity disorder and other developmental disorders as well as frequent absence of insight.Conclusion: These findings show that juvenile OCD is associated with a unique set of correlates that appear to differ from findings reported in studies of adult OCD subjects. Although in need of confirmation, these findings suggest that juvenile OCD may be a developmental subtype of the disorder. Since juvenile OCD is likely to continue into adulthood, these findings stress the importance of considering age at onset in clinical and research studies of adults with OCD.(Abstract from author)

Reference:

Geller D, Biederman J, Jones J, Park K, Schwartz S, Shapiro S, Coffey B. (1998) Is juvenile obsessive-compulsive disorder a developmental subtype of the disorder? A review of the pediatric literature. *J Am Acad Child Adolesc Psychiatry*. 37(4), 420-427. https://pubmed.ncbi.nlm.nih.gov/9549963/

Title: *Early-onset obsessive-compulsive disorder: A subgroup with a specific clinical and familial pattern?*

• https://pubmed.ncbi.nlm.nih.gov/16033636/

Summary: Background: The familial nature of obsessive-compulsive disorder (OCD) has been previously demonstrated. The identification of candidate symptoms such as age at onset may help to disentangle the clinical and genetic heterogeneity of the disorder. In this study, the specificity of early-onset OCD was investigated, focusing on the effect of gender, comorbid conditions and familial risk of tics and OCD by studying a population consisting exclusively of patients with early-onset OCD. Methods: One hundred and forty-four patients having OCD were recruited in the study (108 early-onset probands and 36 late-onset probands). The early-onset probands and 199 of their first-degree relatives were investigated using structured interviews and questionnaires. This sample of early onset was mainly composed of children and adolescents (74 children and adolescents and 34 adults). Results: The average age of onset of OCD is 9.98+/-3.2 years. Forty-four per cent of the probands have a comorbid tic disorder. The age-corrected morbid risk among the first-degree relatives is 17% for OCD and 12% for tics. Morbid risk for OCD and tics was independent of the presence of tics in probands. Only 32.6% of the probands have a positive family history of OCD. Conclusions: These findings are

consistent with other reports in the literature that the morbid risk of OCD is elevated in relatives of probands with early-onset OCD. However, the majority of cases do not have a positive family history of OCD. This result suggests that early onset is not the only specific clinical marker for familial risk in OCD. Thus more work is needed to clearly elucidate other factors related to increased genetic vulnerability for OCD.(Abstract from authors)

Reference:

Chabane, N., Delorme, R., Millet, B., Mouren, M., Leboyer, M., Pauls, D. (2005) Early-onset obsessive-compulsive disorder: A subgroup with a specific clinical and familial pattern? *Journal of Child Psychology & Psychiatry, 46*(8), 881-887. <u>https://pubmed.ncbi.nlm.nih.gov/16033636/</u>

Tourette Syndrome

Title: Prevalence of tic disorders: A systematic review and meta-analysis

• https://pubmed.ncbi.nlm.nih.gov/22759682/

Summary: This study evaluated the prevalence of tic disorders. MEDLINE and EMBASE databases were searched, using terms specific to Tourette syndrome and tic disorders, for studies of incidence, prevalence, and epidemiology. Thirty-five studies reporting data from 1985-2011 on the incidence or prevalence of tic disorders in a defined population were included. One reported incidence, and 34 reported prevalence. Meta-analysis of 13 studies of children yielded a prevalence of Tourette syndrome at 0.77% (95% confidence interval, 0.39-1.51%). Prevalence is higher in boys: 1.06% of boys were affected (95% confidence interval, 0.54-2.09%) vs 0.25% of girls (95% confidence interval, 0.05-1.20%). Transient tic disorder comprised the most common tic disorder in children, affecting 2.99% (95% confidence interval, 1.60-5.61%). Meta-analysis of two studies assessing adults for Tourette syndrome revealed a prevalence of 0.05% (95% confidence interval, 0.03-0.08%). The prevalence of tic disorders was higher in all studies performed in special education populations. Tic disorders are more common in children than adults, in boys than girls, and in special education populations. Parents, educators, healthcare professionals, and administrators should be aware of the frequency with which tic disorders occur, and ensure proper access to appropriate care.(Abstract from authors)

Reference:

Knight, T., Steeves, T., Day, L., Lowerison, M., Jette, N., Pringsheim, T. (2012). Prevalence of tic disorders: A systematic review and meta-analysis. *Pediatric Neurology*, 47(2), 77–90. <u>https://pubmed.ncbi.nlm.nih.gov/22759682/</u>

ADHD

ASD

Title: Inflexible daily behaviour is associated with the ability to control an automatic reaction in autism spectrum disorder

Summary: Inflexible behaviours in people with autism spectrum disorder (ASD) broadly obstruct social communication. Meanwhile, flexibility implicates cognitive control to resolve socially conflicting situations; however, it remains unclear how people with ASD behave in the face of these conflicts in this respect. We used the ultimatum game (UG) and the implicit-association test (IAT) to examine goal-directed/economic flexibility, both of which involve conflict and cognitive control. In addition, we used the Detail and Flexibility Questionnaire (DFlex) to measure inflexible everyday behaviour with diminished cognitive control and attention shifting. We observed the decreased flexibility in participants with ASD (DFlex and IAT); further, their IAT scores positively correlated with DFlex. However, in the UG, contrary to our prediction, participants with ASD accepted unfair offers more frequently than TD. These results suggest that assessing the automatic/attention processing level with the IAT could be a useful approach to study behavioural flexibility among ASD compared with the UG, which might comprise multiple response strategies besides economic rationality. Overall, the severity of inflexible daily behaviours in people with ASD may be associated with a reduced flexible attitude at an automatic level, altered attention processing and decreased cognitive control.(Abstract from authors)

Reference:

Tei, S., Fujino, J., Itahashi, T., Ohta, H., Kanai, C., Kubota, M., Nakamura, M., Kato, N., & Takahashi, H. (2017). Inflexible daily behaviour is associated with the ability to control an automatic reaction in autism spectrum disorder. *Scientific Reports, 8*. <u>https://doi.org/10.1038/s41598-018-26465-7</u>

Title: Deficit, difference, or both? Autism and neurodiversity

Summary: The neurodiversity movement challenges the medical model's interest in causation and cure, celebrating autism as an inseparable aspect of identity. Using an online survey, we examined the perceived opposition between the medical model and the neurodiversity movement by assessing conceptions of autism and neurodiversity among people with different relations to autism. Participants (N = 657) included autistic people, relatives and friends of autistic people, and people with no specified relation to autism. Self-identification as autistic and neurodiversity awareness were associated with viewing autism as a positive identity that needs no cure, suggesting core differences between the medical model and the neurodiversity movement. Nevertheless, results suggested substantial overlap between these approaches to autism. Recognition of the negative aspects of autism and endorsement of parenting practices that celebrate and ameliorate but do not eliminate autism did not differ based on relation to autism or awareness of neurodiversity. These findings suggest a deficit-as-difference conception of autism wherein neurological conditions may represent equally valid pathways within human diversity. Potential areas of common ground in research and practice regarding autism are discussed.(Abstract from authors)

Reference:

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59. doi: 10.1037/a0028353.

Title: Whose expertise is it? Evidence for autistic adults as critical autism experts

Summary: Autistic and non-autistic adults' agreement with scientific knowledge about autism, how they define autism, and their endorsement of stigmatizing conceptions of autism has not previously been examined. Using an online survey, we assessed autism knowledge and stigma among 636 adults with varied relationships to autism, including autistic people and nuclear family members. Autistic participants exhibited more scientifically based knowledge than others. They were more likely to describe autism experientially or as a neutral difference, and more often opposed the medical model. Autistic participants and family members reported lower stigma. Greater endorsement of the importance of normalizing autistic people was associated with heightened stigma. Findings suggest that autistic adults should be considered autism experts and involved as partners in autism research.(Abstract from authors)

Reference:

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*, *8*, 438. <u>https://doi.org/10.3389/fpsyg.2017.00438</u>

Title: Autism, "stigma," disability: A shifting historical terrain.

• https://www.journals.uchicago.edu/doi/full/10.1086/705748

Abstract: Erving Goffman's 1963 foundational discussion of stigma has been both embraced and critiqued in disability studies and other fields. In Goffman's interactional and ahistorical analysis, stigma was presumed to exist as a natural feature of humanity, deflecting attention away from historical analysis. This article, in contrast, argues that stigma—particularly surrounding "mental illness"—is deeply embedded in historically contingent structural conditions of modern capitalism and ideologies of individualism that shape ideals of the modern worker. Specifically, I use the case of autism—and its commodification in the United States—to show how a stigmatized "mental illness" is intertwined with a range of financial interests that come to depend on the continued production of certain diagnoses. For example, an analysis of the "autism industrial complex" in the United States reveals how economic changes set the conditions for a range of practices that promise to reduce stigma; these include special education, activism/advocacy, and self-representation. These occur in the context of a transition toward more flexible employment and the increasing value of technological and artistic skills often associated with neurodiversity. Despite the fact that a capitalist logic continues to define valuations of personhood, families and autistic self-advocates have been empowered in recent years to use a variety of strategies to decouple stigma and illness and resist conventional definitions of autism as a syndrome of deficits.(Abstract from authors)

Reference:

Grinker, R. R. (2020). Autism, "stigma," disability: A shifting historical terrain. *Current Anthropology*, *61*(S21). <u>https://www.journals.uchicago.edu/doi/full/10.1086/705748</u>

Title: Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice https://doi.org/10.3389/fpsyg.2021.635690

Abstract: The growth of autistic self-advocacy and the neurodiversity movement has brought about new ethical, theoretical and ideological debates within autism theory, research and practice. These debates have had genuine impact within some areas of autism research but their influence is less evident within early intervention research. In this paper, we argue that all autism intervention stakeholders need to understand and actively engage with the views of autistic people and with neurodiversity as a concept and movement. In so doing, intervention researchers and practitioners are required to move away from a normative agenda and pay diligence to environmental goodness-of-fit, autistic developmental trajectories, internal drivers and experiences, and autistic prioritized intervention targets. Autism intervention researchers must respond to these debates by reframing effectiveness, developing tools to measure autistic prioritized outcomes, and forming partnerships with autistic people. There is a pressing need for increased reflection and articulation around how intervention practices align with a neurodiversity framework and greater emphasis within intervention programmes on natural developmental processes, coping strategies, autonomy, and well-being. (Abstract from authors)

Reference:

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology*, *12*. <u>https://doi.org/10.3389/fpsyg.2021.635690</u>

Down Syndrome

Title: *Prevalence of Down syndrome among children and adolescents in 10 regions of the United States*

 <u>https://publications.aap.org/pediatrics/article-abstract/124/6/1565/72194/Prevalence-of-D</u> own-Syndrome-Among-Children-and?redirectedFrom=fulltext

Summary: OBJECTIVE: We aimed to estimate the prevalence of Down syndrome (DS) among children and adolescents aged 0 to 19 years in 10 regions of the United States. METHODS: This study was a cross-sectional analysis of live-born infants with DS during 1979–2003 from 10

population-based birth defects registries in the United States. We estimated the prevalence of DS at birth and among children aged 0 to 19 years in each region and in all regions pooled. The prevalence of DS among children and adolescents was calculated overall and according to age group, race/ethnicity, infant gender, and presence of a major heart defect. RESULTS: From 1979 through 2003, the prevalence of DS at birth increased by 31.1%, from 9.0 to 11.8 per 10000 live births in 10 US regions. In 2002, the prevalence among children and adolescents (0–19 years old) was 10.3 per 10000. The prevalence of DS among children in a given age group consistently increased over time but decreased with age within a given birth cohort. The pooled prevalence of DS among children and adolescents was lower among non-Hispanic black individuals and other racial/ethnic groups compared with non-Hispanic white individuals; it was also lower among females than males. CONCLUSIONS: This study provides prevalence estimates of DS among children and adolescents from 10 US regions. These estimates varied according to region, race/ethnicity, and gender, suggesting possible variation in prevalence at birth or in survival rates on the basis of these characteristics. (Abstract from authors)

Reference:

Shin, M., Besser, L. M., Kucik, J. E., Lu, C., Siffel, C., Correa, A., & Congenital Anomaly Multistate Prevalence And Survival (CAMPS) Collaborative. (2009). Prevalence of Down syndrome among children and adolescents in 10 regions of the United States. *Pediatrics* (*Evanston*), 124(6), 1565–1571. <u>Https://Doi.Org/10.1542/Peds.2009-0745</u>

Title: Estimation of the number of people with Down syndrome in the United States

<u>https://www.sciencedirect.com/science/article/pii/S1098360021024333?via%3Dihub</u>

Summary: Purpose: An accurate accounting of persons with Down syndrome (DS) has remained elusive because no population-based registries exist in the United States. The purpose of this study was to estimate this population size by age, race, and ethnicity. Methods: We predicted the number of people with DS in different age groups for different calendar years using estimations of the number of live births of children with DS from 1900 onward and constructing DS-specific mortality rates from previous studies. Results: We estimate that the number of people with DS living in the United States has grown from 49,923 in 1950 to 206,366 in 2010, which includes 138,019 non-Hispanic whites, 27,141 non-Hispanic blacks, 32,933 Hispanics, 6,747 Asians/Pacific Islanders, and 1,527 American Indians/American Natives. Population prevalence of DS in the United States, as of 2010, was estimated at 6.7 per 10,000 inhabitants (or 1 in 1,499). Conclusion: Until 2008, DS was a rare disease. In more recent decades, the population growth of people with DS has leveled off for non-Hispanic whites as a consequence of elective terminations. Changes in childhood survival have impacted the age distribution of people with DS, with more people in their fourth, fifth, and sixth decades of life.(Abstract from author)

Reference:

de Graaf, G., Buckley, F., & Skotko, B. G. (2017). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine*, *19*(4), 439–447. <u>https://doi.org/10.1038/gim.2016.127</u>

Dyslexia

Dysgraphia

Dyscalculia

Title: The Diagnosis and Treatment of Dyscalculia

<u>https://www.aerzteblatt.de/int/archive/article/205469</u>

Summary: Background: 3–7% of all children, adolescents, and adults suffer from dyscalculia. Severe, persistent difficulty performing arithmetical calculations leads to marked impairment in school, at work, and in everyday life and elevates the risk of comorbid mental disorders. The state of the evidence underlying various methods of diagnosing and treating this condition is unclear.Methods: Systematic literature searches were carried out from April 2015 to June 2016 in the PsycInfo, PSYNDEX, MEDLINE, ProQuest, ERIC, Cochrane Library, ICTRP, and MathEduc databases. The main search terms on dyscalculia were the German terms "Rechenstörung," "Rechenschwäche," and "Dyskalkulie" and the English terms "dyscalculia," "math disorder, and "math disability." The data from the retrieved studies were evaluated in a meta-analysis, and corresponding recommendations on the diagnosis and treatment of dyscalculia were jointly issued by the 20 societies and associations that participated in the creation of this guideline. Results: The diagnosis of dyscalculia should only be made if the person in question displays below-average mathematical performance when seen in the context of relevant information from the individual history, test findings, clinical examination, and further psychosocial assessment. The treatment should be directed toward the individual mathematical problem areas. The mean effect size found across all intervention trials was 0.52 (95% confidence interval [0.42; 0.62]). Treatment should be initiated early on in the primary-school years and carried out by trained specialists in an individual setting; comorbid symptoms and disorders should also receive attention. Persons with dyscalculia are at elevated risk of having dyslexia as well (odds ratio [OR]: 12.25); the same holds for attention deficit/hyperactivity disorder and for other mental disorders, both internalizing (such as anxiety and depression) and externalizing (e.g., disorders characterized by aggression and rule-breaking). Conclusion: Symptom-specific interventions involving the training of specific mathematical content yield the best results. There is still a need for high-quality intervention trials and for suitable tests and learning programs for older adolescents and adults.(Abstract from authors)

Reference:

Haberstroh, S., & Schulte-Körne, G. (2019). The diagnosis and treatment of dyscalculia. *Deutsches Arzteblatt international*, *116*(7), 107–114. https://www.aerzteblatt.de/int/archive/article/205469

Title: The diagnosis and treatment of dyscalculia

https://www.aerzteblatt.de/int/archive/article/205469

Summary: Background: 3–7% of all children, adolescents, and adults suffer from dyscalculia. Severe, persistent difficulty performing arithmetical calculations leads to marked impairment in school, at work, and in everyday life and elevates the risk of comorbid mental disorders. The state of the evidence underlying various methods of diagnosing and treating this condition is unclear. Methods: Systematic literature searches were carried out from April 2015 to June 2016 in the PsycInfo, PSYNDEX, MEDLINE, ProQuest, ERIC, Cochrane Library, ICTRP, and MathEduc databases. The main search terms on dyscalculia were the German terms "Rechenstörung," "Rechenschwäche," and "Dyskalkulie" and the English terms "dyscalculia," "math disorder, and "math disability." The data from the retrieved studies were evaluated in a meta-analysis, and corresponding recommendations on the diagnosis and treatment of dyscalculia were jointly issued by the 20 societies and associations that participated in the creation of this guideline. Results: The diagnosis of dyscalculia should only be made if the person in question displays below-average mathematical performance when seen in the context of relevant information from the individual history, test findings, clinical examination, and further psychosocial assessment. The treatment should be directed toward the individual mathematical problem areas. The mean effect size found across all intervention trials was 0.52 (95% confidence interval [0.42; 0.62]). Treatment should be initiated early on in the primary-school years and carried out by trained specialists in an individual setting; comorbid symptoms and disorders should also receive attention. Persons with dyscalculia are at elevated risk of having dyslexia as well (odds ratio [OR]: 12.25); the same holds for attention deficit/hyperactivity disorder and for other mental disorders, both internalizing (such as anxiety and depression) and externalizing (e.g., disorders characterized by aggression and rule-breaking). Conclusion: Symptom-specific interventions involving the training of specific mathematical content yield the best results. There is still a need for high-quality intervention trials and for suitable tests and learning programs for older adolescents and adults. (Abstract from authors)

Reference:

Haberstroh, S., Schulte-Körne, G. (2019). The diagnosis and treatment of dyscalculia. *Deutsches Arzteblatt international*, *116*(7), 107–114. <u>https://www.aerzteblatt.de/int/archive/article/205469</u>

Title: Gender differences in developmental dyscalculia depend on diagnostic criteria

• https://www.sciencedirect.com/science/article/pii/S095947521300025X

Abstract: Developmental dyscalculia (DD) is a learning difficulty specific to mathematics learning. The prevalence of DD may be equivalent to that of dyslexia, posing an important challenge for effective educational provision. Nevertheless, there is no agreed definition of DD and there are controversies surrounding cutoff decisions, specificity and gender differences. In the current study, 1004 British primary school children completed mathematics and reading assessments. The prevalence of DD and gender ratio were estimated in this sample using different criteria. When using absolute thresholds, the prevalence of DD was the same for both

genders regardless of the cutoff criteria applied, however gender differences emerged when using a mathematics-reading discrepancy definition. Correlations between mathematics performance and the control measures selected to identify a specific learning difficulty affect both prevalence estimates and whether a gender difference is in fact identified. Educational implications are discussed. (Abstract from authors)

Reference:

Devine, A., Soltesz, F., Nobes, A., Goswami, U., Szucs, D. (2013). Gender differences in developmental dyscalculia depend on diagnostic criteria. *Learning and Instruction*, 27, 31-39. https://doi.org/10.1016/j.learninstruc.2013.02.004.

Dyspraxia

Title: Dyspraxia or developmental coordination disorder? Unravelling the enigma

• https://adc.bmj.com/content/92/6/534

Summary: Dyspraxia is an enigma to many people, both professional and lay alike—what is it, how does it relate to developmental coordination disorder and associated conditions, how common is it, how is it recognised and diagnosed and how should it be managed? This article attempts to unravel this enigma by: dealing with the terminology of coordination difficulties from the "clumsy child syndrome" through "dyspraxia" to "developmental coordination disorder (DCD)"; briefly examining the debate as to whether dyspraxia or DCD should be regarded as a medical or social disorder; discussing the differential diagnosis of dyspraxia or DCD; considering the assessment of children with dyspraxia or DCD; reviewing the range of current treatment approaches in the UK.(Abstract from authors)

Reference:

Gibbs, J., Appleton, J., & Appleton, R. (2007). Dyspraxia or developmental coordination disorder? Unravelling the enigma. *Archives of Disease in Childhood*, 92(6), 534–539. <u>https://doi.org/10.1136/adc.2005.088054</u>

Ataxia

Title: Ataxia and me – living within a neurological hierarchy

• https://www.tandfonline.com/doi/full/10.1080/09687599.2022.2034110

Summary: By its very nature, the term Neurodiversity promotes the concept of biodiversity, the wonderful realm of neurocognitive functioning. Why is it that a paradigm that sets out to celebrate and give voice to those belonging to the neurodiverse community ostensibly silences those with rarer conditions? Having a rare neurological condition often intrinsically means living within the neurodiverse community alongside those with more prevalent ailments yet simultaneously living diametrically opposed. More uncommon and misunderstood

manifestations are often demonised and condemned as they deviate from what society deems as normal. The neurodiverse community has been limited to those with more prevalent and understood illnesses due to a lack of awareness surrounding other neurological disorders such as ataxia. This article questions the presence of a hierarchy within the neurodiverse community highlighting how it can often exacerbate feelings of inadequacy and shame for those with rarer conditions.(Abstract from authors)

Reference:

Clark, T. (2022). Ataxia and me - living within a neurological hierarchy. *Disability & Society,* 37(6), 1054–1059. <u>https://doi.org/10.1080/09687599.2022.2034110</u>

Title: Ataxia

• <u>https://journals.lww.com/continuum/Fulltext/2016/08000/Ataxia.14.aspx</u>

Summary: Purpose of Review: This article introduces the background and common etiologies of ataxia and provides a general approach to assessing and managing the patient with ataxia.Recent Findings: Ataxia is a manifestation of a variety of disease processes, and an underlying etiology needs to be investigated. Pure ataxia is rare in acquired ataxia disorders, and associated symptoms and signs almost always exist to suggest an underlying cause. While the spectrum of hereditary degenerative ataxias is expanding, special attention should be addressed to those treatable and reversible etiologies, especially potentially life-threatening causes. This article summarizes the diseases that can present with ataxia, with special attention given to diagnostically useful features. While emerging genetic tests are becoming increasingly available for hereditary ataxia, they cannot replace conventional diagnostic procedures in most patients with ataxia. Special consideration should be focused on clinical features when selecting a cost-effective diagnostic test.Summary: Clinicians who evaluate patients with ataxia should be familiar with the disease spectrum that can present with ataxia. Following a detailed history and neurologic examination, proper diagnostic tests can be designed to confirm the clinical working diagnosis.(Abstract from authors)

Reference:

Ashizawa, T., & Xia, G. (2016). Ataxia. *Movement Disorders, 22*(4), 1208–1226. https://doi.org/10.1212/CON.0000000000362

Title: Ataxia

• https://journals.lww.com/continuum/Fulltext/2016/08000/Ataxia.14.aspx

Summary: Ataxia, defined as impaired coordination of voluntary muscle movement, is a physical finding, not a disease, and the underlying etiology needs to be investigated. Ataxia can be the patient's chief complaint or a component among other presenting symptoms. Ataxia is usually caused by cerebellar dysfunction or impaired vestibular or proprioceptive afferent input to the cerebellum. Ataxia can have an insidious onset with a chronic and slowly progressive clinical course (eg, spinocerebellar ataxias [SCAs] of genetic origin) or have an acute onset, especially those ataxias resulting from cerebellar infarction, hemorrhage, or infection, which can have a rapid progression with catastrophic effects. Ataxia can also have a subacute onset, as from infectious or immunologic disorders, which may have a limited window of therapeutic

opportunities. A prompt management strategy for treatable causes of ataxia can save the patient's life and result in a good long-term outcome. Ataxia can also be benign in largely symptomatic disorders (eg, vestibular neuritis). With the advancement of neurogenetics, more inherited causes of cerebellar ataxia can be diagnosed,^{1,2} but many sporadic ataxias, including those with a chronic and progressive course, still remain undiagnosed.³ It cannot be overemphasized that it is easy to give a label of a neurodegenerative cause, but finding a reversible and treatable etiology should be sought. The evaluation of ataxia has been reviewed with many different approaches.^{4–7} This article introduces symptomatology, neuroanatomy, classification, and common etiologies of ataxia and provides a practical approach to the evaluation of ataxia.

Reference

Ashizawa, T., & Xia, G. (2016). Ataxia. *Movement Disorders, 22*(4), 1208–1226. <u>https://doi.org/10.1212/CON.0000000000362</u>

Co-occurring Conditions and Experiences

Discrimination

Title: Creating an Inclusive Society... How Close are We in Relation to Autism Spectrum Disorder? A General Population Survey

• https://onlinelibrary.wiley.com/doi/10.1111/jar.12144

Summary: Background: Children with autism spectrum disorder are increasingly educated in mainstream classrooms in the United Kingdom (Wilkinson & Twist, Autism and Educational Assessment: UK Policy and Practice. NFER, Slough, 2010), and some employers are now specifically seeking out staff on the autism spectrum. Does that mean that we are living in an 'inclusive society' [United Nations Department of Economic and Social Affairs (UNDESA), Creating an Inclusive Society: Practical Strategies to Promote Social Integration 2008], in the sense that inequalities are reduced and full economic, social and cultural participation is advanced for individuals with autism? MethodsA general population survey was conducted to assess how close we, as a society, are to an inclusive society for individuals with autism in Northern Ireland. Public attitudes were examined to (i) visibility and social interaction, (ii) aetiology, needs and interventions, and (iii) rights and resources. Results A stratified, representative sample of 1204 adults took part in the survey; of these, 989 were aware of autism and their attitudes and behavioural projections reflected a mix of acceptance and denunciation. The level of confusion with regard to interventions reflected the general uncertainty within UK policy regarding meeting the needs of individuals on the autism spectrum (International Journal of Disability, Development and Education 61, 134, 2014a). ConclusionTherefore, it seems that inclusion is working to an extent, but more clarity is needed with regard to adequate education, intervention and support for individuals with autism.(Abstract from authors)

Reference:

Dillenburger, K., McKerr, L., Jordan, J. A., Devine, P., & Keenan, M. (2015). Creating an inclusive society... how close are we in relation to autism spectrum disorder? A general population survey. *Journal of Applied Research in Intellectual Disabilities, 28*(4), 330–340. <u>https://doi.org/10.1111/jar.12144</u>

Title: The Crisis Facing Older People Living with Neurodiversity and Their Aging Family Carers: A Social Work Perspective

• https://www.tandfonline.com/doi/full/10.1080/01634372.2021.1920537

Summary: This commentary addresses barriers to care among older adults living with neurodiversity (ND), and their aging family carers in the context of the COVID-19 pandemic in Canada. Factors contributing to inequities are described and the significant negative consequences of current policy decisions on the social and mental health of older adults with ND and their aging family carers are highlighted. The commentary calls for a collective social work response that highlights the critical role of support and advocacy necessary to redress social exclusion.(Abstract from authors)

Reference:

Brotman S., Sussman T., Pacheco L., Dickson D., Lach L., Raymond E., Deshaies M., Freitas Z., & Milot E. (2021). The crisis facing older people living with neurodiversity and their aging family carers: A social work perspective. *Journal of Gerontological Social Work*, 64(5), 547-556. https://doi.org/10.1080/01634372.2021.1920537

Physical and Mental Health

Title:Brief Report: Examining the Association of Autism and Adverse Childhood Experiences in the National Survey of Children's Health: The Important Role of Income and Co-occurring Mental Health Conditions

• <u>https://link.springer.com/article/10.1007/s10803-017-3111-7</u>

Summary:Adverse childhood experiences (ACEs) are risk factors for mental and physical illness and more likely to occur for children with autism spectrum disorder (ASD). The present study aimed to clarify the contribution of poverty, intellectual disability and mental health conditions to this disparity. Data on child and family characteristics, mental health conditions and ACEs were analyzed in 67,067 youth from the 2011–2012 National Survey of Children's Health. In an income-stratified sample, the association of ASD and ACEs was greater for lower income children and significantly diminished after controlling for child mental health conditions, but not intellectual disability. Findings suggest that the association of ACEs and ASD is moderated by family income and contingent on co-occurring mental health conditions.(Abstract from authors)

Reference:

Kerns, C. M., Newschaffer, C. J., Berkowitz, S., & Lee, B. K. (2017). Brief report:

Examining the association of autism and adverse childhood experiences in the national survey of children's health: The important role of income and co-occurring mental health conditions. *Journal of Autism and Developmental Disorders, 47*(7), 2275–2281. <u>https://doi.org/10.1007/s10803-017-3111-7</u>

Title:Levels of anxiety and sources of stress in adults with autism

• <u>https://journals.sagepub.com/doi/10.1177/1744629507083585</u>

Summary:Clinical reports suggest that anxiety is a pertinent issue for adults with autism. We compared 34 adults with autism with 20 adults with intellectual disabilities, utilizing informant-based measures of anxiety and stress. Groups were matched by age, gender and intellectual ability. Adults with autism were almost three times more anxious than the comparison group and gained significantly higher scores on the anxiety subscales of panic and agoraphobia, separation anxiety, obsessive-compulsive disorder and generalized anxiety disorder. In terms of sources of stress, significant differences between the two groups were also found, and stress was found to correlate with high anxiety levels for the autism group, particularly the ability to cope with change, anticipation, sensory stimuli and unpleasant events. That is, the more anxious the individual with autism, the less likely they were able to cope with these demands. This has important implications for clinicians in terms of both assessment and treatment.(Abstract from author)

Reference:

Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities, 11*(4), 359–370. https://doi.org/10.1177/1744629507083585

Title:Rates of Co-occurring Psychiatric Disorders in Autism Spectrum Disorder Using the Mini International Neuropsychiatric Interview

• https://link.springer.com/article/10.1007/s10803-019-04090-1

Summary: Individuals with autism spectrum disorder (ASD) often meet criteria for at least one additional psychiatric disorder. The present study evaluated the utility of the Mini International Neuropsychiatric Interview (MINI) in assessing co-occurring psychiatric disorders in children, adolescents, and young adults with ASD. Ninety-one percent of children/adolescents and thirty-one percent of young adults were diagnosed with one or more co-occurring diagnoses using the MINI. MINI diagnostic rates were comparable to those found in the literature on children/adolescents with ASD; however, in young adults, MINI diagnostic rates were lower relative to rates found in the literature on young adults with ASD. Implications for treatment, transitioning to adulthood, and the need for instruments developed specifically to diagnose co-occurring disorders in ASD are discussed.(Abstract from authors)

Reference:

Mosner, M. G., Kinard, J. L., Shah, J. S., McWeeny, S., Greene, R. K., Lowery, S. C., Mazefsky, C. A., & Dichter, G. S. (2019). Rates of co-occurring psychiatric disorders in autism

spectrum disorder using the Mini International Neuropsychiatric Interview. *Journal of Autism and Developmental Disorders, 49*(9), 3819–3832. <u>https://doi.org/10.1007/s10803-019-04090-1</u>

Title: Adverse Childhood Experiences and Self-reported Liver Disease

• https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/215989

Summary:Objective To examine the relationship of adverse childhood experiences (ACEs), including abuse, neglect, and forms of household dysfunction, to the risk of liver disease by assessing the role of risk behaviors, such as substance abuse and high-risk sexual activity, as mediators of the ACEs-liver disease relationship. Methods Retrospective cohort study data were collected from 17 337 adult health plan members through a survey. Logistic regression adjusted for age, sex, race, and education was used to estimate the strength of the ACEs-liver disease relationship and the impact of the mediators in this relationship. Results Each of 10 ACEs increased the risk of liver disease 1.2 to 1.6 times (P<.001). The number of ACEs (ACE score) had a graded relationship to liver disease (P<.001). Compared with persons with no ACEs, the adjusted odds ratio of ever having liver disease among persons with 6 or more ACEs was 2.6 (P<.001). The ACE score also had a strong graded relationship to risk behaviors for liver disease. The strength of the ACEs-liver disease association was reduced 38% to 50% by adjustment for these risk behaviors, suggesting they are mediators of this relationship.Conclusions The ACE score showed a graded relationship to the risk of liver disease that appears to be mediated substantially by behaviors that increase the risk of viral and alcohol-induced liver disease. Understanding the effect of ACEs on the risk of liver disease and development of these behaviors provides insight into causal pathways, which may prove useful in the prevention of liver disease. (Abstract from authors)

Reference:

Dong, M., Dube, S. R., Felitti, V. J., Giles, W. H., & Anda, R. F. (2003). Adverse childhood experiences and self-reported liver disease: New insights into the causal pathway. *Archives of Internal Medicine*, *163*(16), 1949-1956. https://doi.org/10.1001/archinte.163.16.1949

Title:*Brain-body interactions underlying the association of loneliness with mental and physical health*

• https://www.sciencedirect.com/science/article/pii/S0149763420304425?via%3Dihub

Summary:Loneliness can be operationalized as the actual or perceived absence of those social relationships that serve to meet basic emotional needs. In contrast to solitude, a chosen state of being without company, loneliness is associated with negative affect and emotional distress. Loneliness can have detrimental effects on mental and physical wellbeing, expressed as an increased risk of morbidity and mortality. Higher rates of loneliness are observed in patients suffering from chronic health conditions, mental health conditions, cardiovascular problems, and neurodivergent populations, including autistic individuals. While the link between poor health and loneliness is established, the identification of relevant underlying mechanisms is a difficult

endeavor. In this narrative review, we provide an overview of published research and related literature describing the manifold interactions between loneliness, affective symptomatology, neural and embodied processing relevant to physical health, mental health, and neurodiversity. We propose a framework that can inform the identification of psychophysiological mechanisms underlying the link between loneliness and affective symptomatology that may represent interventional targets to mitigate the associated cycle of biopsychosocial morbidity.(Abstract from authors)

Reference:

Quadt, L., Esposito, G., Critchley, H. D., & Garfinkel, S. N. (2020). Brain-body interactions underlying the association of loneliness with mental and physical health. *Neuroscience and Biobehavioral Reviews, 116*, 283-300. https://doi.org/10.1016/j.neubiorev.2020.06.015

Title: Adverse childhood experiences and smoking during adolescence and adulthood

• https://pubmed.ncbi.nlm.nih.gov/10553792/

Summary: Context: In recent years, smoking among adolescents has increased and the decline of adult smoking has slowed to nearly a halt; new insights into tobacco dependency are needed to correct this situation. Long-term use of nicotine has been linked with self-medicating efforts to cope with negative emotional, neurobiological, and social effects of adverse childhood experiences.Objective: To assess the relationship between adverse childhood experiences and 5 smoking behaviors. Design: The ACE Study, a retrospective cohort survey including smoking and exposure to 8 categories of adverse childhood experiences (emotional, physical, and sexual abuse; a battered mother; parental separation or divorce; and growing up with a substance-abusing, mentally ill, or incarcerated household member), conducted from August to November 1995 and January to March 1996.Setting: A primary care clinic for adult members of a large health maintenance organization in San Diego, Calif.Participants: A total of 9215 adults (4958 women and 4257 men with mean [SD] ages of 55.3 [15.7] and 58.1 [14.5] years, respectively) who responded to a survey questionnaire, which was mailed to all patients 1 week after a clinic visit. Main outcome measures: Smoking initiation by age 14 years or after age 18 years, and status as ever, current, or heavy smoker. Results: At least 1 of 8 categories of adverse childhood experiences was reported by 63% of respondents. After adjusting for age, sex, race, and education, each category showed an increased risk for each smoking behavior, and these risks were comparable for each category of adverse childhood experiences. Compared with those reporting no adverse childhood experiences, persons reporting 5 or more categories had substantially higher risks of early smoking initiation (odds ratio [OR], 5.4; 95% confidence interval [CI], 4.1-7.1), ever smoking (OR, 3.1; 95% CI, 2.6-3.8), current smoking (OR, 2.1; 95% CI, 1.6-2.7), and heavy smoking (OR, 2.8; 95% CI, 1.9-4.2). Each relationship between smoking behavior and the number of adverse childhood experiences was strong and graded (P<.001). For any given number of adverse childhood experiences, recent problems with depressed affect were more common among smokers than among nonsmokers.Conclusions: Smoking was strongly associated with adverse childhood experiences. Primary prevention of

adverse childhood experiences and improved treatment of exposed children could reduce smoking among both adolescents and adults.(Abstract from authors)

Title: Experiences of Autism Acceptance and Mental Health in Autistic Adults

• <u>https://link.springer.com/article/10.1007/s10803-017-3342-7</u>

Summary: Mental health difficulties are highly prevalent in individuals on the autism spectrum. The current study examined how experiences and perceptions of autism acceptance could impact on the mental health of autistic adults. 111 adults on the autism spectrum completed an online survey examining their experiences of autism acceptance, along with symptoms of depression, anxiety and stress. Regression analyses showed that autism acceptance from external sources and personal acceptance significantly predicted depression. Acceptance from others also significantly predicted stress but acceptance did not predict anxiety. Further analyses suggested that experiences of "camouflaging" could relate to higher rates of depression. The current study highlights the importance of considering how autism acceptance could contribute to mental health in autism.(Abstract from authors)

References:

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders, 48*(2), 473–484. <u>https://doi.org/10.1007/s10803-017-3342-7</u>

Title: Adverse childhood experiences and smoking during adolescence and adulthood

• https://pubmed.ncbi.nlm.nih.gov/10553792/

Summary: Context: In recent years, smoking among adolescents has increased and the decline of adult smoking has slowed to nearly a halt; new insights into tobacco dependency are needed to correct this situation. Long-term use of nicotine has been linked with self-medicating efforts to cope with negative emotional, neurobiological, and social effects of adverse childhood experiences.Objective: To assess the relationship between adverse childhood experiences and 5 smoking behaviors. Design: The ACE Study, a retrospective cohort survey including smoking and exposure to 8 categories of adverse childhood experiences (emotional, physical, and sexual abuse; a battered mother; parental separation or divorce; and growing up with a substance-abusing, mentally ill, or incarcerated household member), conducted from August to November 1995 and January to March 1996. Setting: A primary care clinic for adult members of a large health maintenance organization in San Diego, Calif.Participants: A total of 9215 adults (4958 women and 4257 men with mean [SD] ages of 55.3 [15.7] and 58.1 [14.5] years, respectively) who responded to a survey questionnaire, which was mailed to all patients 1 week after a clinic visit. Main outcome measures: Smoking initiation by age 14 years or after age 18 years, and status as ever, current, or heavy smoker. Results: At least 1 of 8 categories of adverse childhood experiences was reported by 63% of respondents. After adjusting for age, sex, race, and education, each category showed an increased risk for each smoking behavior, and these risks were comparable for each category of adverse childhood experiences. Compared with those reporting no adverse childhood experiences, persons reporting 5 or more

categories had substantially higher risks of early smoking initiation (odds ratio [OR], 5.4; 95% confidence interval [CI], 4.1-7.1), ever smoking (OR, 3.1; 95% CI, 2.6-3.8), current smoking (OR, 2.1; 95% CI, 1.6-2.7), and heavy smoking (OR, 2.8; 95% CI, 1.9-4.2). Each relationship between smoking behavior and the number of adverse childhood experiences was strong and graded (P<.001). For any given number of adverse childhood experiences, recent problems with depressed affect were more common among smokers than among nonsmokers.Conclusions: Smoking was strongly associated with adverse childhood experiences. Primary prevention of adverse childhood experiences and improved treatment of exposed children could reduce smoking among both adolescents and adults.(Abstract from author)

Reference:

Anda, R. F., Croft, J. B., Felitti, V. J., Nordenburg, D., Giles, W. H., Williamson, D. F., & Giovino, G. A. (1999). Adverse childhood experiences and smoking during adolescence and adulthood. *JAMA*, 282(17), 1652-1658. <u>https://www.ncbi.nlm.nih.gov/pubmed/10553792</u>

Title: Neurodiversity in the shadow of COVID-19: flexibility and trust

• <u>https://www.achieveability.org.uk/files/1633342857/achieveability-neurodiverse-voices-se</u> cond-interactive-e-journal-2021.pdf

Summary: The last year has presented huge challenges and difficulties for the whole of the UKworkforce. While everyone has been affected by the coronavirus pandemic, it has had a differential impact on sectors and demographics. On a basic level front line workers have typically faced more difficulties than knowledge workers. Knowledge workers and those in secure work who have been better shielded than those in insecure working arrangements.(Abstract from authors)

Reference:

Cooper, R., Kelly, D., Hermanstein, D., & Hewlett, K. (2021). Neurodiverse voices: Good practice in the workplace in a time of COVID. *Achieve Ability,* 2. <u>https://www.achieveability.org.uk/files/1633342857/achieveability-neurodiverse-voices-second-in teractive-e-journal-2021.pdf</u>

Title: The sexual health, orientation, and activity of autistic adolescents and adults

• https://onlinelibrary.wiley.com/doi/10.1002/aur.2604

Summary:Small studies suggest significant differences between autistic and nonautistic individuals regarding sexual orientation and behavior. We administered an anonymized, online survey to n = 2386 adults (n = 1183 autistic) aged 16–90 years to describe sexual activity, risk of sexually transmitted infections (STIs), and sexual orientation. Autistic individuals are less likely to report sexually activity or heterosexuality compared to nonautistic individuals, but more likely to self-report asexuality or an 'other' sexuality. Overall, autistic, and nonautistic groups did not differ in age of sexual activity onset or contraction of STIs. When evaluating sex differences, autistic males are uniquely more likely to be bisexual (compared to nonautistic males); conversely, autistic females are uniquely more likely to be homosexual (compared to nonautistic

females). Thus, both autistic males and females may express a wider range of sexual orientations in different sex-specific patterns than general population peers. When comparing autistic males and females directly, females are more likely to have diverse sexual orientations (except for homosexuality) and engage in sexual activity, are less likely to identify as heterosexual, and have a lower mean age at which they first begin engaging in sexual activity. This is the largest study of sexual orientation of autistic adults. Sexual education and sexual health screenings of all children, adolescents, and adults (including autistic individuals) must remain priorities; healthcare professionals should use language that affirms a diversity of sexual orientations and supports autistic individuals who may have increased risks (affecting mental health, physical health, and healthcare quality) due to stress and discrimination from this intersectionality.(Abstract from authors)

Reference:

Weir, E., Allison, C., & amp; Baron-Cohen, S. (2021). The sexual health, orientation, and activity of autistic adolescents and adults. *Autism Research*, *14*(11), 2342–2354. <u>https://doi.org/10.1002/aur.2604</u>

Title: *Improving mental health in autistic young adults: A qualitative study exploring help-seeking barriers in UK primary care.*

Summary: Background: Autistic people are at increased risk of developing mental health problems. To reduce the negative impact of living with autism in a non-autistic world, efforts to improve take-up and access to care, and support in early years, which will typically start with a GP appointment, must be grounded in the accounts of autistic young adults. Aim: To explore how autistic young adults understand and manage mental health problems; and to consider help seeking as a focus. Design and setting: A cross-sectional, qualitative study. Autistic participants were purposively selected to represent a range of mental health conditions including anxiety and depression. A subsample were recruited from a population cohort screened for autism in childhood. The study concerns access to primary care. Method: Nineteen autistic young adults without learning disabilities, aged 23 or 24 years, were recruited. In-depth, semi-structured interviews explored how they understood and managed mental health problems. Data were analysed thematically. Results: Young adults preferred self-management strategies. Multiple factors contributed to a focus on self-management, including: beliefs about the aetiology of mental health difficulties and increased vulnerability with the context of a diagnosis of autism, knowledge of self-management, and a view that formal support was unavailable or inadequate. Families had limited awareness of professional support. Conclusion: Young autistic adults without learning disabilities, and their families, may hold erroneous beliefs about autism and mental health. This may affect help seeking and contribute to an exacerbation of symptoms. GPs need to be alert to the fact that autistic young adults in their care may be experiencing mental health difficulties but may not recognise them as such. (Abstract from authors)

Reference:

Coleman-Fountain, E., Buckley, C., & Beresford, B. (2020) Improving mental health in autistic young adults: A qualitative study exploring help-seeking barriers in UK primary care.

British Journal of General Practice 70(694) e356-e363 https://doi.org/10.3399/bjgp20X709421

Title: Experiences of Autism Acceptance and Mental Health in Autistic Adults

• https://link.springer.com/article/10.1007/s10803-017-3342-7

Summary: Mental health difficulties are highly prevalent in individuals on the autism spectrum. The current study examined how experiences and perceptions of autism acceptance could impact on the mental health of autistic adults. 111 adults on the autism spectrum completed an online survey examining their experiences of autism acceptance, along with symptoms of depression, anxiety and stress. Regression analyses showed that autism acceptance from external sources and personal acceptance significantly predicted depression. Acceptance from others also significantly predicted stress but acceptance did not predict anxiety. Further analyses suggested that experiences of "camouflaging" could relate to higher rates of depression. The current study highlights the importance of considering how autism acceptance could contribute to mental health in autism.(Abstract from authors)

References:

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders, 48*(2), 473–484. <u>https://doi.org/10.1007/s10803-017-3342-7</u>

Title: Co-occurring physical health challenges in neurodivergent children and young people: A topical review and recommendation.

Summary: Background: Neurodivergence has been established as associated with a significant number of co-occurring physical conditions, particularly for autistic individuals who are at risk for increased pain, hypermobility (including Ehlers-Danlos Syndrome) and gastrointestinal problems. However, data, so far, has been focused on adults and generally limited to discussions of condition prevalence alone. Methods: The following article will present a topical review of the literature considering evidence for increased physical health concerns within neurodivergent populations, particularly autistic individuals, with a focus on the impact that these physical health concerns may have in an educational setting. Results and discussion: The impact of physical health concerns within neurodivergent populations in an educational setting may be concerning. Such populations may face a range of challenges in obtaining appropriate support for physical conditions. We discuss a number of said challenges including; communication challenges, misattributing physical health symptoms as a part of neurodivergence, and a history of not being believed, which limits symptomatic reporting. We further consider the potential impact these physical health concerns may have on scholastic and social development, such as impacts for attainment and attendance. Furthermore, we provide recommendations for teachers, parents/carers and other allied professionals in young people's lives, on supporting young neurodivergent people with physical health concerns. (Abstract from authors)

Reference:

Donaghy, B., Moore, D., & Green, J. (2023). Co-occurring physical health challenges in neurodivergent children and young people: A topical review and recommendation. *Child Care In Practice, 29*(1), 3–21. <u>Https://Doi.Org/10.1080/13575279.2022.2149471</u>

Title: Assessment of Suicidal Behaviors Among Individuals With Autism Spectrum Disorder in Denmark

• https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2774853

Summary: Importance There is limited evidence supporting an association of autism spectrum disorder (ASD) with suicidality and the risk factors for suicide attempt and suicide among people with ASD. Existing research highlights the need for national cohort studies. Objectives To analyze whether people with ASD have higher rates of suicide attempt and suicide compared with people without ASD using national register data, identify potential risk factors for suicide attempt and suicide among those with ASD, and examine associations with comorbid disorders. Design, Setting, and Participants In this cohort study, nationwide register data from January 1, 1995, to December 31, 2016, were gathered on 6 559 266 individuals in Denmark aged 10 years or older. Statistical analysis was performed from November 20, 2018, to November 21, 2020. Main Outcomes and Measures Rates of suicide attempt and suicide among persons with ASD were compared with rates among persons without ASD, using Poisson regression models to calculate incidence rate ratios adjusted for sex, age, and time period Results Of the total study population of 6 559 266 individuals, 35 020 individuals (25 718 male [73.4%]; mean [SD] age at diagnosis, 13.4 [9.3] years) received a diagnosis of ASD. A total of 64 109 incidents of suicide attempts (587 [0.9%] among individuals with ASD) and 14 197 suicides (53 [0.4%] among individuals with ASD) were recorded. Persons with ASD had a more than 3-fold higher rate of suicide attempt (adjusted incidence rate ratio [aIRR], 3.19; 95% CI, 2.93-3.46) and suicide (aIRR, 3.75; 95% CI, 2.85-4.92) than those without ASD. For individuals with ASD, the aIRR for suicide attempt among female individuals was 4.41-fold (95% CI, 3.74-5.19) higher compared with male individuals; for individuals without ASD, the aIRR for female individuals was 1.41-fold (95% CI, 1.39-1.43) higher compared with male individuals. Higher rates of suicide attempt were noted across all age groups for those with ASD. Persons with a diagnosis of ASD only had an aIRR of 1.33 (95% CI, 0.99-1.78) for suicide attempt, whereas those with other comorbid disorders had an aIRR of 9.27 (95% CI, 8.51-10.10) for suicide attempt compared with those without any psychiatric disorders. A total of 542 of 587 individuals with ASD (92.3%) who attempted suicide had at least 1 other comorbid condition and 48 of 53 individuals with ASD (90.6%) who died by suicide had at least 1 other comorbid condition. Conclusions and Relevance This nationwide retrospective cohort study found a higher rate of suicide attempt and suicide among persons with ASD. Psychiatric comorbidity was found to be a major risk factor, with more than 90% of those with ASD who attempted or died by suicide having another comorbid condition. Several risk factors are different from the risk factors in the general population, which suggests the need for tailored suicide prevention strategies. (Abstract from authors)

Reference:

Kõlves, K., Fitzgerald, C., Nordentoft, M., Wood, S. J., & Erlangsen, A. (2021). Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark. *JAMA Network Open*, *4*(1). <u>https://doi.org/10.1001/jamanetworkopen.2020.33565</u>

Title: A scoping review of health disparities in autism spectrum disorder

Summary: Individuals with autism spectrum disorder (ASD) experience increased morbidity and decreased life expectancy compared to the general population, and these disparities are likely exacerbated for those individuals who are otherwise disadvantaged. We conducted a review to ascertain what is known about health and health system quality (e.g., high quality care delivery, adequate care access) disparities in ASD. Nine studies met final inclusion criteria. Seven studies identified racial disparities in access to general medical services for children with ASD. No studies examined disparities in health outcomes or included older adults. We present a model of health disparities (Fundamental Causes Model) that guides future research. Additional work should examine health disparities, and their causal pathways, in ASD, particularly for older adults. (Abstract from authors)

Reference:

Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(11), 3380–3391. https://doi.org/10.1007/s10803-017-3251-9

Title: Brief report: Examining the association of autism and adverse childhood experiences in the national survey of children's health: The important role of income and co-occurring mental health conditions.

Summary: Adverse childhood experiences (ACEs) are risk factors for mental and physical illness and more likely to occur for children with autism spectrum disorder (ASD). The present study aimed to clarify the contribution of poverty, intellectual disability and mental health conditions to this disparity. Data on child and family characteristics, mental health conditions and ACEs were analyzed in 67,067 youth from the 2011–2012 National Survey of Children's Health. In an income-stratified sample, the association of ASD and ACEs was greater for lower income children and significantly diminished after controlling for child mental health conditions, but not intellectual disability. Findings suggest that the association of ACEs and ASD is moderated by family income and contingent on co-occurring mental health conditions.(Abstract from authors)

Reference:

Kerns, C. M., Newschaffer, C. J., Berkowitz, S., & Lee, B. K. (2017). Brief report: Examining the association of autism and adverse childhood experiences in the national survey of children's health: The important role of income and co-occurring mental health conditions. *Journal of Autism and Developmental Disorders*, *47*(7), 2275–2281. <u>https://doi.org/10.1007/s10803-017-3111-7</u>

Title: Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark

• https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2774853

Summary: Autism spectrum disorder (ASD) comprises a set of chronic neurodevelopmental disorders with a wide range of symptoms and levels of severity.1,2 Globally, the prevalence of ASD has been estimated to be 1% to 1.5%,3 with a cumulative incidence up to 2.8% in recent birth cohorts in Denmark.4 Although the onset of ASD is generally in childhood, it may be recognized and diagnosed later in life.2 The number of children with a diagnosis of ASD has increased during recent decades, 1, 2, 5, 6 and professionals have debated whether this increase is due to changes in diagnostic criteria, increased clinical or parental awareness, or increased prevalence of etiologic factors.2,4-7 Lack of social integration, unemployment, and psychiatric disorders have been found to be associated with ASD in adults8 : the same factors are associated with suicidal behavior,9,10 which would suggest a potential link between ASD and suicidal behavior. Nevertheless, little evidence from large-scale studies exists regarding an association between ASD and suicidality.11-15 A recent population-based case-cohort study from Sweden showed an increased risk of suicide and suicide attempt among those with ASD, especially among those without intellectual disability.16 It has yet to be determined what factors are associated with suicidal behavior in people with ASD and whether they differ from the factors associated with suicidal behavior in the population without ASD. To make evidence-based decisions and inform the design of intervention studies, there is a need for largescale national cohort studies on the risk of suicide attempts and suicides among persons with ASD. Therefore, the aims of this retrospective cohort study were to analyze whether people with a diagnosis of ASD had higher rates of suicide attempts and suicides compared with people without ASD, identify risk factors for suicide attempt and suicide among those with ASD, and examine associations with psychiatric comorbid disorders.

Reference:

Kõlves, K., Fitzgerald, C., Nordentoft, M., Wood, S.J., Erlangsen, A. (2021) Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark. *JAMA Network Open*, 4(1). <u>https://doi.org/10.1001/jamanetworkopen.2020.33565</u>

Title: Rates of co-occurring psychiatric disorders in Autism Spectrum Disorder using the mini international neuropsychiatric interview

<u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6669096/</u>

Summary: Those with ASD frequently meet the criteria for one or more psychiatric disorders. When using the MNII, 91% of children/adolescents and 31% of young adults were diagnosed with one or more co-occurring disorders. Some co-occurring disorders included: anxiety 34.3%, depression 28.6%, ADHD 71.4%, OCD 11.4%, Tourette's disorder 5.7%, and ODD 40.0%. Treatment methods: 60.0% were on a stimulant or other ADHD medication, 34.3% were on an SSRI or other antidepressant, 37.1% psychotherapy, and 31.4% occupational therapy. Young adults with ASD work fewer hours and are less likely to be employed than neurotypical, and co-occurring disorders impact their quality of life and functioning. Need measurement tool to specifically measure co-occurring disorders in neurodivergent.

Reference:

Mosner, M. G., Kinard, J. L., Shah, J. S., McWeeny, S., Greene, R. K., Lowery, S. C., Mazefsky, C. A., & Dichter, G. S. (2019). Rates of co-occurring psychiatric disorders in autism spectrum disorder using the Mini International Neuropsychiatric Interview. *Journal of Autism and Developmental Disorders*, 49(9), 3819–3832. <u>https://doi.org/10.1007/s10803-019-04090-1</u>

Title: Dyslexia in Adults Is Associated with Clinical Signs of Fatty Acid Deficiency

• https://www.sciencedirect.com/science/article/abs/pii/S0952327800901959

Summary: Dyslexia is a syndrome whose exact cause is unknown. It is suggested that the problem may lie in fatty acid metabolism, especially in relation to the visual symptoms exhibited by many dyslexics. Two self-report questionnaires were administered to assess the clinical signs of fatty acid deficiency and the symptoms associated with dyslexic and non-dyslexic subjects. Results revealed that fatty acid deficiency signs were significantly elevated in dyslexic subjects relative to the controls, particularly among males. Additionally, the severity of clinical signs of fatty acid deficiency was strongly correlated with the severity of dyslexic signs and symptoms.

Reference:

Taylor, K. E., Higgins, C. J., Calvin, C. M., Hall, J. A., Easton, T., McDaid, A. M., & Richardson,
 A. J. (2000). Dyslexia in adults is associated with clinical signs of fatty acid deficiency.
 Prostaglandins, Leukotrienes and Essential Fatty Acids (PLEFA), 63(1-2), 75-78.

Title: Depressive symptoms within OCD: The role of experiential avoidance

• <u>https://www.cambridge.org/core/journals/behavioural-and-cognitive-psychotherapy/article/examining-depression-symptoms-within-ocd-the-role-of-experiential-avoidance/61DD5067C00F63CD3CF6BC1659355EFB</u>

Summary: OCD and depressive symptoms commonly co-occur. This study evaluates the relationships between distress tolerance (DT), experiential avoidance (EA), depression, and OCD severity of symptoms across intensive residential treatment for OCD. 311 participants with OCD who were in intensive residential treatment were included. At both discharge and admission, higher experiential avoidance, lower distress tolerance, and higher OCD symptom severity were significantly associated with more depressive symptoms. Experiential avoidance was found to be the treatment target for OCD.

Reference:

Browning, M., Van Kirk, N., & Krompinger, J. (2022). Examining depression symptoms within OCD: The role of experiential avoidance. *Behavioural and Cognitive Psychotherapy*, *50*(4), 367-380. doi:10.1017/S1352465821000497

Title: Brain-body interactions underlying the association of loneliness with mental and physical *health*

 <u>https://www.sciencedirect.com/science/article/pii/S0149763420304425?casa_token=xTE</u> <u>eK8QnGOYAAAAA:8flrnFlxh7P2P8BpdOFhld_8AzHi1h05w7UHq4P6osP9WThhB_I7mN</u> <u>mgUlwmhDu3HcLxhUET</u>

Summary: Neurodivergent individuals are more at risk for experiencing distress from social isolation and negative physical consequences associated with loneliness. ASD and ADHD are at an increased risk for mental and physical health conditions including depression, anxiety, chronic pain conditions, and immunological challenges. Research demonstrates that ASD and ADHD adults are more likely to feel lonely than neurotypical adults. Studies have found that adults with ADHD often experience decreased social satisfaction (poor quality relationships), challenges in marital relationships, and poor social support. People with ADHD are more vulnerable to mental health conditions like anxiety and depression. ASD children/adolescents have higher rates of loneliness and higher levels of social anxiety. In children/adolescents, loneliness correlates negatively with social skills and social competence and correlates positively with social anxiety. Results from large-scale studies have shown that loneliness is up to four times higher in ASD adults than in neurotypical adults. Loneliness may exacerbate inflammatory responses, which may be what causes negative physical health outcomes. Perceptions of social isolation create an increase in focus on social threats, which is correlated with reductions in health-related behaviors, poor quality of sleep, and higher levels of stress. Loneliness has a significant relationship between diabetes, migraines, and cardiovascular disease. This means that because neurodivergent individuals experience more loneliness than those who are neurotypical, they are more at risk for negative mental and physical health outcomes.

Reference:

 Quadt, L., Esposito, G., Critchley, H. D., Garfinkel, S. N. (2020). Brain-body interactions underlying the association of loneliness with mental and physical health. *Neuroscience and Biobehavioral Reviews*, 116, 283-300. <u>https://reader.elsevier.com/reader/sd/pii/S0149763420304425?token=3F6250AD253F57</u> <u>919CD9D0B5440695FFCAE010DE37F8244C81DF5FCB5F80A4301007F03A4ECAC00</u> <u>9388551A53489E0D3&originRegion=us-east-1&originCreation=20221011175230</u>

Title: Long-term condition management in adults with intellectual disability in primary care: A systematic review.

<u>https://bjgpopen.org/content/2/1/bjgpopen18X101445</u>

Summary: Background: Adults with intellectual disabilities have higher morbidity and earlier mortality than the general population. Access to primary health care is lower, despite a higher prevalence of many long-term conditions. Aim: To synthesise the evidence for the management of long-term conditions in adults with intellectual disabilities and identify barriers and facilitators to management in primary care. Design & setting: Mixed-methods systematic review. Method: Seven electronic databases were searched to identify both quantitative and qualitative studies concerning identification and management of long-term conditions in adults with intellectual

disability in primary care. Both the screening of titles, abstracts, and full texts, and the quality assessment were carried out in duplicate. Findings were combined in a narrative synthesis. Results Fifty-two studies were identified. Adults with intellectual disabilities are less likely than the general population to receive screening and health promotion interventions. Annual health checks may improve screening, identification of health needs, and management of long-term conditions. Health checks have been implemented in various primary care contexts, but the long-term impact on outcomes has not been investigated. Qualitative findings highlighted barriers and facilitators to primary care access, communication, and disease management. Accounts of experiences of adults with intellectual disabilities reveal a dilemma between promoting self-care and ensuring access to services, while avoiding paternalistic care. Conclusion: Adults with intellectual disabilities face numerous barriers to managing long-term conditions. Reasonable adjustments, based on the experience of adults with intellectual disability, in addition to intervention such as health checks, may improve access and management, but longer-term evaluation of their effectiveness is required. (Abstract from authors)

Reference:

Hanlon, P., MacDonald, S., Wood, K., Allan, L., & Cooper, S. (2018). Long-term condition management in adults with intellectual disability in primary care: A systematic review. *BJGP Open*, 2(1). DOI: <u>https://doi.org/10.3399/bjgpopen18X101445</u>

Comorbid Neurodiversity Conditions

Title: Learning disabilities and ADHD: Overlapping spectrum disorders

• <u>https://pubmed.ncbi.nlm.nih.gov/15495544/</u>

Summary: Clinical and psychoeducational data were analyzed for 119 children ages 8 to 16 years who were evaluated in a child diagnostic clinic. A learning disability (LD) was present in 70% of the children with attention-deficit/hyperactivity disorder (ADHD), with a learning disability in written expression two times more common (65%) than a learning disability in reading, math, or spelling. Children with LD and ADHD had more severe learning problems than children who had LD but no ADHD, and the former also had more severe attention problems than children who had ADHD but no LD. Further, children with ADHD but no LD had some degree of learning problem, and children with LD but no ADHD had some degree of attention problem. Results suggest that learning and attention problems are on a continuum, are interrelated, and usually coexist.(Abstract from authors)

Reference:

Mayes, S., Calhoun, S., Crowell, E. (2000). Learning disabilities and ADHD: Overlapping spectrum disorders. *Journal of Learning Disabilities, 33*(5), 417–424. https://pubmed.ncbi.nlm.nih.gov/15495544/ Title: The Neurobiological Link Between OCD and ADHD

• https://link.springer.com/content/pdf/10.1007/s12402-014-0146-x.pdf

Summary: OCD and ADHD are two of the most common mental disorders diagnosed in the pediatric community. OCD and ADHD have a comorbidity level of at least 40-50%. Familial studies found that there is high heritability in ADHD and OCD. Neuroimaging and neuropsychological studies suggest that party similar executive functions are affected in both of these disorders. This article examines the current neuroimaging, neurochemical circuitry, neuropsychological, and genetic findings from the current literature. They found several similarities and differences between OCD and ADHD.

Reference:

Brem, S., Grünblatt, E., Drechsler, R., Riederer, P., & Walitza, S. (2014). The neurobiological link between OCD and ADHD. *ADHD Attention Deficit and Hyperactivity Disorders*, *6*(3), 175-202. <u>https://link.springer.com/content/pdf/10.1007/s12402-014-0146-x.pdf</u>

Title: Measuring the emergence of specific abilities in young children with Autism Spectrum Disorders: The example of early hyperlexic traits

• https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8225194/

Summary: Hyperlexia is early word reading skills and interest in written material that occurs without explicit teaching and is above typical language comprehension and general cognitive level. Hyperlexia is considered a superability and is part of special skills among those with ASD. Hyperlexia also occurs in those with developmental delays, Down syndrome, Turner syndrome, and ADHD. Hyperlexia is higher in ASD than in other neurodevelopmental disorders and ranges from 6-20%. Hyperlexia occurs mostly in boys. This study found that 9% of children with ASD had early hyperlexic traits.

Reference:

Solazzo, S., Kojovic, N., Robain, F., & Schaer, M. (2021). Measuring the emergence of specific abilities in young children with Autism Spectrum Disorders: The example of early hyperlexic traits. *Brain Sciences*, 11(6), 692. <u>https://doi.org/10.3390/brainsci11060692</u>

Title: Dyscalculia and Dyslexia in Adults: Cognitive Bases of Comorbidity

<u>https://reader.elsevier.com/reader/sd/pii/S1041608014002179?token=988A2386B907B0</u>
 <u>551425C34BE0C4DF7C06ED9251C8E23CDDEBB4073724B2E5A2DEDF2BF6B317FB</u>
 <u>6F478D3B358775F49B&originRegion=us-east-1&originCreation=20221013141910</u>

Summary: Dyslexia and dyscalculia have a prevalence of 10% or more when combined, and a co-occurrence rate of around 40%. This study examined the comorbidity in four groups of 85 individuals. A computerized testing battery including core components of mathematics and reading was used. The study argues that the presence of several underlying impairments support complex multifactorial models of comorbidity.

Reference:

Wilson, A. J., Andrewes, S. G., Struthers, H., Rowe, V. M., Bogdanovic, R., & Waldie, K. E. (2015). Dyscalculia and dyslexia in adults: Cognitive bases of comorbidity. *Learning and individual differences*, 37, 118-132.

Title: Defining and understanding dyslexia: Past, present and future

• https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7455053/

Summary: Dyslexia is difficulty learning to decode and spell. Around 40% of children with a reading disorder/dyslexia will also have another disorder. Developmental Language Disorder (difficulties in expressive/receptive language) is a major risk factor for dyslexia. Dyslexia frequently co-occurs with attentional and motor coordination problems (dyspraxia), speech sound disorder, socio-emotional and behavioral disorders, and internalizing problems (anxiety, depression, etc.). Dyscalculia, a mathematics disorder, is comorbid with dyslexia in about 30-70% of cases.

Reference:

Snowling, M. J., Hulme, C., & Nation, K. (2020). Defining and understanding dyslexia: Past, present and future. *Oxford Review of Education*, *46*(4), 501–513. https://doi.org/10.1080/03054985.2020.1765756

Title: Comorbidities, social impact, and quality of life in Tourette syndrome.

• https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4893483/#__ffn_sectitle

Summary: Tourette syndrome (TS) is more than having motor and vocal tics, and this review will examine the varied comorbidities as well as the social impact and quality of life (QoL) in individuals with TS. The relationship between any individual and his/her environment is complex, and this is further exaggerated in the case of a person with TS. For example, tics may play a significant role in shaping the person's experiences, perceptions, and interactions with the environment. Furthermore, associated clinical features, comorbidities, and coexisting psychopathologies may compound or alter this relationship. In this regard, the common comorbidities include attention-deficit hyperactivity disorder and disruptive behaviors, obsessive compulsive disorder, and autism spectrum disorder, and coexistent problems include anxiety, depression, and low self-esteem, which can all lead to poorer psychosocial functioning and QoL. Thus, the symptoms of TS and the associated comorbid conditions may interact to result in a vicious cycle or a downward spiraling of negative experiences and poor QoL. The stigma and social maladjustment in TS and the social exclusion, bullying, and discrimination are considered to be caused in large part by misperceptions of the disorder by teachers, peers, and the wider community. Improved community and professional awareness about TS and related comorbidities and other psychopathologies as well as the provision of multidisciplinary services to meet the complex needs of this clinical population are critical. Future research to inform the risk and resilience factors for successful long-term outcomes is also warranted. (Abstract from author

Reference:

Eapen, V., Cavanna, A. E., Robertson, M. M. (2016). Comorbidities, social impact, and quality of life in Tourette syndrome. *Frontiers in Psychiatry*, *7*(97). doi: <u>10.3389/fpsyt.2016.00097</u>

Victimization and Perpetration

Title: Childhood adversity, resilience, and autism: a critical review of the literature

Summary: The long-term, negative physical and mental health effects of childhood adversity are well-documented in the literature, as are the mitigating effects of resilience factors. However, for those on the autism spectrum, these phenomena are relatively unstudied and not well-understood. Articulating the concept of mental health as a function of childhood adversity, resilience, and autistic identity, provides a foundation from which to conduct research and provide clinical mental health supports to individuals on the autism spectrum. Research on adversity and resilience in this population must consider neurodiversity and foreground the perspectives of the autism and autistic communities in research design, study implementation, and findings dissemination.(Abstract from authors)

Reference:

Heselton, G.A. (2021). Childhood adversity, resilience, and autism: a critical review of the literature. *Disability & Society*. <u>https://www.tandfonline.com/doi/full/10.1080/09687599.2021.1983416</u>

Title: Victimization and perpetration experiences of adults with autism

• https://www.frontiersin.org/articles/10.3389/fpsyt.2018.00203/full

Summary: People with Autism Spectrum Conditions report experiencing more victimization as children (physical abuse, property crime, bullying, sexual assault by peers). People with ASCs also reported more victimization as adults (bullying and sexual assault). There were no significant differences found between groups for the perpetration of crimes. This nuance could be due to the difference in the presentation of behaviors in a neurotypical person versus someone with an ASC. This has led previous research to equate the symptomatology of ASCs with criminal behavior.

Reference:

Weiss, J. A., & Fardella, M. A. (2018). Victimization and perpetration experiences of adults with autism. *Front Psychiatry*. <u>https://doi.org/10.3389%2Ffpsyt.2018.00203</u>

Title: Bullying victimization and perpetration among US children with and without Tourette syndrome

• https://pubmed.ncbi.nlm.nih.gov/34050089/

Summary: Objective: Tourette syndrome (TS) and co-occurring mental, behavioral, and developmental disorders (MBDDs) have been shown to affect peer relationships. This study

provides nationally representative estimates of diagnosed TS prevalence and the prevalence of parent-reported bullying victimization and perpetration among US children with and without TS. Methods: This study included 2016-2017 National Survey of Children's Health data on children aged 6 to 17 years (N = 51,001) with parent-reported responses about TS diagnosis and their child's experiences with bullying victimization and perpetration. We calculated weighted prevalence estimates of diagnosed TS and of bullying indicators among children ever diagnosed with TS compared with peers without TS. We conducted a logistic regression analysis to estimate adjusted prevalence ratios of bullying involvement by TS status, controlling for age, sex, and co-occurring MBDDs.

Results: By parent report, 0.3% of US children had ever received a diagnosis of TS; most children with a TS diagnosis (83.2%) had a co-occurring MBDD. Among children with TS, 56.1% experienced bullying victimization, 20.7% experienced bullying perpetration, and 15.9% experienced both, compared with 21.6%, 6.0%, and 4.1% for children without TS, respectively. After adjusting for age, sex, and co-occurring MBDDs, only the association between TS and bullying victimization remained statistically significant.

Conclusion: Compared with children without TS, children with TS overall experience more bullying victimization and perpetration. Health care professionals treating children with TS could assess challenges with peer relationships and co-occurring disorders to provide targeted support and referral.(Abstract from authors)

Reference:

Charania, S., Danielson, M., Claussen, A., Lebrun-Harris, L., Kaminski, J., Bitsko, R. (2021). Bullying victimization and perpetration among US children with and without Tourette syndrome. *Journal of Developmental and Behavioral Pediatrics, 43*(1), 23-31. https://pubmed.ncbi.nlm.nih.gov/34050089/

Poverty and Unemployment

Title:Understanding Vulnerable Families in Multiple Service Systems Understanding Vulnerable Families

https://www.jstor.org/stable/10.7758/rsf.2019.5.2.05

Summary:We analyze Illinois families facing multiple barriers and their interactions with public-sector services. Using administrative data from five state agencies to identify families' receipt of child welfare, mental health, and substance abuse services as well as adult and juvenile incarcerations, we identify individuals across systems using probabilistic record-linkage techniques, defining family clusters based on networks of individuals who share child welfare and food stamp cases. We show that 23 percent receive services in two or more of these areas. This concentration accounts for 86 percent of the funding for these services used by the entire sample. They experience more and more severe problems. This population is otherwise heterogeneous, engaging with different types of services and clustered in certain parts of the state.(Abstract from authors)

Reference:

Goerge, R. M., & Wiegand, E. R. (2019). Understanding vulnerable families in multiple service systems understanding vulnerable families. *RSF: The Russell Sage Foundation Journal of the Social Sciences*, *5*(2). <u>https://doi.org/10.7758/rsf.2019.5.2.05</u>

Title:Household and community-level Adverse Childhood Experiences and adult health outcomes in a diverse urban population

Summary: Adverse Childhood Experiences (ACEs), which include family dysfunction and community-level stressors, negatively impact the health and well being of children throughout the life course. While several studies have examined the impact of these childhood exposures amongst racially and socially diverse populations, the contribution of ACEs in the persistence of socioeconomic disparities in health is poorly understood. To determine the association between ACEs and health outcomes amongst a sample of adults living in Philadelphia and examine the moderating effect of Socioeconomic Status (SES) on this association, we conducted a cross-sectional survey of 1,784 Philadelphia adults, ages 18 and older, using random digit dialing methodology to assess Conventional ACEs (experiences related to family dysfunction), Expanded ACEs (community-level stressors), and health outcomes. Using weighted, multivariable logistic regression analyses along with SES stratified models, we examined the relationship between ACEs and health outcomes as well as the modifying effect of current SES. High Conventional ACE scores were significantly associated with health risk behaviors, physical and mental illness, while elevated Expanded ACE scores were associated only with substance abuse history and sexually transmitted infections. ACEs did have some differential impacts on health outcomes based on SES. Given the robust impact of Conventional ACEs on health, our results support prior research highlighting the primacy of family relationships on a child's life course trajectory and the importance of interventions designed to support families. Our findings related to the modifying effect of SES may provide additional insight into the complex relationship between poverty and childhood adversity.(Abstract from authors)

Reference:

Wade, R., Cronholm, P. F., Fein, J. A., Forke, C. M., Davis, M. B., Harkins-Swartz, M., Pachter, L. M., & Blair-Merritt, M. H. (2016). Household and community-level adverse childhood experiences and adult health outcomes in a diverse urban population. *Child Abuse & Neglect, 52*, 135-145. <u>https://doi.org/10.1016/j.chiabu.2015.11.021</u>

Title:*National Autism Indicators Report: Children on the autism spectrum and family financial hardship*

 <u>https://drexel.edu/~/media/Files/autismoutcomes/publications/2020%20Nair%20report.a</u> <u>shx</u>

Summary: This report describes financial hardship among families of children with ASD (ages 3-17 years) and their participation in safety net programs. This builds on our 2018 National Indicators Report which found that low-income and minority youth with ASD have greater impairment severity, poorer outcomes and less access to needed services compared to other disability groups.6 This current report focuses on indicators of financial need and supports

across disability groups, federal poverty level, age and race. This report also fills an important knowledge gap by characterizing the subpopulation of children with ASD living in poverty.(Abstract from authors)

Reference:

Anderson, K., Rast, J., Roux, A., Garfield, T., & Shattuck, P. (2020). National autism indicators report: Children on the autism spectrum and family financial hardship. Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University. <u>https://drexel.edu/~/media/Files/autismoutcomes/publications/2020%20Nair%20report.ashx</u>

Title:Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The adverse childhood experiences (ACE) study.

Summary: Background: The relationship of health risk behavior and disease in adulthood to the breadth of exposure to childhood emotional, physical, or sexual abuse, and household dysfunction during childhood has not previously been described. Methods: A questionnaire about adverse childhood experiences was mailed to 13,494 adults who had completed a standardized medical evaluation at a large HMO; 9,508 (70.5%) responded. Seven categories of adverse childhood experiences were studied: psychological, physical, or sexual abuse; violence against mother; or living with household members who were substance abusers, mentally ill or suicidal, or ever imprisoned. The number of categories of these adverse childhood experiences was then compared to measures of adult risk behavior, health status, and disease. Logistic regression was used to adjust for effects of demographic factors on the association between the cumulative number of categories of childhood exposures (range: 0-7) and risk factors for the leading causes of death in adult life. Results: More than half of respondents reported at least one, and one-fourth reported > or = 2 categories of childhood exposures. We found a graded relationship between the number of categories of childhood exposure and each of the adult health risk behaviors and diseases that were studied (P < .001). Persons who had experienced four or more categories of childhood exposure, compared to those who had experienced none, had 4to 12-fold increased health risks for alcoholism, drug abuse, depression, and suicide attempt; a 2- to 4-fold increase in smoking, poor self-rated health, > or = 50 sexual intercourse partners, and sexually transmitted disease; and 1.4- to 1.6-fold increase in physical inactivity and severe obesity. The number of categories of adverse childhood exposures showed a graded relationship to the presence of adult diseases including ischemic heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease. The seven categories of adverse childhood experiences were strongly interrelated and persons with multiple categories of childhood exposure were likely to have multiple health risk factors later in life. Conclusions: We found a strong graded relationship between the breadth of exposure to abuse or household dysfunction during childhood and multiple risk factors for several of the leading causes of death in adults.(Abstract from authors)

Reference:

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many

of the leading causes of death in adults. The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine*, *14*(4), 245–258. <u>https://doi.org/10.1016/S0749-3797(98)00017-8</u>

Title: Associations between childhood learning disabilities and adult-age mental health problems, lack of education, and unemployment

• <u>https://journals.sagepub.com/doi/full/10.1177/0022219418775118</u>

Summary: We studied the impact of diverse subtypes of learning disabilities (LD) on adult-age mental health, education, and employment by comparing the LD group (n = 430) with a matched control group without a known history of LD (n = 2,149). The clinical archived data were merged with lifelong register data on sickness allowances/disability pensions granted on the basis of psychiatric illnesses, reimbursements for psychoactive medication, having a degree after compulsory education, and having received unemployment allowances. Differences emerged between the LD and control groups in all outcomes, suggesting that a higher proportion of individuals with LD had mental health problems compared to the control group, and a notable share of them had not attained a degree after compulsory education and had been unemployed for an extended period. Subgroup comparisons indicated that math disability (MD) was associated with antidepressant use and unemployment, whereas the reading disability (RD) group showed the least problems with employment. Interactions between subgroup and gender suggested that MD (with/without RD) may pose a higher risk than RD for females, whereas RD seemed to pose a risk for males. The findings suggest the need for researchers, clinicians, and those involved with adult education to consider mental health and educational problems among individuals with LD. .(Abstract from authors)

Reference:

- Aro, T., Eklund, K., Eloranta, A.-K., Närhi, V., Korhonen, E., & Ahonen, T. (2019). Associations between childhood learning disabilities and adult-age mental health problems, lack of education, and unemployment. *Journal of Learning Disabilities*, 52(1), 71–83. <u>https://doi.org/10.1177/0022219418775118</u>
- Title: Mental disorders and disabilities among low-income children
 - https://pubmed.ncbi.nlm.nih.gov/26632628/

Summary: Children living in poverty are more likely to have mental health problems, and their conditions are more likely to be severe. Of the approximately 1.3 million children who were recipients of Supplemental Security Income (SSI) disability benefits in 2013, about 50% were disabled primarily due to a mental disorder. An increase in the number of children who are recipients of SSI benefits due to mental disorders has been observed through several decades of the program beginning in 1985 and continuing through 2010. Nevertheless, less than 1% of children in the United States are recipients of SSI disability benefits for a mental disorder. At the request of the Social Security Administration, Mental Disorders and Disability Among Low-Income Children compares national trends in the number of children with mental disorders with the trends in the number of children receiving benefits from the SSI program, and describes

the possible factors that may contribute to any differences between the two groups. This report provides an overview of the current status of the diagnosis and treatment of mental disorders, and the levels of impairment in the U.S. population under age 18. The report focuses on 6 mental disorders, chosen due to their prevalence and the severity of disability attributed to those disorders within the SSI disability program: attention-deficit/hyperactivity disorder, oppositional defiant disorder/conduct disorder, autism spectrum disorder, intellectual disability, learning disabilities, and mood disorders. While this report is not a comprehensive discussion of these disorders, Mental Disorders and Disability Among Low-Income Children provides the best currently available information regarding demographics, diagnosis, treatment, and expectations for the disorder time course - both the natural course and under treatment.

Reference:

Boat, T., Wu, J., Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders, Board on the Health of Select Populations, Board on Children, Youth, and Families, Institute of Medicine, Division of Behavioral and Social Sciences and Education, & The National Academies of Sciences, Engineering, and Medicine (Eds.). (2015). Mental disorders and disabilities among low-income children (pp.281-294). In *Prevalence of learning disabilities*. National Academies Press (US). https://pubmed.ncbi.nlm.nih.gov/26632628/

Neurodiversity Among LGBTQIA Community

Title:*Differences in Experiences of Discrimination in Accessing Social Services Among Transgender/Gender Nonconforming Individuals by (Dis)Ability*

 https://www.tandfonline.com/doi/abs/10.1080/1536710X.2017.1299661?journalCode=ws wd20

Summary: Transgender and gender nonconforming (GNC) individuals frequently experience discrimination and potentially a lack of respect from service providers, suggesting they have decreased access to professionals with cultural competency. Similarly, people with disabilities experience higher levels of discrimination in social services than their nondisabled counterparts. From an intersectional perspective, this study examines rates of discrimination in accessing social services faced by transgender and GNC people, comparing across ability. Data indicate that although transgender and GNC individuals of all abilities experience gender-based discrimination when accessing social services, those with disabilities experience higher levels of antitransgender discrimination in mental health centers, rape crisis centers, and domestic violence shelters.(Abstract from authors)

Reference:

Kattari, S. K., N. Walls, N. E., & Speer, S. R. (2017). Differences in experiences of discrimination in accessing social services among transgender/ gender nonconforming individuals by (dis)ability. *Journal of Social Work in Disability & Rehabilitation*, 16(2), 116-140. <u>https://doi.org/10.1080/1536710X.2017.1299661</u>

Title: Sexual Orientation in Autism Spectrum Disorder

• https://onlinelibrary.wiley.com/doi/10.1002/aur.1892

Summary: Clinical impressions suggest a different sexual profile between individuals with and without Autism Spectrum Disorder (ASD). Little is presently known about the demographics of sexual orientation in ASD. Sexual Orientation was surveyed using the Sell Scale of Sexual Orientation in an international online sample of individuals with ASD (N = 309, M = 90, F= 219), aged (M = 32.30 years, SD = 11.93) and this was compared to sexual orientation of typically-developing individuals (N = 310, M = 84, F= 226), aged (M = 29.82 years, SD = 11.85). Findings suggested that sexual orientation was contingent on diagnosis (N = 570, χ 2(9)=104.05, P < 0.001, φ = 0.43). In the group with ASD, 69.7% of the sample reported being non-heterosexual, while in the TD group, 30.3% reported being non-heterosexual. The group with ASD reported higher rates of homosexuality, bisexuality and asexuality, but lower rates of heterosexuality. The results support the impression that non-heterosexuality is more prevalent in the autistic population. Increased non-heterosexuality in ASD has important clinical implications to target unique concerns of this population, and suggests a need for specialized sex education programs for autistic populations for increased support and awareness.(Abstract from authors)

Reference:

George, R., & Stokes, M. A. (2018). Sexual orientation in autism spectrum disorder. *Autism Research*, *11*(1), 133–141. <u>https://doi.org/10.1002/aur.1892</u>

Title:Lesbian, Gay, Bisexual, and Transgender Youth with Disabilities: A Meta-Synthesis

• <u>https://www.tandfonline.com/doi/full/10.1080/19361653.2011.519181</u>

Summary: This meta-synthesis of empirical and nonempirical literature analyzed 24 journal articles and book chapters that addressed the intersection of disability, [homo]sexuality, and gender identity/expression in P–12 schools, colleges and universities, supported living programs, and other educational and social contexts in Australia, Belgium, Canada, New Zealand, Sweden, the United Kingdom, and the United States. The articles and chapters emphasized the diversity of lesbian, gay, bisexual, and transgender youth with disabilities—culturally, linguistically, sexually, and in terms of abilities, disabilities, and related service needs—while noting that all (or certainly most) lesbian, gay, bisexual, and transgender youth with disabilities possess multiple stigmatized identities as sexual/gender minorities and young people with disabilities.(Abstract from authors)

Reference:

Duke, T. S. (2011). Lesbian, Gay, Bisexual, and Transgender Youth with Disabilities: A Meta-Synthesis. *Journal of LGBT Youth, 8*(1), 1–52. https://doi.org/10.1080/19361653.2011.519181

Title: A clinical program for transgender and gender-diverse neurodiverse/autistic adolescents developed through community-based participatory design

<u>https://www.tandfonline.com/doi/pdf/10.1080/15374416.2020.1731817?needAccess=tru</u>
 <u>e</u>

Summary: This study included autistic/neurodiverse youth who are also gender diverse (identified as A/ND-GD) and their parents, A/ND-GD self advocates, and expert clinicians. The study sought to develop a stakeholder-driven clinical group program. The results of the need assessments of adolescents and parents revealed the importance for connecting A/ND-GD youth with others who are A/ND-GD, the benefit of experiencing a variety of gender-diverse role models to make gender exploration/affirmation concrete, and the need for A/ND support for children and A/ND friendly environments which encourage exploration of gender expressions. By integrating the youth and parent priorities, 11 new clinical techniques were created for the A/ND-GD population.

Reference:

Strang, J. F., Knauss, M., van der Miesen, A., McGuire, J. K., Kenworthy, L., Caplan, R., Freeman, A., Sadikova, E., Zaks, Z., Pervez, N., Balleur, A., Rowlands, D. W., Sibarium, E., Willing, L., McCool, M. A., Ehrbar, R. D., Wyss, S. E., Wimms, H., Tobing, J... Anthony, L. G. (2021). A clinical program for transgender and gender-diverse neurodiverse/autistic adolescents developed through community-based participatory design. *Journal of Clinical Child & Adolescent Psychology*, 50(6), 730-745. DOI: <u>10.1080/15374416.2020.1731817</u>

Title:*LGBTQ* + and autism spectrum disorder: Experiences and challenges

• https://www.tandfonline.com/doi/full/10.1080/15532739.2019.1594484

Summary:Background: Research focused on gender identity, autism spectrum disorder (ASD), and the experiences of those who identify as LGBTQ+, remains minimal. Initial findings have indicated that those on the autism spectrum may be more likely to identify as homosexual and experience more fluid gender identity. Insufficient consideration has been given to intersectionality around a disability status and gender identity, and few have focused this conversation specifically on the experiences of those with ASD.

Aim: The aim of this study was to improve current understanding of the first-hand experiences of those on the autism spectrum who identify as LGBTQ+, particularly regarding challenges stemming from these dual identities.Method: A focus group was conducted with four participants with ASD who presented with a range of gender identities (as they defined them) including male, transgender; agender/nonbinary; agender; and queer.Results: Qualitative analysis of the focus group transcription identified key themes: (1) Effect of Dual Identities: experiencing dual identities, autism spectrum, and LGBTQ+; (2) Multiple Minority Stressors: challenges experienced by the participants, the impact of discrimination/misunderstanding, and holding minority statuses; (3) Isolation: barriers caused by lack of understanding; (4) Lack of Service Provision.Discussion: These preliminary findings underline the need for better support, understanding, and practices regarding sexuality and gender identity among those on the autism spectrum. The current study is important for giving voice to adults on the autism

spectrum who identify as LGBTQ+, and has implications for the disability community more broadly.(Abstract from author)

Reference:

Hillier, A., Gallop, N., Mendes, E., Tellez, D., Buckingham, A., Nizami, A., & OToole, D. (2020). LGBTQ + and autism spectrum disorder: Experiences and challenges. *International Journal of Transgender Health*, *21*(1), 98–110. https://doi.org/10.1080/15532739.2019.1594484

Title: *"They thought it was an obsession": Trajectories and perspectives of autistic transgender and gender-diverse adolescents.*

https://link.springer.com/article/10.1007/s10803-018-3723-6#citeas

Summary: Despite research exploring autism in gender-diverse adolescents, no studies have elicited these individuals' perspectives. In-depth interviews with 22 well-characterized autistic gender-diverse adolescents revealed critical themes, including: recollections of pre-pubertal gender nonconformity; vivid experiences of gender dysphoria; a fear of social gender expression due to perceived animosity toward transgender people; and specific challenges that result from the interplay of gender diversity and neurodiversity. During the ~ 22 month study social gender affirmation increased in six participants and gender dysphoria attenuated in four participants. Given the ethical imperative to understand and prioritize the voiced perspectives and needs of autistic gender minority adolescents as well as the discovery of shared themes and experiences in this population, results should inform clinical research approaches and priorities..(Abstract from authors)

Reference:

Strang, J. F., Powers, M. D., Knauss, M., Sibarium, E., Leibowitz, S. F., Kenworthy, L., Sadikova, E., Wyss, S., Willing, L., Caplan, R., Pervez, N., Nowak, J., Gohari, D., Gomez-Lobo, V., Call, D., & Anthony, L. G. (2018). "They thought it was an obsession": Trajectories and perspectives of autistic transgender and gender-diverse adolescents. *Journal of Autism and Developmental Disorders*, 48, 4039–4055. https://doi.org/10.1007/s10803-018-3723-6

Title: Lesbian, gay, bisexual, and transgender youth with disabilities: a meta-synthesis

• https://www.tandfonline.com/doi/full/10.1080/19361653.2011.519181

Abstract: This meta-synthesis of empirical and nonempirical literature analyzed 24 journal articles and book chapters that addressed the intersection of disability, [homo]sexuality, and gender identity/expression in P–12 schools, colleges and universities, supported living programs, and other educational and social contexts in Australia, Belgium, Canada, New Zealand, Sweden, the United Kingdom, and the United States. The articles and chapters emphasized the diversity of lesbian, gay, bisexual, and transgender youth with disabilities—culturally, linguistically, sexually, and in terms of abilities, disabilities, and related

service needs—while noting that all (or certainly most) lesbian, gay, bisexual, and transgender youth with disabilities possess multiple stigmatized identities as sexual/gender minorities and young people with disabilities.(Abstract from authors)

Reference:

Duke, T. S. (2011). Lesbian, gay, bisexual, and transgender youth with disabilities: a meta-synthesis. *Journal of LGBT Youth, 8*:1, 1-52, DOI: <u>10.1080/19361653.2011.519181</u>

Title: Discrimination in healthcare and LGBTQ+ information and care-seeking behaviors

• https://doi.org/10.1002/pra2.468

Abstract: Members of the Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, plus (LGBTQ+) community may face discrimination in healthcare, which can subsequently impact information and care-seeking patterns. A tendency to avoid or delay health care is particularly concerning for LGBTQ+ people who face both physical and mental health disparities. This paper presents a literature review of literature on healthcare discrimination, LGBTQ+ care-seeking, and associated information behaviors in order to generate a preliminary model of LGBTQ+ decision-making around care and well-being, called the *Model of the Pathways to LGBTQ+ Well-Being*. This model can be used to investigate links between information behavior and relevant health behaviors and outcomes in a marginalized population.

Reference:

Brown, L. K., & Veinot, T. C. (2021). Discrimination in healthcare and LGBTQ+ information and care-seeking behaviors. *Proceedings of the Association for Information Science and Technology*, *58*(1), 405–409. <u>https://doi.org/10.1002/pra2.468</u>

Title: Differences in experiences of discrimination in accessing social services among transgender/ gender nonconforming individuals by (dis)ability.

 https://www.tandfonline.com/doi/abs/10.1080/1536710X.2017.1299661?journalCode=ws wd20

Abstract: Transgender and gender nonconforming (GNC) individuals frequently experience discrimination and potentially a lack of respect from service providers, suggesting they have decreased access to professionals with cultural competency. Similarly, people with disabilities experience higher levels of discrimination in social services than their nondisabled counterparts. From an intersectional perspective, this study examines rates of discrimination in accessing social services faced by transgender and GNC people, comparing across ability. Data indicate that although transgender and GNC individuals of all abilities experience gender-based discrimination when accessing social services, those with disabilities experience higher levels of antitransgender discrimination in mental health centers, rape crisis centers, and domestic violence shelters.(Abstract from authors)

Reference:

Kattari, S. K., N. Walls, N. E. & Speer, S. R. (2017). Differences in experiences of discrimination in accessing social services among transgender/ gender nonconforming individuals by (dis)ability. *Journal of Social Work in Disability & Rehabilitation*, *16*:2, 116-140, DOI: 10.1080/1536710X.2017.1299661

Interventions

Title:Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice

• https://www.frontiersin.org/articles/10.3389/fpsyg.2021.635690/full

Summary: The growth of autistic self-advocacy and the neurodiversity movement has brought about new ethical, theoretical and ideological debates within autism theory, research and practice. These debates have had genuine impact within some areas of autism research but their influence is less evident within early intervention research. In this paper, we argue that all autism intervention stakeholders need to understand and actively engage with the views of autistic people and with neurodiversity as a concept and movement. In so doing, intervention researchers and practitioners are required to move away from a normative agenda and pay diligence to environmental goodness-of-fit, autistic developmental trajectories, internal drivers and experiences, and autistic prioritized intervention targets. Autism intervention researchers must respond to these debates by reframing effectiveness, developing tools to measure autistic prioritized outcomes, and forming partnerships with autistic people. There is a pressing need for increased reflection and articulation around how intervention practices align with a neurodiversity framework and greater emphasis within intervention programmes on natural developmental processes, coping strategies, autonomy, and well-being. (Abstract from authors)

Reference:

Leadbitter , K., Buckle , K. L., Ellis , C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice . *Frontiers in Psychology* , 12. <u>https://doi.org/10.3389/fpsyg.2021.635690</u>

Title:Awareness and knowledge of autism and autism interventions: A general population survey

• https://www.sciencedirect.com/science/article/abs/pii/S175094671300175X?via%3Dihub

Summary: Recent figures show that autism spectrum disorder (ASD) affects at least 1 in 88 of the population, yet for years, international public awareness of ASD was limited. Over the past 5-10 years intense efforts have been made to raise autism awareness in the general population in countries such as UK and US. In this paper we report data from a large-scale general population survey (N = 1204) in which we assessed autism awareness, knowledge about autism, and perceptions about autism interventions in Northern Ireland. We found high levels of autism awareness, in fact over 80% of the sample were aware of ASD and over 60% of these respondents knew someone with ASD in their own family, circle of friends or work colleagues. Generally, knowledge of strengths and challenges faced by individuals with ASD was relatively

accurate. However, perceptions of interventions and service provider responsibilities were vague and uncertain. Results show that local and international autism awareness campaigns have largely been successful and that the focus should shift towards disseminating accurate information regarding intervention and service provider responsibilities.(Abstract from authors) **Reference**:

Dillenburger, K., Jordan, J.A., McKerr, L., Devine, P., Keenan, M. (2013). Awareness and knowledge of autism and autism interventions: A general population survey. *Research in Autism Spectrum Disorders*. 7(12):1558–1567. <u>https://doi.org/10.1016/i.rasd.2013.09.004</u>

Title: Neurodiverse Applicant Screening, Interviewing, and Selection

 https://www.taylorfrancis.com/chapters/edit/10.4324/9781003023616-4/neurodiverse-ap plicant-screening-interviewing-selection-matthew-saleh-hsiao-ying-chang-susanne-bruy %C3%A8re-timothy-vogus

Summary: In Neurodiverse Applicant Screening, Interviewing, and Selection, the authors point out that there are a range of modifications to screening and application procedures (e.g., the job interview) that can help ensure hiring practices avoid implicit biases and are more equitable for Autistic individuals. This especially includes factors that affect hiring decisions (e.g., non-verbal and verbal cues, self-presentation and promotion), which may not actually be meaningfully related to actual future job performance in any way. In exploring how to effectively address potentially problematic processes for neurodiverse populations, Saleh et al. provide a brief overview of traditional and emerging screening and selection methods and summarize what is known about affirmative screening/selection approaches from other underrepresented labor force populations that may be relevant for Autistic candidates. They finally discuss the disparate impact (for neurodivergent applicants) and other risks stemming from relying on selection criteria (e.g., social behavior) that does not predict job performance and share recommendations for approaches that will promote fairer processes not only for neurodiverse job candidates, but also for more diverse talent pools generally.(Abstract from authors)

Reference:

Saleh, M. C., Chang, H., Bruyère, S. M., & Vogus, T. J. (2022). Neurodiverse applicant screening, interviewing, and selection. In S. M. Bruyère, & A. Colella (Eds.), *Neurodiversity in the workplace: Interests, issues, and opportunities* (1st ed.) (pp. 98-123). Routledge. <u>https://doi.org/10.4324/9781003023616-4</u>

Title: A Spectrum of Solutions for Clients with Autism

 <u>https://www.taylorfrancis.com/books/edit/10.4324/9780429299391/spectrum-solutions-cli</u> ents-autism-rachel-bedard-lorna-hecker

Summary: This book is a comprehensive resource to guide work with individuals on the autism spectrum. It reflects the true range of needs presented by individuals with autism, pulling together the most salient aspects of treatment with invaluable information from several disciplines synthesized to guide your work.Divided into topical sections with chapters from three field experts in each, this book features contributions from therapists, educators, and medical

doctors, as well as financial planners, health advocates, and innovators. The diverse disciplines and backgrounds of each author lend a different voice and perspective to each chapter, reflecting the continuum of care necessary when working with clientele on the autism spectrum, and that, for clients on the spectrum, one solution does not fit all.For use by psychotherapists, counselors, applied behavioral analysts, occupational therapists, social workers, teachers, and more, this text presents readers with expertise from various contributing disciplines to give them a treatment resource that can inform and guide their daily work with clients on the autism spectrum.(Abstract from authors)

Reference:

Bédard, R., & Hecker, L. L. (2020). A spectrum of solutions for clients with autism: Treatment for adolescents and adults (1st ed). Routledge, Taylor and Francis Group. <u>https://doi.org/10.4324/9780429299391</u>

Title: Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach

Summary: Stress among parents and other primary caregivers of children with developmental disabilities is pervasive and linked to lower quality of life, unhealthy family functioning, and negative psychological consequences. However, few programs address the needs of parents or caregivers of children with developmental disabilities. A mindfulness-based stress reduction (MBSR) program is a well-suited approach for these parents and caregivers, who may be overwhelmed by their children's situation, anticipating future challenges and reliving past traumas. We aimed to develop, implement, and evaluate the feasibility of an MBSR program designed for this population in a community-based participatory setting. Parents and caregivers were equal partners with researchers in curriculum development, recruitment, implementation and evaluation. Two concurrent classes, morning and evening, were conducted weekly in English with simultaneous Spanish translation over 8-weeks. Classes consisted of meditation practice, supported discussion of stressors affecting parents/caregivers, and gentle stretching. Of 76 participants recruited, 66 (87 %) completed the program. All participants experienced a significant reduction (33 %) in perceived stress (p < 0.001) and parents (n = 59) experienced a 22 % reduction (p < 0.001) in parental stress. Parents/caregivers also reported significantly increased mindfulness, self-compassion, and well-being (p < 0.05). Participants continued to report significant reduction in stress 2 months after the program. Our study suggests that a community-based MBSR program can be an effective intervention to reduce stress and improve psychological well-being for parents and caregivers of children with developmental disabilities. Additional research should assess the effect of cultural or socioeconomic factors on the outcomes of the intervention and further expand MBSR programs to include community-based participatory settings.(Abstract from authors)

Reference:

Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach. *Journal of Child and Family Studies, 24*(2), 298–308. <u>https://doi.org/10.1007/s10826-013-9836-9</u> **Title:** The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service

Summary: It is well established that families caring for a child with an autism spectrum disorder (ASD) experience increased psychological distress compared to other families (e.g., Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Lee et al., 2009). However, little research has captured the range of variables linked to family outcomes, and research in the early childhood period has been largely atheoretical. The current study sought to investigate the applicability of the double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983) in understanding the factors underlying family outcomes when children with ASD attend early intervention. Participants included 43 parents (18 males, 25 females) of children aged 2.5 to 6 years (M = 49.35, SD = 9.21 months; 8 female, 35 male) with ASD who were attending an autism-specific intervention service. Participants completed standardised questionnaire measures of constructs of the double ABCX Model. As predicted by the model, family systems outcomes (individual, relationship, or family) were linked to symptom severity (challenging behaviour), pile-up demands, internal and external resources, appraisals, and active-avoidant coping styles. Level of ASD symptoms however, were not significantly linked to outcomes. Limitations, directions for future research, and practical implications are discussed. (Abstract from authors)

Reference:

Paynter, J., Riley, E., Beamish, W., Davies, M., & Milford, T.M. (2013). The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. *Research in Autism Spectrum Disorders*, 7(10), 1183-1195. <u>https://www.sciencedirect.com/science/article/abs/pii/S1750946713001232</u>

Title: Neurodivergence-informed therapy

• https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.15384

Summary: This article discussed the need for clinicians to have a healthy level of skepticism on pathology paradigm research since it often assumes and reproduces negative biases about neurodivergent populations. Increased effort should be established to make clinical training accessible to neurodivergent people since they may do well working with neurodivergent clients. Clinicians need to ensure they are allowing neurodivergent clients to have agency around which divergencies are targeted for normalization. Neurodivergence-informed therapy should be developed which resists default normalization, considers neurodivergent perspectives, recognizes disablement as relational and political, and incorporates strengths associated with a disability like community and pride.

Reference:

Chapman, R., & Botha, M. (2022). Neurodivergence-informed therapy. *Developmental Medicine* & *Child Neurology*, 1-8. <u>https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.15384</u>

Title: Special issue on occupational therapy with neurodivergent people

 <u>https://research.aota.org/ajot/article/75/3/7503170010/12510/Special-Issue-on-Occupati</u> onal-Therapy-With

Summary: This article researched the results of several studies and concluded that neurodivergent people continue to need occupational therapy beyond high school, yet most supports and services end after high school. Services and support need to acknowledge the variety of needs of autistic people throughout their life. In a study with 5,000 caregivers (92% mothers), 96% reported their children received nondrug therapy, 80% received speech-language therapy or occupational therapy, and 52% received occupational and speech-language therapy. A longitudinal study of about 200 autistic students, in which 59% presented with co-occurring intellectual disabilities, revealed that with each year of high school progressed there was a decrease in services (especially for autistic students without co-occurring intellectual disabilities). Occupational therapy hones in on contextual factors and utilizes them through environmental and personal factors to promote participation. Occupational therapy practitioners assist with developing skills and compensatory strategies, adaptive approaches, and tools/technology that aid independent living and promote communication and social engagement. Occupational therapy can assist in executive functioning and management of life tasks needed for community living, school, work, health care, and transportation/driving. Suggestions for occupational therapy are to increase focus on self-determination, empowerment, and inclusion instead of primarily focusing on addressing impairments.

Reference:

Kornblau, B. L., Robertson, S. M. (2021). Special issue on occupational therapy with neurodivergent people. *The American Journal of Occupational Therapy*, 75(3). https://doi.org/10.5014/ajot.2021.753001

Title: Complementary and alternative treatments for autism part 2: Identifying and avoiding non-evidence-based treatments

• <u>https://journalofethics.ama-assn.org/article/complementary-and-alternative-treatments-a</u> utism-part-2-identifying-and-avoiding-non-evidence-based/2015-04

Summary: Autism research has increased rapidly over the past five years, but no cause or cure has been identified. Some parents attempt to find cures for their autistic children through complementary and alternative medicine (CAM). CAM includes mind-body interventions (targeting interactions between brain and behavior), biology-based treatments (natural substances as treatment), manipulative and body-based practices, and energy medicine (using "energy" to promote healing). CAM treatment techniques include dietary supplements, vitamins, hyperbaric oxygen, hormone injections, swimming with dolphins, horseback riding, yoga, and massage. Research has demonstrated that 50-75% of children with autism utilize CAM as a way to improve symptoms. About 50% of the children who use CAM use biology-based therapies, 30 percent use mind-body therapies, and 25 percent use manipulation or body-based therapies. Despite the tendency to use CAM treatments, studies do not demonstrate effectiveness. For example, studies looking at the efficacy of a gluten-free and casein-free diet as a treatment for autism revealed no statistically significant findings, despite some parents reporting improvement in their children. Chelation therapy involves administering chemicals to the body that bind to

heavy metals, like mercury, and eliminating them. There's no evidence autism is caused by heavy metal poisoning nor evidence showing this therapy to be safe or effective. In 2005, a child died undergoing chelation therapy when an agent bonded with calcium and stopped the child's heart. Another treatment, Lupron, which is a testosterone-inhibiting drug (treats prostate cancer and precocious puberty), has been used on children with autism because of the idea that testosterone increases the effect of mercury and by reducing testosterone the effects of mercury are reduced. Again, like other CAM treatments, Lupron is not proven effective. Lupron can cause numbness, weakness, difficulty breathing, trouble swallowing, hives, blood in the urine, bone pain, testicular pain, and osteoporosis. Holding therapy is a body-based therapy that was created with the notion that autism is caused by a caregiver's failure to bond with their child. During holding therapy, caregivers physically restrain their children and force eye contact. The intense physical pressure applied by caregivers has led to fatalities and there is no evidence to support its effectiveness. Some evidence-based treatments proven to mitigate symptoms of autism included applied behavior analysis, speech therapy, occupational therapy, and physical therapy.

Reference:

Singer, A., & Ravi, R. (2015). Complementary and alternative treatments for autism part 2: Identifying and avoiding non-evidence-based treatments. *AMA Journal of Ethics*, 17(4), 375-380. doi: 10.1001/journalofethics.2015.17.4.sect2-1504

Title: The line between intervention and abuse' – autism and applied behaviour analysis'

• <u>https://journals.sagepub.com/doi/10.1177/0952695117702571</u>

Summary: In the 1960s, Lovaas' original form of applied behavior analysis (ABA), which was created on the basis of earlier behaviorists, was harsh. The original ABA included harsh physical aversives. When ABA dropped these aversives, it started to become popular for treating autism. The language used in discussions around ABA can be offensive. For instance, using person-first language is rejected by many autistic people who consider autism a large part of themselves. In addition, the use of 'treatment' and 'therapy' are often rejected on the basis that autism isn't a disease needing to be cured. The utilization of ABA varies widely across the world, but it is very popular in North America and widely respected by the medical industry. Autism-focused organizations, including Autism Speaks, are very vocal supporters of ABA. ABA is based on the antecedent (the trigger which precedes the behavior), the behavior itself, and the consequences of the behavior (positive/negative). During ABA the practitioner controls the environment with rewards and punishments. The goal is that practitioners diminish the 'undesirable' behaviors and encourage the 'pro-social' ones (ex. Eye contact or verbal communication). Scientists have argued that the benefits of ABA have been overestimated as some have attempted to reproduce Lovaas' results to no avail. It's also been highlighted that there's low-quality research on ABA and little high-quality evidence for Lovaas' model. Since the 1990s, autistic people have been arguing against the need for therapy at all, and have campaigned against the use of physical aversives. Their arguments are that the problems surrounding autistic people's behavior stem from a lack of tolerance from non-autistic people. These autistic advocates argue that autism is a neutral difference, not a deficit and that ABA can damage individuals psychologically. For example, ABA practitioners discourage behavior that can be considered a form of communication even if it isn't typical. ABA may take away their voice and practitioners may be inhibiting behaviors that seem unusual, but are self-soothing.

Reference:

Kirkham, P. (2017). 'The line between intervention and abuse' – autism and applied behaviour analysis. *History of the Human Sciences*, *30*(2), 107–126. https://doi.org/10.1177/0952695117702571

Title: Applied behavior analysis: Autism and beyond

• https://onlinelibrary.wiley.com/doi/10.1002/bin.1335

Summary: A review has found that ABA has narrowed its focus to issues affecting populations with ASD, while being less attentive to issues of general education being faced by society. The work performed by applied behavior analysts in autism has greatly improved the lives of many individuals, but applied behavior analysts have largely neglected the learners in general education that make up the vast majority of students. The abundance of ABA research conducted in developmental disabilities, the employment opportunities in ABA, and the desire of many individuals to work exclusively within developmental disabilities all seem to have yielded a public perception that ABA is not for general education.

Reference:

Axelrod, S. (2012). Applied behavior analysis: Autism and beyond. *Behavioral Interventions*. <u>https://doi.org/10.1002/bin.1335</u>

Title: The effectiveness of applied behavior analytic interventions for children with Autism Spectrum Disorder: A meta-analytic study

<u>https://www.sciencedirect.com/science/article/pii/S1750946718300485?via%3Dihub</u>

Summary: Applied behavior analysis is widely used with children with ASD, and it has been found to be highly effective. Despite this, research has not been consistent regarding the degree of ABA's effectiveness. This meta-analysis provides an updated evaluation of ABA programs for children with ASD. Results show that ABA programs are moderate to highly effective, and bring significant benefits for children with ASD in the following three areas: a) IQ scores provided by verbal and non-verbal standardized tests, b) receptive and expressive language, and c) adaptive behavior. They were highly effective in improving intellectual abilities, communication skills, expressive language skills, and receptive language skills. ABA was found to be moderately effective in improving IQ provided by non-verbal tests, adaptive behavior, and socialization. Finally, ABA had low effectiveness in improving daily living skills.

Reference:

Makrygianni, M. K., Gena, A., Katoudi, S., & Galanis, P. (2018). The effectiveness of applied behavior analytic interventions for children with Autism Spectrum Disorder: A

meta-analytic study. *Research in Autism Spectrum Disorders,* (51), 18-31. <u>https://doi.org/10.1016/j.rasd.2018.03.006</u>

Title: Comprehensive behavioral intervention for tics reduces perception-action binding during inhibitory control in Gilles de la Tourette syndrome

• https://www.nature.com/articles/s41598-020-58269-z

Summary: Gilles de la Tourette Syndrome (GTS) is a developmental disorder. Empirical studies and an emerging cognitive framework on GTS suggest that GTS is a disorder of abnormally strong 'perception-action binding'. Theoretical considerations imply that the effectiveness of long-established behavioral interventions might be related to a normalization of increased binding in GTS. This has not been tested yet. We examined the effect of a standardized Comprehensive Behavior Intervention for Tics (CBIT) in N = 21 adolescent GTS patients and N = 21 healthy controls on perception-action binding in an inhibitory control paradigm. Prior to CBIT, GTS patients showed compromised performance compared to controls, specifically when inhibitory control was triggered by uni-modal visual compared to bi-modal stimuli. After CBIT intervention, GTS patient's performance was at the same level as healthy controls. This is supported by a Bayesian data analysis. CBIT specifically affected inhibitory control in a condition where reconfigurations of perception-action bindings are necessary to perform inhibitory control. A power of 95% was evident for these effects. CBIT reduces increased 'binding' between perception and action in GTS and thereby increases the ability to perform response inhibition. The results are the first to provide insights as to why CBIT is effective by relating elements of this intervention to overarching cognitive theoretical frameworks on perception-action bindings.(Abstract from authors)

Reference:

Petruo, V., Bodmer, B., Bluschke, A., Munchau, A., Roessner, V., & Beste, C. Comprehensive Behavioral Intervention for Tics reduces perception-action binding during inhibitory control in Gilles de la Tourette syndrome. Sci Rep 10, 1174 (2020). https://doi.org/10.1038/s41598-020-58269-z

Title: A self-determination theory approach to psychotherapy: The motivational basis for effective change.

• https://psycnet.apa.org/doiLanding?doi=10.1037%2Fa0012753

Abstract: The application of self-determination theory (SDT) to psychotherapy is particularly relevant because a central task of therapy is to support the client to autonomously explore, identify, initiate, and sustain a process of change. In this article, the authors discuss the experimental work, field studies, and clinical trials representing the application of SDT to the domain of psychotherapy. Evidence supports the importance of client autonomy for the attainment and maintenance of treatment outcomes. In addition, intervention studies suggest that therapist autonomy support enhances the likelihood that treatment gains will be achieved and maintained. The authors discuss some of the processes involved in enhancing autonomy, including the role of awareness, the importance of exploring and challenging introjects and

external regulations, attention to need-related goal contents, and therapist attitudes required for a therapy approach that is process- rather than outcome-focused.(Abstract from authors)

Reference:

Ryan, R. M., & Deci, E. L. (2008). A self-determination theory approach to psychotherapy: The motivational basis for effective change. *Canadian Psychology / Psychologie canadienne*, 49(3), 186–193. https://doi.org/10.1037/a0012753

Title: Person-centered therapy: A pluralistic perspective 10.1080/14779757.2011.599517

Abstract: The aim of this paper is to articulate a "pluralistic" understanding of what it means to be person-centered. This perspective places particular emphasis on an understanding of clients as unique, nonstandardizable "othernesses," whose therapeutic wants and needs are likely to be highly heterogeneous and unknowable in advance. Based on this idiographic standpoint, it is argued that a person-centered understanding of therapeutic change necessitates an openness to, and appreciation of, the many different ways in which clients may benefit from therapy including, but not limited to, established person-centered and experiential (PCE) practices. To translate such pluralistic principles into practice, it is suggested that therapists should specifically orientate their work toward clients' goals, and enhance their levels of dialogue and metacommunication with clients regarding the goals, tasks and methods of therapy. This pluralistic approach to person-centered therapy holds other perspectives and practices within the PCE community in high regard, as well as other non-PCE therapies; but it does challenge "dogmatic person-centeredness" and encourages PCE practitioners to be aware of the limits of their work. It also provides a coherent, "client-centered" framework through which PCE therapists can incorporate a wide body of practices, research findings and theories into their work.(Abstract from authors)

Reference:

Cooper M. & McLeod J. (2011) Person-centered therapy: A pluralistic perspective. *Person-Centered & Experiential Psychotherapies, 10*(3), 210-223, Doi: <u>10.1080/14779757.2011.599517</u>

Title: ADDIE Model

• http://www.aijcrnet.com/journals/Vol_5_No_6_December_2015/10.pdf

Summary:Before starting to evaluate the educational design we want to know what Instructional Design means. Instructional design is known as instructional technology. It means a systematic process that helps in creating and developing effective, appealing, and efficient instructional materials within a supportive environment using art, science, learning, and instructional theory. The components of the instructional design include analysis of learners' problems and needs, designing of instructional design include activities and materials. Development of objective goals is also done in order to meet the learners' need, implementation includes training, and finally it includes evaluating the instruction and the learners' outcomes. Additionally, there are instructional design models that are used by the instructional designer and the developers of training. I am going to choose the model that is called the ADDIE model in order to evaluate all of the components of the design.(Abstract from authors) **Reference**:

Aldoobie, N. (2015). ADDIE model. *American International Journal of Contemporary Research*, *5*(6). http://www.aijcrnet.com/journals/Vol_5_No_6_December_2015/10.pdf

Neurodiversity and Culture

Title:Understanding the Barriers to Receiving Autism Diagnoses for Hispanic and Latinx Families

• https://journals.healio.com/doi/10.3928/19382359-20220322-03

Summary:Significant disparities exist in early identification of autism spectrum disorder (ASD) for Hispanic and Latinx children. ASD prevalence estimates are approximately identical for White and Black children but lower for Hispanic and Latinx children. Reasons for these racial and ethnic variations are likely multifactorial. This review sought to understand previously described barriers and limitations to accessing ASD diagnostic services in the Latinx and Hispanic communities. Three main categories of existing barriers were identified: (1) parent/family, (2) community, and (3) systemic. These barriers are complex and multifactorial in nature, including circumstantial limitations such as limited English proficiency, noncitizenship, and low-income status. These can limit health care access, and can lead to family and community cultural barriers, poor knowledge about ASD, and social stigma related to disabilities. Understanding and mitigating barriers is essential to reduce disparities to ASD diagnosis in the Hispanic and Latinx community. [*Pediatr Ann.* 2022;51(4):e167–e171.] (Abstract from author)

Reference:

Guerrero, M. G. B., & Sobotka, S. A. (2022). Understanding the barriers to receiving autism diagnoses for Hispanic and Latinx families. *Pediatric Annals, 51*(4), E167–E171. <u>Https://Doi.Org/10.3928/19382359-20220322-03</u>

Title: "Us Against Them": Schools, Families, and the Diagnosis of ADHD Among Black Children https://link.springer.com/article/10.1007/s40615-016-0298-9

Summary:Prior research indicates that attention-deficit/hyperactivity disorder (ADHD) is underdiagnosed, or less likely to be diagnosed, among Black children relative to White children and children in other non-Black racial categories. Scholars have suggested that this may be a result of cultural biases or misconceptions that affect the ways classroom behavior is interpreted. The purpose of this pilot study was to engage a larger theoretical framework that explores the relationships between parents and teachers and to examine some of the ways in which common cultural misconceptions can lead to flawed behavioral ascriptions in the classroom, producing negative social outcomes for Black children. Findings from ethnography and interviews reveal that the most common barriers in this low-income neighborhood school setting included poor parent-teacher rapport, a general lack of basic understanding for how ADHD can affect classroom behavior, and faulty procedures in the school setting based on cultural stereotypes. These findings suggest that school officials' disinclination to recommend ADHD testing for Black children may be largely a result of the aforementioned obstacles. A larger study based on these results may produce more robust findings about the barriers that contribute to racial disparities in ADHD diagnoses.(Abstract from authors)

Reference:

Moody, M. D. (2017). "US against them": Schools, families, and the diagnosis of ADHD among black children. *Journal of Racial and Ethnic Health Disparities, 4*(5), 949–956. <u>https://doi.org/10.1007/s40615-016-0298-9</u>

Title: *"We Had to Keep Pushing": Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care*

• <u>https://meridian.allenpress.com/idd/article-abstract/56/5/321/1713/We-Had-to-Keep-Pus</u> <u>hing-Caregivers-Perspectives-on?redirectedFrom=fulltext</u>

Summary: Black children with autism spectrum disorder (ASD) are diagnosed later than their White peers, are more likely to be misdiagnosed, and are less likely to receive early intervention services or a developmental evaluation by three years old. Using a grounded theory approach, we solicited the perspectives of parents and other primary caregivers of Black children with ASD on barriers and facilitators to ASD screening and referrals in primary care. A socioeconomically diverse sample of 22 female caregivers participated. Four themes emerged. First, while some caregivers noted their child's primary healthcare providers facilitated a timely ASD diagnosis, other participants reported these providers ignored early concerns about child developmental delays. Second, many participants felt racial bias negatively impacted caregiver-primary healthcare provider interactions. Third, legal/custodial issues slowed caregivers' abilities to follow up on referrals from their primary healthcare providers. Finally, caregivers described denial, shame, and stigma relating to ASD in the Black community as possible factors for delayed follow up to referrals. Differences based on socioeconomic status are discussed. Efforts to improve family-centered, culturally relevant care for all Black caregivers raising children with or at-risk for ASD are needed, particularly for those families experiencing the multiple effects of poverty.(Abstract from authors)

Reference:

Dababnah, S., Shaia, W. E., Campion, K., & Nichols, H. M. (2018). "We had to keep pushing": Caregivers' perspectives on autism screening and referral practices of black children in primary care. *Intellectual and developmental disabilities*, 56(5), 321–336. <u>https://doi.org/10.1352/1934-9556-56.5.321</u>

Title: Understanding the barriers to receiving autism diagnoses for Hispanic and Latinx families

Summary: Significant disparities exist in early identification of autism spectrum disorder (ASD) for Hispanic and Latinx children. ASD prevalence estimates are approximately identical for White and Black children but lower for Hispanic and Latinx children. Reasons for these racial and ethnic variations are likely multifactorial. This review sought to understand previously described barriers and limitations to accessing ASD diagnostic services in the Latinx and Hispanic communities. Three main categories of existing barriers were identified: (1) parent/family, (2) community, and (3) systemic. These barriers are complex and multifactorial in nature, including circumstantial limitations such as limited English proficiency, noncitizenship, and low-income status. These can limit health care access, and can lead to family and community cultural barriers, poor knowledge about ASD, and social stigma related to disabilities. Understanding and mitigating barriers is essential to reduce disparities to ASD diagnosis in the Hispanic and Latinx community.(Abstract from authors)

Reference:

Guerrero, & Sobotka, S. A. (2022). Understanding the barriers to receiving autism diagnoses for Hispanic and Latinx families. *Pediatric Annals*, *51*(4), E167–E171. <u>Https://Doi.Org/10.3928/19382359-20220322-03</u>

Title: Conceptualization of autism in the Latino community and its relationship with early diagnosis

 <u>https://journals.lww.com/jrnldbp/Abstract/2014/10000/Conceptualization_of_Autism_in_t</u> <u>he_Latino.5.aspx</u>

Summary: Objective: Early identification of autism spectrum disorders (ASD) has been linked to improved long-term developmental outcomes. However, Latino children are diagnosed later than white non-Latino children. We aimed to qualitatively assess the understanding and conceptualization of ASD in the Latino community to understand potential community barriers to early diagnosis. Methods: We conducted 5 focus groups and 4 qualitative interviews with 30 parents of typically developing Latino children in Oregon. Participants were asked structured questions concerning video vignettes that follow a Latina mother from the time she begins to worry about her 3-year-old son's behaviors to the time he receives an ASD diagnosis. Focus groups and interviews were audio-recorded, transcribed, and independently coded. Coded data were analyzed using thematic analysis. Results: Many Latino families in the study had not heard of ASD or had little information about it. Families sometimes assumed that ASD red flags were normal or could be attributed to family dysfunction. Families also had concerns about provider communication and access to language services. Having a child with a developmental delay was associated with embarrassment, rejection, and family burden, making it difficult for parents to raise developmental concerns with providers. Conclusions: Pediatric providers should not assume that Latino parents have heard of ASD or know its symptoms. Providers should be aware that parents may be reluctant to mention concerns because of cultural factors. The health care system needs to improve resources for Latino parents with limited English proficiency. Policies should encourage the use of developmental screening in primary care. (Abstract from authors)

Reference:

Zuckerman, K. E., Sinche, B., Cobian, M., Cervantes, M., Mejia, A., Becker, T., & Nicolaidis, C. (2014). Conceptualization of autism in the Latino community and its relationship with early diagnosis. *Journal of Developmental & Behavioral Pediatrics*, 35(8), 522–532. <u>https://doi.org/10.1097/dbp.000000000000001</u>

Title: Asian American parents' experiences of raising children with autism: Multicultural family perspective

• <u>https://journals.sagepub.com/doi/10.1177/0021909612467421</u>

Summary: This article describes the experiences of Mandarin-speaking immigrant parents – an understudied population – raising a child with autism in the United States. Using purposive sampling, semi-structured interviews were conducted with four sets of parents and two mothers of children with autism. The interviews were transcribed and translated verbatim and analyzed using content analysis. Three main themes regarding parents' experiences were derived from the data: immigration and cultural accommodation; impact of autism and cognitive response; and outlook for the future. Implications for developing cultural competency to serve culturally and linguistically diverse populations were discussed. It is suggested that more cultural studies involving participants of diverse backgrounds should be conducted in further studies.(Abstract from authors)

Reference:

Wang, H.-T., & Casillas, N. (2012). Asian American parents' experiences of raising children with autism: Multicultural family perspective. *Journal of Asian and African Studies*, 48(5), 594–606. <u>https://doi.org/10.1177/0021909612467421</u>

Title: Cultural considerations for conducting autism assessment with Asian American and Pacific Islander students

• https://onlinelibrary.wiley.com/doi/10.1002/pits.22671

Summary: In public schools, Asian American and Pacific Islander (AAPI) students are overidentified with autism (AU) but are underrepresented in other special education categories. Such patterns may be result, in part, from overaggregation of data from students representing diverse AAPI ethnic groups. Yet, professionals' implicit biases, limited cultural responsivity in evaluation and research, and structural and systemic racism also likely contribute to the pervasive AU disproportionality in school-based identification. To improve accuracy of AU identification and appropriateness of school services and programming, the current paper aims to enhance school psychologists' (SPs') awareness and knowledge about AAPI cultures and to improve their efforts in conducting culturally responsive evaluation with AAPI students suspected of AU. An overview of historical and current anti-AAPI issues and AAPI cultural perceptions of AU are provided. Then, through the lens of sociocultural theory and using a framework of cultural humility, specific suggestions for culturally responsive autism assessment approaches are offered for SPs working with AAPI students and their families.(Abstract from authors)

Reference:

Truong, D. M., Barth, A. M., Mire, S. S., Ayala, M. L., Ramclam, A. N., Tan, S. X., & McKee, S. L. (2022). Cultural considerations for conducting autism assessment with Asian American and Pacific Islander students. *Psychology in the Schools*, 59(7), 1430–1444. <u>https://doi.org/10.1002/pits.22671</u>

Title: Challenges in ADHD care for ethnic minority children: A review of the current literature • https://journals.sagepub.com/doi/10.1177/1363461520902885

Summary: While attention deficit hyperactivity disorder (ADHD) has been extensively studied in the past decades, the role of social and cultural practices in its assessment, diagnosis, and treatment has been often overlooked. This selective review provides an overview of research that explores social and cultural influences on help-seeking behavior in ethnic minority children with ADHD. Studies were selected that address cultural diversity in three areas of ADHD help-seeking: problem recognition, access to mental health services, and treatment. Special attention was given to studies of treatment selection and adherence in minority groups. Findings suggested that cultural disparities in ADHD care among ethnic minority children occur in the early stages of problem recognition, through service selection, and in the quality of treatment. Ethnic minority children were less likely than their nonminority counterparts to be diagnosed with ADHD and its comorbid conditions and less likely to be prescribed and adhere to stimulant drug treatment. These differences reflect cultural diversity in norms and attitudes towards mental health issues (e.g., fear of social stigma) as well as limited access to gualified health care. Paradoxically, cultural, racial, and language bias may also lead to the overidentification of ethnic minority children as disabled and to higher ratings of ADHD symptoms. This review highlights the importance of sociocultural factors in understanding developmental psychopathology and help-seeking behavior. In addition, it further supports calls for increasing cultural competence in communications during clinical assessment, diagnosis, and treatment in minority communities. Clinical, theoretical, and methodological considerations for future research are discussed. (Astract from author)

Reference:

Slobodin, O., & Masalha, R. (2020). Challenges in ADHD care for ethnic minority children: A review of the current literature. *Transcultural Psychiatry*, *57*(3), 468–483. https://doi.org/10.1177/1363461520902885

Title: "US against them": Schools, families, and the diagnosis of ADHD among black children

• <u>https://link.springer.com/article/10.1007/s40615-016-0298-9</u>

Summary: Prior research indicates that attention-deficit/hyperactivity disorder (ADHD) is underdiagnosed, or less likely to be diagnosed, among Black children relative to White children and children in other non-Black racial categories. Scholars have suggested that this may be a result of cultural biases or misconceptions that affect the ways classroom behavior is interpreted. The purpose of this pilot study was to engage a larger theoretical framework that

explores the relationships between parents and teachers and to examine some of the ways in which common cultural misconceptions can lead to flawed behavioral ascriptions in the classroom, producing negative social outcomes for Black children. Findings from ethnography and interviews reveal that the most common barriers in this low-income neighborhood school setting included poor parent-teacher rapport, a general lack of basic understanding for how ADHD can affect classroom behavior, and faulty procedures in the school setting based on cultural stereotypes. These findings suggest that school officials' disinclination to recommend ADHD testing for Black children may be largely a result of the aforementioned obstacles. A larger study based on these results may produce more robust findings about the barriers that contribute to racial disparities in ADHD diagnoses.(Abstract from authors)

Reference:

Moody, M. D. (2017). "US against them": Schools, families, and the diagnosis of ADHD among black children. *Journal of Racial and Ethnic Health Disparities, 4*(5), 949–956. https://doi.org/10.1007/s40615-016-0298-9

Title: From under-diagnoses to over-representation: Black children, ADHD, and the school-to-prison pipeline

• <u>https://link.springer.com/article/10.1007/s12111-016-9325-5</u>

Summary: This study argues that the under-diagnosis of attention deficit hyperactive disorder in Black children is a result of racism that is structurally and institutionally embedded within school policing policies and the tendency to not recognize Black illness. The purpose of this research is to examine how micro-processes lead to structural inequality within education for Black children. It seeks to better understand how institutional racism and flawed behavioral ascriptions lead to the under-diagnosis of attention deficit hyperactive disorder (ADHD) in Black children and how that may also contribute to their over-representation in the "school-to-prison pipeline." The goal of this study was to review ethnographic, empirical data and examine the ways (1) how racism within some schools may contribute to the under-diagnosis of ADHD in Black children, (2) how their under-diagnosis and lack of treatment leads to their over-punishment, and (3) how they are over-represented in today's school-to-prison pipeline phenomenon, possibly as a result of such disparities. (Abstract from author)

Reference:

Moody, M. (2016). From under-diagnoses to over-representation: Black children, ADHD, and the school-to-prison pipeline. *Journal of African American Studies*, *20*(2), 152–163. <u>https://doi.org/10.1007/s12111-016-9325-5</u>

Title: Experiences of African American mothers of sons with autism spectrum disorder: Lessons for improving service delivery

• https://www.jstor.org/stable/26420423

Summary: Previous research has indicated that having a child with autism spectrum disorder (ASD) presents a unique set of challenges that impacts the entire family unit and individual

family members' health, well-being, and experiences across the lifespan (Patterson, 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006). Very few studies have addressed the role that racial and cultural identity may play in the experiences of these families, in particular, the experiences of African American families with children with ASD. The purpose of the present study was to qualitatively interview three African American caregivers of children with ASD to gain their perspectives on their experiences with their child and examine whether there may be a unique set of experiences associated with being an African American family of a child with ASD. Several themes emerged that suggested increased hardships for African American mothers of children with ASD. Implications of findings, including the need for a culturally-responsive approach across many domains of service (e.g., diagnosis, autism services, and special education services), are provided.

Reference:

Lovelace, T. S., Robertson, R. E., & Tamayo, S. (2018). Experiences of African American mothers of sons with autism spectrum disorder: Lessons for improving service delivery. *Education and Training in Autism and Developmental Disabilities*, 53(1), 3–16. <u>https://www.jstor.org/stable/26420423</u>

Title: The assessment and treatment of autism spectrum disorder: A cultural examination

• https://psycnet.apa.org/doiLanding?doi=10.1037%2Fpri0000067

Summary: In the United States, cultural minorities with autism spectrum disorder (ASD) are diagnosed less frequently and later in life than are White Americans. Furthermore, cultural minorities, compared to White Americans, are less likely to receive evidence-based interventions, and they often start receiving treatment at later ages. These health disparities underscore the influence of cultural variables in ASD, which are often overlooked in the existing literature. In this article, we review the current literature to highlight how cultural variables may exacerbate minority health disparities in the assessment and treatment of ASD. To illustrate these issues, we provide a composite case example and conclude by offering action steps for working with cultural minority families with ASD. As cultural factors are more thoroughly understood and researched, more effective assessment and treatment practices can be designed for culturally diverse children with ASD and their families.(Abstract from authors)

Reference:

La Roche, M. J., Bush, H. H., & D'Angelo, E. (2018). The assessment and treatment of autism spectrum disorder: A cultural examination. *Practice Innovations*, *3*(2), 107–122. <u>https://doi.org/10.1037/pri0000067</u>

Title: *Influence of community-level cultural beliefs about autism on families' and professionals' care for children*

• <u>https://journals.sagepub.com/doi/10.1177/1363461518779831</u>

Summary: This qualitative study aimed to understand how community-level cultural beliefs affect families' and professionals' care for children with autism and developmental delays in

immigrant communities, as a first step towards promoting early identification and access to early intervention services. The study was part of the larger New York City (NYC) Korean Community Autism Project, which was designed to identify strategies to increase awareness of autism and reduce delays in treatment seeking within the NYC Korean-American community. Our study elicited early childcare workers' and church leaders' beliefs about autism and developmental disorders and, in particular, early intervention. We also elicited responses to newly developed outreach materials targeting this community. An inductive approach was used to identify concepts and categories associated with autism. Our study confirmed that discomfort, stigma and discrimination are the prevailing community. Families' and professionals' understanding of autism and their care for children are affected by these community beliefs. Approaching immigrant communities with general information about child development and education rather than directly talking about autism and developmental disorders is likely to engage more families and professionals in need for diagnostic evaluation and early intervention for autism.(Abstract from authors)

Reference:

Kang-Yi, C. D., Grinker, R. R., Beidas, R., Agha, A., Russell, R., Shah, S. B., Shea, K., & Mandell, D. S. (2018). Influence of community-level cultural beliefs about autism on families' and professionals' care for children. *Transcultural Psychiatry*, *55*(5), 623–647. <u>https://doi.org/10.1177/1363461518779831</u>

Title: Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families

• <u>https://journals.sagepub.com/doi/10.1177/1088357610361344</u>

Summary: Three multilingual immigrant South Asian Muslim families who have children with autism were interviewed to ascertain their beliefs about autism. Data were drawn from interviews and conversations recorded during 17 months of ethnographic fieldwork in homes and community. Results indicate that families understood the task of raising a child with autism in religious terms. In keeping with the precepts of Islam, their overarching goal was to raise their children as normally as possible, incorporating them into ordinary social, linguistic, and religious practices at home and in the community. Parents strongly contested experts' understandings of autism, which they believed undermined rather than promoted their children's development. Findings have implications for multicultural teacher education and enhancing home, community, and school collaboration.(Abstract from authors)

Reference:

Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities*, 25(2), 98–109. <u>https://doi.org/10.1177/1088357610361344</u> **Title:** Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: A systematic review

https://www.frontiersin.org/articles/10.3389/fpsyg.2018.00280/full

Summary: Background: This paper aimed to review the literature on the factors associated with parenting stress and resilience among parents of children with autism spectrum disorder (ASD) in the South East Asia (SEA) region. Methods: An extensive search of articles in multiple online databases (PsycNET, ProQuest, PudMed, EMBASE, CINAHL, Web of Science, and Google Scholar) resulted in 28 papers that met the inclusion criteria (i.e., conducted in the SEA region, specific to ASD only, published in a peer-reviewed journal, full text in English). Studies found were conducted in the following countries: Brunei, n = 1; Indonesia, n = 2; Malaysia, n = 12; Philippines, n = 5; Singapore, n = 5, Thailand, n = 2; and Vietnam, n = 1, but none from Cambodia, East Timor, Laos, and Myanmar were identified. Results: Across the studies, six main factors were found to be associated with parenting stress: social support, severity of autism symptoms, financial difficulty, parents' perception and understanding toward ASD, parents' anxiety and worries about their child's future, and religious beliefs. These six factors could also be categorized as either a source of parenting stress or a coping strategy/resilience mechanism that may attenuate parenting stress. Conclusion: The findings suggest that greater support services in Western countries may underlie the cultural differences observed in the SEA region. Limitations in the current review were identified. The limited number of studies yielded from the search suggests a need for expanded research on ASD and parenting stress, coping, and resilience in the SEA region especially in Cambodia, East Timor, Laos, and Myanmar. The identified stress and resilience factors may serve as sociocultural markers for clinicians. psychologists, and other professionals to consider when supporting parents of children with ASD. (Abtsract from author)

Reference:

Ilias, K., Cornish, K., Kummar, A. S., Park, M. S.-A., & Golden, K. J. (2018). Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: A systematic review. *Frontiers in Psychology*, 9(280). <u>https://doi.org/10.3389/fpsyq.2018.00280</u>

Title: Assessing ADHD in Latino families

• https://journals.sagepub.com/doi/10.1177/1087054711427396

Summary: Objective: In an effort to combat the mental health disparities that exist among Latinos, the current study aimed to add to our knowledge related to culturally appropriate assessments for Latino children presenting with ADHD. Method: As part of a larger study, a community sample of 68 Spanish-speaking, Latino parents completed the Spanish translation of the Disruptive Behavior Disorders Rating Scale (DBD-S), a commonly used, parent-report measure of ADHD. Results: Results suggest that although both the Inattentive and Hyperactive/Impulsive subscales of the DBD-S are psychometrically sound, the Hyperactive/Impulsive subscale may not be culturally appropriate with some Latino families, particularly those who are less acculturated. This was further supported by preliminary evidence

suggesting that this subscale also was not diagnostically useful with the current, community sample. Conclusion: The potential problems associated with the overemphasis on symptomatology when working with Latino families, the importance of examining functional impairment as part of a culturally appropriate assessment, and the need to replicate the current findings with a clinical sample are discussed.(Abstract from authors)

Reference:

Gerdes, A. C., Lawton, K. E., Haack, L. M., & Hurtado, G. D. (2013). Assessing ADHD in Latino families. *Journal of Attention Disorders*, *17*(2), 128–140. https://doi.org/10.1177/1087054711427396

Title: A phenomenological examination of the influence of culture on treating and caring for Hispanic children with autism

• <u>https://eric.ed.gov/?id=EJ1046003</u>

Summary: Researchers have found that cultural factors may lead to lower rates of diagnosis in Hispanic children with autism and that parents lack the knowledge of therapies and practices used in the treatment of the autism spectrum disorder (ASD). Five research questions guided this phenomenological study. The focus of the first two questions was how culture may affect families seeking assistance; the third question queried how professionals play a part in the choice of therapies ; the fourth question dealt with how do families choose a therapy to aid their child with ASD. The focus of the last question was the involvement of other family members. The major themes included professional influences, concerns for children's futures as adults, parental involvement, and personalismo/familismo. The outcomes of the study demonstrate the influence professionals have on the families and the choices families make to aid their children with ASD. These findings will assist professionals to understand the Hispanic culture as it may relate to having a child with ASD and thus assist families to understand how to acquire the services needed.(Abstract from authors)

Reference:

Estrada, L., & Deris, A. R. (2014). A phenomenological examination of the influence of culture on treating and caring for Hispanic children with autism. *International Journal of Special Education*, 29(3), 4–15. <u>https://eric.ed.gov/?id=EJ1046003</u>

Title: A systematic review of cultural considerations and adaptation of social skills interventions for individuals with autism spectrum disorder

<u>https://www.sciencedirect.com/science/article/pii/S1750946718300758?via%3Dihub</u>

Summary: Background: There is an increasing need for culturally competent interventions for individuals with ASD. Given the dynamic relationship between culture and social behavior, the effectiveness of social skills interventions may be particularly influenced by the degree to which they are culturally appropriate. The extent to which ASD social skills intervention research has considered the role of culture (either through including diverse samples or by implementing cultural adaptations) is not well understood. Method: The current study is a systematic review of

social skills intervention studies for individuals with ASD. The aims of the current review were to evaluate the extent to which studies have included diverse samples, and the extent to which cultural adaptations have been made to social skills interventions. Results: Sixty-two percent of studies published since 2010 reported the race, ethnicity, or nationality of participants. Minority populations were notably underrepresented in studies conducted in the United States. Only five studies incorporated cultural adaptations to social skills interventions, and these studies included both surface and deep structure adaptations for diverse populations. Conclusion: Greater diversity is needed in studies of social skills interventions for children and adolescents with ASD. Although a few studies highlighted the feasibility of incorporating cultural adaptation strategies for ASD interventions, future research is needed to examine the extent to which cultural adaptations enhance the effectiveness of social skills interventions in this population.(Abstract from authors)

Reference:

Davenport, M., Mazurek, M., Brown, A., & McCollom, E. (2018). A systematic review of cultural considerations and adaptation of social skills interventions for individuals with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 52, 23–33. <u>https://doi.org/10.1016/j.rasd.2018.05.003</u>

Title: *"We had to keep pushing": Caregivers' perspectives on autism screening and referral practices of black children in primary care*

• <u>https://meridian.allenpress.com/idd/article-abstract/56/5/321/1713/We-Had-to-Keep-Pus</u> <u>hing-Caregivers-Perspectives-on?redirectedFrom=fulltext</u>

Summary: Black children with autism spectrum disorder (ASD) are diagnosed later than their White peers, are more likely to be misdiagnosed, and are less likely to receive early intervention services or a developmental evaluation by three years old. Using a grounded theory approach, we solicited the perspectives of parents and other primary caregivers of Black children with ASD on barriers and facilitators to ASD screening and referrals in primary care. A socioeconomically diverse sample of 22 female caregivers participated. Four themes emerged. First, while some caregivers noted their child's primary healthcare providers facilitated a timely ASD diagnosis, other participants reported these providers ignored early concerns about child developmental delays. Second, many participants felt racial bias negatively impacted caregiver-primary healthcare provider interactions. Third, legal/custodial issues slowed caregivers' abilities to follow up on referrals from their primary healthcare providers. Finally, caregivers described denial, shame, and stigma relating to ASD in the Black community as possible factors for delayed follow up to referrals. Differences based on socioeconomic status are discussed. Efforts to improve family-centered, culturally relevant care for all Black caregivers raising children with or at-risk for ASD are needed, particularly for those families experiencing the multiple effects of poverty.(Abstract from authors)

Reference:

Dababnah, S., Shaia, W. E., Campion, K., & Nichols, H. M. (2018). "We had to keep pushing": Caregivers' perspectives on autism screening and referral practices of black children in primary care. Intellectual and Developmental Disabilities, 56(5), 321–336. https://doi.org/10.1352/1934-9556-56.5.321

Title: African American families on autism diagnosis and treatment: The influence of culture

• https://link.springer.com/article/10.1007/s10803-015-2482-x

Summary: Cultural factors such as health care access and autism spectrum disorder (ASD) symptom interpretations have been proposed as impacting delayed diagnosis and treatment for African American children with ASD. A qualitative study of urban African American families caring for their child with autism was conducted with 24 family members and 28 ASD professionals. Cultural caring meant families protected their child from harm including potential or actual distrustful encounters, and took action for their child and community to optimize their child's health and address the knowledge deficits of ASD within their community. Families and professionals believed cultural influences delayed families' receiving and seeking appropriate health care for the African American child with ASD affecting timely autism diagnosis and treatment. (Abstract from authors)

Reference:

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders, 45*(10), 3244–3254. <u>https://doi.org/10.1007/s10803-015-2482-x</u>

Title: Anglo-latino differences in parental concerns and service inequities for children at risk of autism spectrum disorder

• <u>https://journals.sagepub.com/doi/10.1177/1362361318818327</u>

Summary: In an evaluation of Anglo and Latina mothers and their children at risk of autism, this study compared mother-reported child behavioral concerns to staff-observed symptoms of autism. Within Latina mothers, the impact of primary language (English/Spanish), mothers' education, and child age on ratings of developmental concerns was examined. Participants were 218 mothers (Anglo = 85; Latina = 133) of children referred to a no-cost autism screening clinic. Mothers reported on behavioral concerns, autism symptomology, and services received; children were administered the Autism Diagnostic Observation Schedule by certified staff. Results revealed that Anglo and Latino children did not differ by autism symptoms or classification. However, Anglo mothers reported significantly more concerns than Latina mothers. Within the Latina group, analyses revealed significant interaction effects of language and child age: Spanish-speaking mothers of preschoolers endorsed fewer concerns, while Spanish-speaking mothers of school-aged children endorsed more concerns. Despite these reports, Anglo children with a classification of autism spectrum disorder were receiving significantly more services than Latino children with autism spectrum disorder, suggesting early beginnings of a service divide as well as the need for improved parent education on child development and advocacy for Latino families.(Abstract from authors)

Reference:

Blacher, J., Stavropoulos, K., & Bolourian, Y. (2019). Anglo-latino differences in parental concerns and service inequities for children at risk of autism spectrum disorder. *Autism*, 23(6), 1554–1562. <u>https://doi.org/10.1177/1362361318818327</u>

Multidisciplinary Professionals and Neurodiverse Clients

Health

Title:The Need for Improved Health Professionals' Education in the Treatment of Persons with Developmental Disabilities

Summary:Problem Statement: Health professionals' education lacks specific training in providing care for patients with developmental disabilities (DD). It is important for health professionals to have communication and hands-on skills necessary to treat patients with DD.Purpose: The purpose of this study was to identify patient satisfaction with the quality of health care received from medical and dental professionals.

Methods: This pilot study focused on the health care transition experience of young adults with developmental disabilities and their family members to gain new insights into their medical and dental needs. A mixed research design was used to identify a convenience sample of 15 in which descriptive and qualitative data were gathered in a structured 45 minute interview. This pilot study was approved by the University of Texas Health Science Center San Antonio Institutional Review Board, May 6, 2009, approval number HSC2009033H.Results: Patients most commonly reported (33%) that their general physician was not prepared to treat those with DD. Other results include the patients' perception that their general dentist was not prepared to treat patients with DD (27%), patients reporting being very dissatisfied with the quality of dental care they have received (13%) and patients reporting being very dissatisfied with the quality of medical care they have received (13%). Furthermore, families often felt segregated during appointments and treatment planning. Lastly, patients would like doctors to "explain, listen and answer questions, take more time, make sentences shorter" when communicating.Conclusions: Health professionals lack training specific to interacting with young adults with developmental disabilities. Training of new health professionals should focus on "patient and family centered care". Licensed healthcare professionals should attend continuing education courses designed to educate professionals on treatment and communication of patients with DD.(Abstract from author)

Reference:

Garza, G. R., Cunningham, M., Perez, K., Agado, V., Yeung, C., & Nguyen, C. (2013). The need for improved health professionals' education in the treatment of persons with developmental disabilities. *Journal of Dental Hygiene (Online)*, *87*(6), 388-389.

https://www.proquest.com/scholarly-journals/need-improved-health-professionals-education/docview/1521942177/se-2

Title: Staff Training in Autism: The One-Eyed Wo/Man...

• <u>https://www.mdpi.com/1660-4601/13/7/716</u>

Summary: Having well-trained staff is key to ensuring good guality autism services, especially since people affected with autism generally tend to have higher support needs than other populations in terms of daily living, as well as their mental and physical health. Poorly-trained staff can have detrimental effects on service provision and staff morale and can lead to staff burn-out, as well as increased service user anxiety and stress. This paper reports on a survey with health, social care, and education staff who work within the statutory autism services sector in the UK that explored their knowledge and training with regards to autism. Interview data obtained from staff and service users offer qualitative illustrations of survey findings. Overall, the findings expose an acute lack of autism-specific training that has detrimental impacts. At best, this training was based on brief and very basic awareness raising rather than on in-depth understanding of issues related to autism or skills for evidence-based practice. Service users were concerned with the effects that the lack of staff training had on the services they received. The paper concludes with a discussion of policy routes to achieving quality staff training based on international best practice. The focus is on improving the quality of life and mental health for services users and staff, as well as making potentially significant cost-savings for governments.(Abstract from authors)

Reference:

Dillenburger, K., McKerr, L., Jordan, J.-A., & Keenan, M. (2016). Staff training in autism: The one-eyed wo/man. *International Journal of Environmental Research and Public Health*, *13*(7), 716. <u>https://doi.org/10.3390/ijerph13070716</u>

Title:Healthcare Providers' Experiences with Autism: A Scoping Review

• https://link.springer.com/article/10.1007/s10803-019-03912-6

Summary:Gaps in research knowledge exist regarding patient-provider interactions with individuals with autism in healthcare settings. To address this, a scoping review was conducted focusing on the experiences of healthcare professionals working with individuals with autism. A systematic search and screen of the literature resulted in 27 relevant studies. Six key themes were found across these 27 studies including (1) complexity beyond usual role, (2) limited knowledge and resources, (3) training/prior experience, (4) communication and collaboration, (5) need for information and training, and (6) need for care coordination and systemic changes. The results of this review have implications for future research and practice and should be considered when reflecting on opportunities to enhance research and service provision with individuals with autism.(Abstract from authors)

Reference:

Morris, R., Greenblatt, A., & Saini, M. (2019). Healthcare providers' experiences with autism: A scoping review. *Journal of Autism and Developmental Disorders*, *49*(6), 2374–2388. https://doi.org/10.1007/s10803-019-03912-6

Title:Inclusion of disability-related content in nurse practitioner curricula

<u>https://journals.lww.com/jaanp/Fulltext/2015/04000/Inclusion_of_disability_related_conte_nt_in_nurse.8.aspx</u>

Summary: Purpose: To examine the integration of disability-content in a national sample of nurse practitioner curricula.Data sources: Responses of National Organization of Nurse Practitioner Faculties (NONPF) members to an online 34-item survey designed to assess disability-related content included in nurse practitioner (NP) curricula; populations of people with disabilities addressed; models of disability; and resources used to teach about disability, facilitators and barriers to inclusion of disability, and respondents' assessment of the adequacy of coverage of disability in their programs. A survey used previously to assess integration of disability content in undergraduate nursing programs was modified to make it relevant to NP curricula. Nursing faculty and people with disability validated the survey to ensure its completeness and sensitivity to the disability community. Participating programs represent 111 (33.6%) NP programs.Conclusions: Lack of disability-related content reported by NP faculty in the majority of programs suggests that there is considerable room for improvement in efforts to address this often vulnerable population. Because people with disabilities can be found in any setting where health care is provided, all NPs need to be prepared to care for people with disabilities across the life span. Implications for practice: Strategies need to be developed and implemented to increase the awareness of NP faculty about the health issues of people with disabilities and integration of disability-related content without disrupting existing overloaded NP curricula.(Abstract from author)

Reference:

Smeltzer, S. C., Blunt, E., Marozsan, H., & Wetzel-Effinger, L. (2015). Inclusion of disability-related content in nurse practitioner curricula. *Journal of the American Association of Nurse Practitioners*, 27(4), 213–221. <u>https://doi.org/10.1002/2327-6924.12140</u>

Title:*A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System*

• https://link.springer.com/article/10.1007/s10803-015-2579-2

Summary:We conducted an online survey of adult health care providers at Kaiser Permanente Northern California and semi-structured interviews with a subset of physicians. The survey assessed providers' ability to recognize autism spectrum disorder (ASD), asked them to rate their autism knowledge, comfort level in treating affected patients, and evaluated training and resource needs. 922 providers completed the survey (response rate 25.3 %), and 9 were interviewed by telephone regarding their autism training and experiences caring for patients with autism. Most providers reported lacking skills and tools to care for this adult patient population.

A high proportion of adult providers were not aware that they had patients with ASD. These findings underscore the need to educate physicians caring for adults with ASD.(Abstract from authors)

Reference:

Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A study of physician knowledge and experience with autism in adults in a large integrated healthcare system. *Journal of Autism and Developmental Disorders*, *45*(12), 4002–4014. <u>https://doi.org/10.1007/s10803-015-2579-2</u>

Title: A survey of Registered Nurses' educational experiences and self-perceived capability to care for people with intellectual disability and/or autism spectrum disorder

• <u>https://www.tandfonline.com/doi/full/10.3109/13668250.2021.1967897</u>

Summary:Aims and Objectives: To survey the educational experience of Registered Nurses in Australia, at undergraduate, post graduate and continuing professional development levels.Background: It has been previously demonstrated that nurses feel unprepared to care for people with intellectually disability and/or autism spectrum disorder in mainstream clinical settings. Specific undergraduate pre-registration curricula content in this domain has been identified to be low in volume, and in the absence of any studies to determine it, it has been presumed that it has diminished over time.Methods:A cross-sectional survey of Australian Registered Nurses using a descriptive survey tool.Results:The level of education undertaken related to intellectual disability and autism spectrum disorder has been consistently low across time and it predates the move from pre-registration hospital based training to the tertiary sector. A relationship was identified between the experience of education and self-reported preparedness, comfort and knowledge to care for people with intellectual disability and/or autism spectrum disorder.Conclusion:Increased educational preparation for nurses to care for people with intellectual disability and/or autism is indicated.(Abstract from authors)

Reference:

Cashin, A., Pracilio, A., Buckley, T., Kersten, M., Trollor, J., Morphet, J., Howie, V., Griffin, K., & Wilson, N. J. (2022). A survey of registered nurses' educational experiences and self-perceived capability to care for people with intellectual disability and/or autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, *47*(3), 227–239. https://doi.org/10.3109/13668250.2021.1967897

Title: Adverse childhood experiences are associated with the risk of lung cancer: a prospective cohort study

• <u>https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-10-20</u>

Summary:BackgroundStrong relationships between exposure to childhood traumatic stressors and smoking behaviours inspire the question whether these adverse childhood experiences (ACEs) are associated with an increased risk of lung cancer during adulthood. MethodsBaseline survey data on health behaviours, health status and exposure to adverse childhood experiences (ACEs) were collected from 17,337 adults during 1995-1997. ACEs included abuse (emotional, physical, sexual), witnessing domestic violence, parental separation or divorce, or growing up in a household where members with mentally ill, substance abusers, or sent to prison. We used the ACE score (an integer count of the 8 categories of ACEs) as a measure of cumulative exposure to traumatic stress during childhood. Two methods of case ascertainment were used to identify incident lung cancer through 2005 follow-up: 1) hospital discharge records and 2) mortality records obtained from the National Death Index.Results

The ACE score showed a graded relationship to smoking behaviors. We identified 64 cases of lung cancer through hospital discharge records (age-standardized risk = 201 × 100,000-1 population) and 111 cases of lung cancer through mortality records (age-standardized mortality rate = 31.1 × 100,000-1 person-years). The ACE score also showed a graded relationship to the incidence of lung cancer for cases identified through hospital discharge (P = 0.0004), mortality (P = 0.025), and both methods combined (P = 0.001). Compared to persons without ACEs, the risk of lung cancer for those with \geq 6 ACEs was increased approximately 3-fold (hospital records: RR = 3.18, 95%CI = 0.71-14.15; mortality records: RR = 3.55, 95%CI = 1.25-10.09; hospital or mortality records: RR = 2.70, 95%CI = 0.94-7.72). After a priori consideration of a causal pathway (i.e., ACEs \rightarrow smoking \rightarrow lung cancer), risk ratios were attenuated toward the null, although not completely. For lung cancer identified through hospital or mortality records, persons with ≥ 6 ACEs were roughly 13 years younger on average at presentation than those without ACEs.ConclusionsAdverse childhood experiences may be associated with an increased risk of lung cancer, particularly premature death from lung cancer. The increase in risk may only be partly explained by smoking suggesting other possible mechanisms by which ACEs may contribute to the occurrence of lung cancer. (Abstract from authors)

Reference:

Brown, D. W., Anda, R. F., Felitti, V. J., Edwards, V. J., Malarcher, A. M., Croft, J. B., & Giles, W. H. (2010). Adverse childhood experiences are associated with the risk lung cancer: A prospective cohort study. *BMC Public Health*, *10*(20). <u>https://doi.org/10.1186/1471-2458-10-20</u>

Criminal Justice

Title:*University-Community Mental Health Training Collaboration: Teaching Criminal Legal Stakeholders About Autism*

• https://ps.psychiatryonline.org/doi/10.1176/appi.ps.20220254

Summary: Individuals with autism spectrum disorder (ASD) are disproportionately represented in the criminal legal system, yet ASD-specific training is rarely provided to frontline clinical staff or legal professionals. This column describes a collaboration between university researchers and a state mental health department to promote ASD awareness, knowledge, and intervention skills among clinical and legal professionals working with autistic individuals with criminal legal involvement. Descriptions of how specific needs were identified, how tailored educational workshops were developed, and how workshop efficacy was assessed are provided. Lessons learned and recommendations for researchers and health care systems interested in similar collaborations are offered.(Abstract from authors)

Reference:

Kois, L. E., Cox, J., Simmons, G. L., White, S. W., & Scott-Adams, V. (2023). University-Community Mental Health Training Collaboration: teaching criminal legal stakeholders about autism. *Psychiatric Services*. <u>https://doi.org/10.1176/appi.ps.20220254</u>

Title: Incorporating Neurodiversity into Therapeutic Jurisprudence: Exploring the Policy Diffusion Potential of Pennsylvania's Autism Training Law for Juvenile Court Judges

 <u>https://www.cjcj.org/media/incorporating_neurodiversity_into_therapeutic_jurisprudence.</u> pdf

Summary: Many persons with autism encounter criminal justice practitioners over the course of their lives, just as neurotypical persons do. Autistic persons face distinct challenges in such a context, however: a lack of eye contact may communicate suspicious behavior (at best) or outright defiant and disrespectful behavior (at worst) to a police officer or a judge. While many policing agencies implemented autism-training curriculums, judicial training for autism lags behind police training. The following policy analysis draws upon innovation in a single jurisdiction – Pennsylvania – requiring mandatory autism training for magisterial district court judges (MDJ's) to explore the policy diffusion potential of this innovation to juvenile courts in other jurisdictions and to other levels of the Pennsylvania judiciary.(Abstract from authors)

Reference:

Drapela, L. (2022). Incorporating neurodiversity into therapeutic jurisprudence: Understanding the policy diffusion potential of Pennsylvania's Mandatory Autism Training Law for district court judges. Forthcoming, Justice Policy Journal.

Title:Considerations regarding child and parent neurodiversity in family court

• https://onlinelibrary.wiley.com/doi/10.1111/fcre.12655

Summary:Family court professionals must continually be developing a greater appreciation of diversity in its many forms. As with cultural diversity and non-traditional families, neurodiversity in children and parents is another social justice issue in which overt or implicit bias may impact child custody decision-making, such as when a divorcing parent has a significant psychiatric or neurocognitive condition. The neurodiversity perspective, while having its limitations, can help reduce bias in family court by recognizing that there is a broad range of brain functioning, while taking a strengths-based approach, as opposed to a pathology orientation. This article will define neurodiversity, address how the stigma of mental health conditions can lead to automatic negative presumptions about parental competency, as well examine how the voices of neurodiverse children can be better heard in family court processes. Lastly, principles for court personnel to consider with neurodiverse parents and children will be elucidated. (Abstract from authors)

Reference:

Pickar, D. B. (2022). Considerations regarding child and parent neurodiversity in family court. *Family Court Review*, 60(3), 492-506. <u>Https://Doi.Org/10.1111/Fcre.12655</u>

Title:Judicial Spectrum Primer: What Judges Need to Know About Children with Autism Spectrum Disorders

Summary: Ricky's story is a real Family Court case. Although most cases involving ASD may not be as dramatic, the growing prevalence of ASD-1 in 88 children1-may signify Ricky's case as a harbinger of the future for juvenile and family courts. His case underscores the importance of early identification of ASD, and demonstrates the necessity for judges to understand the disorder as well as seeking and getting expert recommendations to allow for meaningful decision making. This article aims to provide information to juvenile and family court judges to help them make effective decisions concerning children with ASD. Part I, written by a pediatrician and geneticist, will present an overview of medical knowledge concerning ASD, including its prevalence, how ASD is diagnosed, and its treatment and prognosis. Part II will review the federal cases involving ASD, with an emphasis on those involving the Individuals with Disabilities Education Act (IDEA), because it will help judges craft orders for services. Part III will provide an in-depth look at the few published appellate family law cases involving children with ASD, and will apply the medical and legal information to issues that have or may arise in child protection, custody, visitation, juvenile delinquency, and child support cases. Finally, the Appendix contains resources including a checklist that can help courts gather information to assist in tailoring court orders and rendering decisions on ASD cases. (Abstract from authors)

Reference:

Dicker, S., & Marion, R. (2012). Judicial spectrum primer: What judges need to know about children with autism spectrum disorders. *Juvenile and Family Court Journal*, 63(2), 1–19. https://doi.org/10.1111/j.1755-6988.2012.01074.x

Title Autism and the criminal justice system: An analysis of 93 cases

• https://onlinelibrary.wiley.com/doi/10.1002/aur.2690

Summary:We investigate whether autistic people's vulnerability is taken into account at each stage of the criminal justice system (CJS). Defense lawyers from 12 nations were included in the study although the sample was predominantly from the UK. Lawyers completed an online survey regarding one case in which they had defended an autistic client between January 2015 and January 2020; and on one case in which they had defended a nonautistic client charged with a similar offense, to provide a comparison group. Ninety-three lawyers (85% in the UK) reported on one autistic case, and 53 also reported on one nonautistic case. 75% of autistic clients were not given reasonable adjustments during the process. Only 43% were offered an appropriate adult during police investigations, even though they had an existing diagnosis of autism. 59% of prosecution barristers and 46% of judges said or did something during the trial that made the lawyers concerned that they did not have an adequate understanding of autism. Lawyers were 7.58 times more likely to be concerned about their autistic client's effective participation in court and were 3.83 times more likely to be concerned that their autistic clients.

would engage in self-harm, compared with their nonautistic clients. There is a failure to identify and address autistic peoples' disability within the CJS. There is a need for mandatory autism training for police officers and the judiciary, with a focus on identifying autism and understanding the needs of autistic people so that reasonable adjustments are offered in all cases.(Abstract from authors)

Reference:

Slavny-Cross, R., Allison, C., Griffiths, S., & Baron-Cohen, S. (2022). Autism and the criminal justice system: An analysis of 93 cases. *Autism Research*, 15(5), 904–914. <u>Https://Doi.Org/10.1002/Aur.2690</u>

Title:*Responding to neurodiversity in the courtroom: A brief evaluation of environmental accommodations to increase procedural fairness*

https://onlinelibrary.wiley.com/doi/10.1002/cbm.2239

Summary: Recent research has highlighted that a high prevalence of young adults who have various forms of neurodivergence come into contact with the criminal justice system. Currently, many courts are not designed to respond to neurological differences often seen in young people who engage with them. The aim of this study was to identify ways to make locality courts more accessible, engaging, and ultimately more responsive to neurodivergence. A panel of neurodivergence specialists reviewed the general district courtroom environment of a new specialised young adult list court in Aotearoa New Zealand to identify potential barriers to accessibility and to highlight areas for improvement. The methodology involved naturalistic observation of a typical morning in the courtroom. We identified a series of recommendations with the potential to improve the court experience and increase access to justice for neurodivergent young adults. This study identified specific need for neurodiversity education and screening within the court environment.(Abstract from author)

Reference:

Clasby, B., Mirfin-Veitch, B., Blackett, R., Kedge, S., & Whitehead, E. (2022). Responding to neurodiversity in the courtroom: A brief evaluation of environmental accommodations to increase procedural fairness. *Criminal Behaviour and Mental Health, 32*(3), 197–211. <u>https://doi.org/10.1002/cbm.2239</u>

Title: Policing along the spectrum: Reducing risk and improving service delivery

Summary: Autism spectrum disorder is a complex life-long neurodevelopmental disorder that affects social skills, language, learning, cognitive function, physical abilities, and behavior. Moreover, autism is becoming increasingly prevalent in Canada and abroad. Inevitably, law enforcement professionals will interact with the autistic population in their duties; however, many exchanges produce poor outcomes. Physical restraint is often used, and the benefit of autism-trained Crisis Intervention Teams is underutilized, especially in Canada. In addition, current training outcomes for law enforcement professionals are ephemeral and unlikely to yield

mastery. This article argues three antidotes to improve service delivery and reduce risk: Crisis Intervention Teams that incorporate autism training; methodologically sound and rigorously evaluated practical training; and community outreach, which creates relationships proactively and fosters trust. Future research should: analyze the outcomes of autistic-trained Crisis Intervention Teams; determine qualitatively what the population with autism and their stakeholders seek in a comprehensive training curriculum; and determine the success of nascent training courses and community outreach goals.(Abstract from authors)

Reference:

Leydier, T. B. (2022). Policing along the spectrum: Reducing risk and improving service delivery. *International Journal of Police Science & Management, 24*(4), 427–436. <u>https://doi.org/10.1177/14613557221119117</u>

Title: Responding to neurodiversity in the courtroom: A brief evaluation of environmental accommodations to increase procedural fairness

• https://onlinelibrary.wiley.com/doi/10.1002/cbm.2239

Summary: Recent research has highlighted that a high prevalence of young adults who have various forms of neurodivergence come into contact with the criminal justice system. Currently, many courts are not designed to respond to neurological differences often seen in young people who engage with them. The aim of this study was to identify ways to make locality courts more accessible, engaging, and ultimately more responsive to neurodivergence. A panel of neurodivergence specialists reviewed the general district courtroom environment of a new specialised young adult list court in Aotearoa New Zealand to identify potential barriers to accessibility and to highlight areas for improvement. The methodology involved naturalistic observation of a typical morning in the courtroom. We identified a series of recommendations with the potential to improve the court experience and increase access to justice for neurodivergent young adults. This study identified specific need for neurodiversity education and screening within the court environment.(Abstract from authors)

Reference:

Clasby, B., Mirfin-Veitch, B., Blackett, R., Kedge, S., & Whitehead, E. (2022). Responding to neurodiversity in the courtroom: A brief evaluation of environmental accommodations to increase procedural fairness. *Criminal Behaviour and Mental Health*, 32(3). https://doi.org/10.1002/cbm.2239

Social Services

Title:*Addressing the Need for Training More School Psychologists to Serve Toddlers and Preschoolers with Autism Spectrum Disorders*

• https://link.springer.com/article/10.1007/s40688-022-00434-4

Summary:The prevalence of autism spectrum disorder (ASD) has risen significantly in the past two decades. Unfortunately, there is a shortage of mental health providers who have specialized

training in delivering evidenced-based services to this population. Early intensive behavioral intervention (EIBI) is an evidenced-based treatment recommended for toddlers with ASD, and school psychologists are uniquely positioned to help children with ASD receive it. However, many school psychologists do not receive adequate training in this subspecialty. This paper makes recommendations to school psychology training programs about how to add or improve training in this subspecialty based on the results of an Office of Special Education Programs grant-funded ASD training program which involved collaboration between a NASP-approved and APA-accredited school psychology training program and a community-based early intensive behavioral intervention (EIBI) clinic. The grant supported development of an interdisciplinary didactic and clinical training program to increase the ASD knowledge, skills, and competencies of school psychology graduate students, with the broader goals of developing a replicable training model and increasing the workforce of trained providers for this underserved population. Fifteen graduate students completed the training program. Outcomes related to trainee knowledge, skills, and competencies, trainee satisfaction, and lessons learned over time analyzed within a logic model that guided the project's development and execution can be informative for other school psychology programs undertaking training in this subspecialty.(Abstract from authors)

Reference:

Mathews, T. L., Daly, E., Kunz, G. M., Lugo, A. M., McArdle, P., Menousek, K., & Kupzyk, K. (2022). Addressing the need for training more school psychologists to serve toddlers and preschoolers with autism spectrum disorders. *Contemporary School Psychology*, 1-16. <u>https://doi.org/10.1007/s40688-022-00434-4</u>

Title:*Training Staff to Provide Quality Support for Adults with Autism Spectrum Disorder: Recommended Practices and Target Skills*

• https://link.springer.com/article/10.1007/s41252-019-00107-z

Summary:Many adults with autism spectrum disorder (ASD) receive support from staff within human service agencies. Those staff, and especially personnel in direct service roles, usually require training to ensure they have the skills to provide desired support in a quality manner. Staff training is particularly important in regard to adults with severe symptoms of ASD who require more staff support than individuals with less significant ASD challenges. This paper describes training of front-line, human service staff in key performance skills for providing quality support for adults with severe symptoms of ASD. A summary of performance- and competency-based behavioral skills training is initially provided as a means of ensuring staff acquire skills to fulfill job expectations. A description of skills that warrant training based on behavior analytic research involving adults with severe ASD symptoms is then presented. The targeted skills focus on how to provide meaningful day activities tailored for adults with severe symptoms of ASD, teach in a naturalistic manner in light of common staffing characteristics of adult service settings, promote daily happiness, provide beneficial social attention, and treat adults with ASD in general with dignity. The important yet qualified role of staff training in the overall provision of quality support is also emphasized.(Abstract from authors)

Reference:

Reid, D. H. (2019). Training staff to provide quality support for adults with autism spectrum disorder: Recommended practices and target skills. Advances in Neurodevelopmental Disorders, 3(4), 457–467. <u>https://doi.org/10.1007/s41252-019-00107-z</u>

Title: Autism spectrum disorder and the science of social work: A grand challenge for social work research

• https://www.tandfonline.com/doi/full/10.1080/15332985.2018.1509411

Summary: The social work profession has not yet taken a leadership role in addressing the myriad of challenges that individuals on the autism spectrum encounter across the lifespan. In this essay, we argue that social workers are well equipped to engage in research and practice aimed at promoting full and meaningful inclusion in society, as well as social and economic justice, for individuals on the autism spectrum. We highlight short- and long-term goals that provide the social work profession with a framework to engage in research, practice, education, and advocacy aimed at supporting individuals on the autism spectrum and their families.(Abstract from authors)

Reference:

Bishop-Fitzpatrick, L., Dababnah, S., Baker-Ericzén, M. J., Smith, M. J., & Magaña, S. M. (2019). Autism spectrum disorder and the science of social work: A grand challenge for social work research. *Social Work in Mental Health*, *17*(1), 73–92. https://doi.org/10.1080/15332985.2018.1509411

Title: Innovative models and best practices in case management and support coordination

• <u>https://ici.umn.edu/products/prb/191/</u>

Summary: In this time of decreasing human services resources, expanding demand for these resources, and the increasing expectations of self-determination on the part of individuals with disabilities and their families, many states are examining their case management and/or support coordination structures. There are strong federal pressures to limit or decrease case management expenditures while improving quality and expanding consumer choice. Professionals as well as persons receiving services are asking questions such as: Is case management necessary? How should it be organized? What roles should it have in the overall support system? What are the most effective models of, and best practices in, case management or support coordination?(Abstract from authors)

Reference:

University Center for Excellence in Developmental Disabilities (UCEDD). (2008). Innovative models and best practices in case management and support coordination. *Policy Research Brief*, *19*(1). University of Minnesota. <u>https://ici.umn.edu/products/prb/191/</u>

Title: On the effectiveness of case management for people with disabilities

• https://labourmarketresearch.springeropen.com/articles/10.1186/s12651-021-00299-9

Summary: Case managers provide individual and comprehensive support to employees who have become incapable of working. Using data from a large insurance company we find that overall, 43.9% of the people in our sample could be reintegrated. Controlling for personal characteristics, we analyze the effectiveness of case management by modelling the probability of reintegrating people being incapable of working into the labor market. Using parametric and semiparametric decomposition methods, we control for observational differences. We analyze how much of the difference in the reintegration rate between people who participate in case management and those who do not, is due to differences in characteristics and how much is due to case management itself. We find that the estimated probability of reintegration is 18.9% higher if people participate in case management. Moreover, our results show that no more than 15% are due to differences in characteristics and at least 85% can be attributed to case management itself.(Abstract from authors)

Reference:

Draheim, M., Schanbacher, P., & Seiberlich, R. (2021). On the effectiveness of case management for people with disabilities. *Journal for Labour Market Research*, *55*(15). <u>https://doi.org/10.1186/s12651-021-00299-9</u>

Title: Autism spectrum disorder and the science of social work: A grand challenge for social work research

 https://www.tandfonline.com/doi/abs/10.1080/15332985.2018.1509411?journalCode=ws mh20

Summary: The social work profession has not yet taken a leadership role in addressing the myriad of challenges that individuals on the autism spectrum encounter across the lifespan. In this essay, we argue that social workers are well equipped to engage in research and practice aimed at promoting full and meaningful inclusion in society, as well as social and economic justice, for individuals on the autism spectrum. We highlight short- and long-term goals that provide the social work profession with a framework to engage in research, practice, education, and advocacy aimed at supporting individuals on the autism spectrum and their families.(

Reference:

Bishop-Fitzpatrick, L., Dababnah, S., Baker-Ericzén, M. J., Smith, M. J., & Magaña, S. M. (2018). Autism spectrum disorder and the science of social work: A grand challenge for social work research. *Social Work in Mental Health*, *17*(1), 73–92. <u>https://doi.org/10.1080/15332985.2018.1509411</u>

Title: ADHD and social work with children and adolescents

• <u>https://www.tandfonline.com/doi/full/10.1080/13691457.2019.1592122</u>

Summary: The social work profession can make important contributions to understanding a phenomenon (ADHD) that is common among children and adolescent clients, that is often

comorbid with other conditions such as conduct disorder and that is linked to social adversity. We argue that research on ADHD in the child welfare systems should be a top priority in social work, and outline some important questions that need to be addressed by both researchers and social workers. Future research and considerations should be focused on the prevalence of children who have been diagnosed with ADHD within child protection services. Emphasis should be placed on longitudinal studies which track temporal trends in ADHD within child protection services, as well as the different ways that ADHD is approached and handled in different care settings (child welfare agencies, residential units, etc.). The authors also encourage further research to be done on the management of medical treatment within residential settings, etc., and explore the role that social workers play in initiating ADHD diagnoses and medication. Finally, future questions should focus on the ways in which a diagnosis of ADHD in parents and/ or children can be used to coerce those within the child protection system.

Reference:

Karlsson, P., & Lundström, T. (2019). ADHD and social work with children and adolescents. *European Journal of Social Work*, 24(1), 151-161. https://doi.org/10.1080/13691457.2019.1592122

- **Title:** Working with children with autism and their families: Pediatric hospital social worker perceptions of family needs and the role of social work
 - https://www.tandfonline.com/doi/full/10.1080/00981389.2018.1461730

Summary: Social workers who work in healthcare settings can play a key role in enhancing family-centered care through crisis intervention, counseling, collaboration, advocacy, and resource gathering for patients and their families. Professionals who work with children with autism and their families report that a lack of education and training can create obstacles to effective and successful service delivery. Several participants observed that the complexity of a child's autism presentation had impacted the family's healthcare experience. Several social workers were concerned that families of children with autism may move more slowly through the inpatient system and could become a time drain on hospitals that are unprepared to manage the complexities that these children and families may pose. Several participants felt that a better understanding of autism by staff would help to reduce this stigma. Social workers reported that it is essential to understand the toll that caring for a child with ASD takes on their caregivers. Challenges of pediatric hospital social work with children with ASD included limited knowledge of relevant community resources and lack of clarity regarding the social work role related to autism. Benefits included the promotion of family-centered care and family expertise, the promotion of resilience in families, facilitating communication, advocacy for hospital accommodations, service navigation, and consultation with experts. Consideration of sensory adaptations in healthcare environments may reduce barriers to seeking and accessing care. Social workers may be able to play a role in advocating for environmental assessments and adaptations such as low-sensory rooms or desensitization procedures or clinics. Social workers may benefit from exploring opportunities for knowledge dissemination, advocacy, and policy

recommendations that may reduce the challenges presented and reinforced in healthcare systems.

Reference:

Morris, R., Muscat, B, & Greenblatt, A. (2018). Working with children with autism and their families: Pediatric hospital social worker perceptions of family needs and the role of social work. Social Work in Health Care, 57 (7), 483-501. https://doi.org/10.1080/00981389.2018.1461730

Title: Dyslexia in The Context of Social Work: Screening and Early Intervention

• https://journals.sagepub.com/doi/full/10.1177/10443894211042323

Summary: Dyslexia is the most common learning disability and is associated with poor vocational, economic, and health outcomes. Dyslexia is disproportionately untreated and undiagnosed in children who are black, indigenous, and people of color who live in poverty. Early identification and interventions can effectively mitigate poor outcomes for children at risk for dyslexia. Screenings and interventions largely occur in schools; however, social workers have responsibilities to address dyslexia. They can do this through several avenues, including advocacy, identification, referrals, and education. Social workers have an ethical duty to promote equity and improve the quality of life across the life course for those with dyslexia. This article defines dyslexia, early screening, and interventions; dyslexia as a social justice problem, and social workers' role in addressing dyslexia.

Reference:

Schelbe, L., Pryce, J., Petscher, Y., Fien, H., Stanley, C., Gearin, B., & Gaab, N. (2022). Dyslexia in the context of social work: Screening and early intervention. *Families in Society*, *103*(3), 269–280. <u>https://doi.org/10.1177/10443894211042323</u>

Neurodiversity in Education

Title: *The Inclusion of Students with Dyslexia in Higher Education: A Systematic Review Using Narrative Synthesis*

https://onlinelibrary.wiley.com/doi/10.1002/dys.1484

Summary: This article reports on a study focusing on the inclusion of students with dyslexia in higher education (HE). A systematic review was carried out to retrieve, critically appraise and synthesize the available evidence on how the inclusion of students with dyslexia can be fostered in HE. The 15 studies included in the final synthesis employed descriptive designs and overwhelmingly used qualitative methods to explore dyslexic students' perceptions on the impact of teaching, support and accommodation in their own learning experience. A critical appraisal of these studies revealed a landscape of significant gaps in the available stock of evidence on the inclusion of students with dyslexia in HE. The synthesis of the available evidence is presented in a narrative of five cross-study thematic areas: student coping strategies, being identified as dyslexic, interaction with academic staff, accessibility and

accommodations, and using assistive technologies and information and communication technologies. Implications for practice and future research are discussed. ©2014 The Authors. *Dyslexia* published by John Wiley & Sons, Ltd.(Abstract from authors)

Reference:

Pino, M., & Mortari, L. (2014). The inclusion of students with dyslexia in higher education: a systematic review using narrative synthesis: The inclusion of students with dyslexia in HE. Dyslexia (Chichester, England), 20(4), 346–369. <u>https://doi.org/10.1002/dys.1484</u>

Title:*Leadership Roles for School Counselors in Identifying and Supporting Twice-Exceptional* (2*E*) *Students*

• https://journals.sagepub.com/doi/10.1177/2156759X20940636

Summary:School counselors have a variety of opportunities to serve as advocates and leaders for students identified as twice exceptional (2E). We explore these opportunities and discuss the academic and social/emotional challenges 2E students face and current operational definitions for this population. We also discuss strategies school counselors can use to help students increase their academic and social success. We introduce strengths-based educational approaches as a best practice for working with this unique population, including the use of support strategies, enrichment clusters, and extracurricular activities.(Abstract from authors)

Reference:

Renzulli, S. J., & Gelbar, N. (2020). Leadership roles for school counselors in identifying and supporting twice-exceptional (2E) students. *Professional School Counseling*, 23(1), 1–11. https://doi.org/10.1177/2156759x20940636

Title:Neurodiversity in higher education: a narrative synthesis

• <u>https://link.springer.com/article/10.1007/s10734-020-00513-6</u>

Summary:Neurodiversity is an umbrella term, including dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autistic spectrum and Tourette syndrome. The increasing number of students with learning difficulties associated with neurodiversity entering higher education (HE) poses a shared and growing challenge internationally for teachers and institutional leaders. This narrative synthesis draws together a corpus of international literature on how neurodiverse students experience higher education and the ways in which higher education institutions respond to the cluster of neurodiverse conditions. A systematic review was carried out to search, retrieve, appraise and synthesize the available evidence to provide an original contribution to the literature and significant insights of worth to higher education internationally. An inclusive approach to data extraction was used to ensure that all the relevant studies were included. All stages of the review process, including the initial search, screening, sample selection and analysis, are described. Three main themes and 11 subthemes were identified. Although the majority of publications focus on either dyslexia, autistic spectrum disorder, or ADHD, some common themes are evident in student experience across learning difficulties associated with neurodiversity. Although support services and technologies are

available to meet students' specific needs, there is an apparent dislocation between the two. Fear of stigmatization and labelling worsens the divide between what is needed and what is available to ensure neurodiverse students' success in higher education, where good intentions are evidently not enough.(Abstract from authors)

Reference:

Clouder, L., Karakus, M., Cinotti, A., Ferreyra, M. V., Fierros, G. A., & Rojo, P. (2020). Neurodiversity in higher education: A narrative synthesis. *Higher Education*, *80*(4), 757–778. <u>https://doi.org/10.1007/s10734-020-00513-6</u>

Title: Background and enrollment characteristics of students with autism in higher education

<u>https://www.sciencedirect.com/science/article/pii/S1750946719301126?via%3Dihub</u>

Summary: Background: The number of students with Autism Spectrum Disorder (ASD) entering Universities is growing. Recent studies show an increased understanding of students with ASD in higher education. Yet, current research generally relies on small samples, lacks information about student characteristics prior to enrollment, and does not compare students with ASD to other students. Method: Background and enrollment characteristics of students with ASD (n = 97) were compared to students with other disabilities (OD; n = 2252) and students with no recorded disabilities (ND; n = 24,794) based on administrative data of first-year bachelor enrollments (n = 27,143). Results: From 2010 to 2016 the proportion of students with ASD significantly increased from 0.20% to 0.45%. The characteristics of ASD students at enrollment were similar to other students, but it took ASD students more time to reach higher education compared to ND students, and they were at heightened risk of comorbidity compared to OD students. No difficulties were found with participation in preparatory activities, and goal setting. Conclusions: These quantitative insights are a valuable addition to the more qualitative evidence so far. For parents of children with ASD and individuals with ASD, these findings could help to adjust lower expectations. As this kind of administrative data is available to most institutions in higher education in day-to-day information systems, this study is promising for institutions to gain better insights in the enrollment of their students with ASD, and improve transition support. (Abstract from authors)

Reference:

Bakker, T., Krabbendam, L., Bhulai, S., & Begeer, S. (2019). Background and enrollment characteristics of students with autism in higher education. *Research in Autism Spectrum Disorders*, 67(101424). https://doi.org/10.1016/j.rasd.2019.101424

Title: Health needs and College readiness in autistic students: The freshman survey results.

Summary: With an increase in the diagnosis of autism spectrum disorder in the United States, many of whom have higher intellectual ability, there is a predicted increase in the number of college-bound students. Affected young adults face a "Services Cliff" as they transition into adulthood. Our study examined a nationally represented sample of freshman students and

found that academic achievements in autistic students are comparable to their peers when they first enter college. The students however have more mental health and physical health problems compared to their non-autistic peers. Poor health maybe a major contributing factor to the lower graduation rates among autistic students. College-bound autistic students may continue to require services through college for them to be successful and graduate. (Abstract from author)

Reference:

Fernandes, P., Haley, M., Eagan, K., Shattuck, P. T., & Kuo, A. A. (2021). Health needs and College readiness in autistic students: The freshman survey results. *Journal of Autism* and Developmental Disorders, 51(10), 3506–3513. https://doi.org/10.1007/s10803-020-04814-8

Title: Stories of resilience: Learning from adult students' experiences of studying with dyslexia in tertiary education

Summary: Stories from adult students with dyslexia are not widely heard in Aotearoa/New Zealand. While working alongside students with dyslexia we have gained access to some powerful stories of struggle and triumph. Our own practices, as a learning development lecturer and a literacy advisor, have been challenged by what we heard and this has prompted us to investigate dyslexia and the discourses that are associated with it in more depth. In order to learn more we interviewed four students about their study journeys , and asked them to identify what lecturers did or could do to make learning easier. Using a narrative analysis approach we identified five clear themes: resilience (these students were studying successfully); the positive impact of identification ; the importance of self-awareness; implementation of compensatory strategies; and, the positive consequences of being open about dyslexia in terms of receiving institutional assista, ce and accessing support in the learning environment, for example, assistive technologies. Recommendations are also made about what lecturers can do to make learning easier for students with dyslexia.(Abstract from authors)

Reference:

Wilson, M., & Savery, N. (2013). Stories of resilience: Learning from adult students' experiences of studying with dyslexia in tertiary education. *Journal of Adult Learning Actearoa New Zealand, 40*(1), 110-123. <u>https://www.researchbank.ac.nz/handle/10652/2595</u>

Title: Evaluating the effects of a self-advocacy training program for undergraduates with disabilities.

Summary: The purpose of this study is to explore the efficacy of a training program with a group of college students who have physical, sensory, and/or learning disabilities regarding their acquisition of knowledge and skills related to their rights to reasonable accommodations under several disability-related federal laws (e.g., Section 504, Americans with Disabilities Act [ADA]). This investigation seeks to address the following research question: Do participants in a knowledge- and skill-based training program successfully acquire knowledge and behaviors associated with understanding their disability-related rights and how to request disability-related

accommodations? The study showed significant results concerning student acquisition of knowledge (***p < .001) and accommodation skills (***p < .001). Future applications for this research are discussed.(Abstract from authors)

Reference:

White, G. W., Summers, J. A., Zhang, E., & Renault, V. (2014). Evaluating the effects of a self-advocacy training program for undergraduates with disabilities. *The Journal of Postsecondary Education and Disability*, 27(3), 229-244. <u>https://files.eric.ed.gov/fulltext/EJ1048818.pdf</u>

Title: "For a long time our voices have been hushed": Using student perspectives to develop supports for neurodiverse college students.

Summary: Although the challenges that autistic students face adapting to college are often pronounced, they are similar to the challenges that students with other disabilities face (e.g., difficulties with social interaction, self-advocacy, and executive functioning). However, extant evaluations of services for autistic college students are very limited despite an emerging literature examining supports for college students with a range of other disabilities. Given that many autistic students do not self-identify as autistic in college, and consequently might avoid autism-specific services, autistic students might benefit from services that are designed to support a broad range of neurodiverse students, or services that are structured according to the principles of Universal Design. In order to develop such services, we assessed the self-reported needs of autistic college students and their peers with other disabilities. Guided by needs assessments and feedback from students, we developed and evaluated two semesters of mentor-led group programming for autistic college students and students with other disabilities. The first semester of the program focused on social skills; after receiving feedback from participants, the curriculum for the second semester focused on self-advocacy. Participation in social-skills groups was associated with decreased anxiety and autism symptoms. Participation in self-advocacy groups was associated with increased perceived social support from friends, academic self-efficacy, and more accurate definitions of self-advocacy. This research suggests that supports for neurodiverse college students should be developed with their input and should include opportunities to engage with diverse peers. (Abstract from authors)

Reference:

Gillespie-Lynch, K., Bublitz, D., Donachie, A., Wong, V., Brooks, P. J., & D'Onofrio, J. (2017).
 "For a long time our voices have been hushed": Using student perspectives to develop supports for neurodiverse college students. *Frontiers in Psychology, 8*, 544.
 <u>https://doi.org/10.3389/fpsyg.2017.00544</u>

Title: Universal design for learning as a theory of inclusive practice for use by educational psychologists

Summary: Educational psychologists seek to keep abreast of significant theoretical and practical developments within the field of inclusive education. This paper outlines and discusses Universal Design for Learning as a theory of inclusion, highly applicable for use by educational psychologists. The Universal Design for Learning (UDL) framework is introduced by exploring the contextual history of its development and explaining the three pillars of the framework; the 'affective networks', the 'recognition networks', and the 'strategic networks'. Application of the UDL framework is demonstrated with classroom-based examples, drawing on existing research. A critical stance is taken towards understanding the current drawbacks of UDL, and direct links to educational psychology practice are made and critically reviewed considering these.(Abstract from authors)

Reference:

Sewell, A., Kennett, A, & Pugh, V. (2022). Universal design for learning as a theory of inclusive practice for use by educational psychologists. *Educational Psychology in Practice, 38*(4), 364-378. doi: 10.1080/02667363.2022.2111677

Title: Universal design for learning in postsecondary education: reflections on principles and their application

Summary: Authored by the teaching staff of T-560: Meeting the Challenge of Individual Differences at the Harvard Graduate School of Education, this article reflects on potential applications of universal design for learning (UDL) in university courses, illustrating major points with examples from T-560. The article explains the roots of UDL in cognitive neuroscience, and the three principles of UDL: multiple means of representing information, multiple means of expressing knowledge, and multiple means of engagement in learning. The authors also examine the ways UDL has influenced their course goals and objectives, media and materials, teaching methods, and assessment techniques, including discussion groups, lectures, textbooks, and the course website. The authors emphasize the ongoing developmental nature of the course and UDL principles as tools or guidelines for postsecondary faculty, rather than a set of definitive rules. UDL is proposed as a way to address diversity and disabilities as constructs of individuals and their environment in higher education classrooms. (Contains 2 endnotes and 3 figures.)(Abstract from authors)

Reference:

Rose, D. H., Harbour, W. S., Johnston, C. S., Daley, S. G., & Abarbanell, L. (2006). Universal design for learning in postsecondary education: reflections on principles and their application. *Journal of Postsecondary Education and Disability*, *19*(2), 135-151. <u>https://eric.ed.gov/?id=EJ844630</u>

Title: Universal design for learning: Supporting college inclusion for students with intellectual disabilities

Summary: As college becomes an increasingly important prerequisite for employment, it is important that all students have access to postsecondary education (PSE). The passage of the

Higher Education Opportunity Act has provided students with intellectual disability (ID) a pathway to college, though some barriers in this transition still exist. This article is meant to highlight strategies instructors at the postsecondary level can utilize to support the transition and inclusion of students with ID in college-level courses. The role PSE programs play establishing what college readiness for individuals with ID is also discussed. A specific focus will be paid to how the universal design for learning (UDL) framework can be applied to instructional materials to support the inclusion of students with ID in college, and how these strategies can be modeled for secondary educators to support the transition planning process for students with ID.(Abstract from authors)

Reference:

Love, M. L., Baker, J. N., & Devine, S. (2019). Universal design for learning: Supporting college inclusion for students with intellectual disabilities. *Career Development and Transition for Exceptional Individuals, 42*(2), 122–127. <u>https://doi.org/10.1177/2165143417722518</u>

Title: Measuring the effectiveness of universal design for learning intervention in postsecondary education

Summary: To date, a mere handful of studies have been conducted to determine the effectiveness of providing training to university instructors on the principles of Universal Design for Learning (UDL) and the impact this training has on student outcomes, especially for students with disabilities. While these studies offer some useful data, their results may be considered inconclusive because they did not use control groups and therefore had no comparative data regarding outcomes in courses where UDL was not implemented. This paper, which builds on a study published by these authors in a previous issue of JPED (Schelly, Davies, & Spooner, 2011), responds to the gap in the literature by measuring the effectiveness of instructor training regarding the principles of UDL and techniques for its implementation. It does so by comparing student perceptions of instructor teaching methods, as measured by a UDL questionnaire, completed before and after the instructors received UDL training and by comparing those results to a control group of students taking the same course in a different section where instructors did not receive UDL training.(Abstract from authors)

Reference:

Davies, P. L., Schelly, C. L., & Spooner, C. L. (2013). Measuring the effectiveness of universal design for learning intervention in postsecondary education. *Journal of Postsecondary Education and Disability*, 26(3), 195-220. <u>https://eric.ed.gov/?id=EJ1026883</u>

Title: The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)

https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf

Summary: This document uses information about these former secondary school students to describe the experiences of young adults with disabilities in the postsecondary education, employment, independence, and social domains in their first 8 years out of high school.

Reference:

Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X., Cameto, R., Contreras, E., Ferguson, K., Greene, S., & Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSER 2011-3005). Menlo Park, CA: SRI International. <u>https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf</u>

Title: Autism and accommodations in higher education: Insights from the autism community

• https://pubmed.ncbi.nlm.nih.gov/29243099/

Summary: This article builds on the growing body of research on higher education for autistic students by soliciting input from autistic adults on their higher education experiences and suggestions on making these experiences more 'autism-friendly'. Sixty-six individuals participated in a national exploratory survey and thirty-one participated in follow-up, online focus groups. The article reviews the accommodations individuals received and the accommodations they would have liked to receive. Concrete strategies are provided for institutes of higher education to address the social and sensory needs of autistic students, areas many participants reported being neglected in their academic experience, such as mentors and a neurodiverse space. These suggestions are intended to complement traditional academic accommodations to improve the outcomes of autistic students.(Abstract from authors)

Reference:

Sarrett, J. C. (2017). Autism and accommodations in higher education: Insights from the autism community. *Journal of Autism and Developmental Disorders*, *48*(3), 679–693. doi: 10.1007/s10803-017-3353-4

Title: Disclosure, accommodations and self-care at work among adolescents with disabilities

• https://www.tandfonline.com/doi/full/10.3109/09638288.2013.775356

Summary: Purpose: The purpose of this study is to explore whether adolescents with disabilities disclose their condition and what types of accommodations are requested at work. Method: In-depth, qualitative semi-structured interviews were conducted with 18 adolescents with a physical and/or mobility-related disability. We also reviewed their self- and staff assessments completed throughout an employment training program in which they took part. Results: The findings show that most youth were able to disclose their conditions and recognize some of their limitations in performing tasks at work. Youth requested physical accommodations, more time to complete tasks and cognitive accommodations. Youth also performed several self-care tasks to manage their disability at work including personal care, pain management and fatigue. Conclusions: Within the context of this employment training program, youth were able to disclose their condition to their employer, ask for accommodations and manage their disability in the workplace.(Abstract from authors)

Reference:

Lindsay, S., McDougall, C., & Sanford, R. (2013). Disclosure, accommodations and self-care at work among adolescents with disabilities. *Disability and Rehabilitation*, *35*(26), 2227–2236. <u>https://doi.org/10.3109/09638288.2013.775356</u>

Title: A systematic review of barriers and facilitators of disability disclosure and accommodations for youth in post-secondary education

 <u>https://www.tandfonline.com/doi/abs/10.1080/1034912X.2018.1430352?journalCode=cij</u> <u>d20</u>

Summary: This review critically appraised the literature on disability disclosure and accommodations for youth with disabilities in post-secondary education (PSE). Systematic searches of 8 databases identified 36 studies meeting our inclusion criteria. These studies were analysed with respect to the characteristics of the participants, methodology, results of the studies and quality of evidence. Five thousand, one hundred and seventy four participants (mean age 26.4) were represented across six countries. Barriers to disability disclosure and requests for accommodations in PSE included stigma, discrimination, lack of knowledge of supports and how to access them, type of course and instructor, coping styles, and nature of the disability. Facilitators included supports and resources, coping and self-advocacy skills, mentorship, and realising the benefits of disclosure. Factors affecting the process and timing of disability disclosure in PSE included the type of disability, and mode of disclosure. There was a lack of consensus on the timing of disclosure.(Abstract from authors)

Reference:

Lindsay, S., Cagliostro, E., & Carafa, G. (2018). A systematic review of barriers and facilitators of disability disclosure and accommodations for youth in post-secondary education. *International Journal of Disability, Development and Education, 65*(5), 526-556. doi: 10.1080/1034912X.2018.1430352

Title: Students' perceptions of testing accommodations: what we know, what we need to know, and why it matters

• <u>https://www.tandfonline.com/doi/abs/10.1080/15377903.2013.751477</u>

Summary: Students with disabilities are often given tests under accommodated conditions to reduce the effect of their disability on their scores. Students' perceptions of their own accommodations are important for several reasons and have been the topic of a number of research studies. Some studies have tested students under multiple conditions and asked for their reactions; other studies have given general attitude surveys about accommodations. Research has shown that accommodations generally reduce anxiety and discomfort during testing, but students' opinions about the practice of providing accommodations are often conflicted and depend on the particular accommodation under discussion. This review describes the current research on students' perceptions of accommodations, derives implications for practicing school psychologists, and offers further questions to guide future research. (Abstract from authors)

Reference:

Lovett, B. J., & Leja, A. M. (2013). Students' perceptions of testing accommodations: what we know, what we need to know, and why it matters. *Journal of Applied School Psychology*, *29*(1), 72-89. doi: 10.1080/15377903.2013.751477

Title: The Development of Individualized Education Programs: Where Have We Been and Where Should We Go Now?

• https://doi.org/10.1177/2158244014530411

Abstract: There are more than 6.6 million students with disabilities in U.S. public schools who receive special education services, which means that there are 6.6 million Individualized Education Programs (IEPs) that have been developed and are being implemented at any given time. Each IEP represents real cost in educational opportunity, relationship building between families and schools, time, and resource allocation. Given this information, it is important to examine what we have learned from research on the development of IEPs, and to begin charting a new direction for research and practice related to IEP development. This literature review examines published, peer-reviewed research studies that have examined IEP development since the 1997 reauthorization of the Individuals With Disabilities Education Act (IDEA). The review concludes with a discussion of how findings from previous research on IEP development can inform future research agendas, educator practice, and federal and state policies.(Abstract from authors)

Reference:

Blackwell, W. H., & Rossetti, Z. S. (2014). The development of individualized education programs: Where have we been and where should we go now? *SAGE Open*, *4*(2). https://doi.org/10.1177/2158244014530411

Title: Individualized Education Programs (IEPs) in Special Education—From Intent to Acquiescence

• <u>https://doi.org/10.1177/001440299005700102</u>

Abstract: Evaluations of individualized education programs (IEPs) over the past decade have pointed to an inoperative IEP process and a questionable document. A three-phased review of data-based research and position papers from 1975 to 1989 reveals a history of IEP inadequacies and passive compliance. These findings are in contrast to the original intent and spirit of Public Law 94–142, the Education for All Handicapped Children Act (EAHCA). Implications for special education policy and practice have not been considered. Recommendations include a reexamination of the IEP in the context of the current special education reform debate. (Abtsract from author)

Reference:

Smith, S. W. (1990). Individualized Education Programs (IEPs) in special education—From intent to acquiescence. *Exceptional Children*, *57*(1), 6–14. https://doi.org/10.1177/001440299005700102

High vs. Low Functioning: Autism isn't Linear

Title: Does the heterogeneity of autism undermine the neurodiversity paradigm?

• <u>https://onlinelibrary.wiley.com/doi/10.1111/bioe.12780</u>

Summary: The neurodiversity paradigm is presented by its proponents as providing a philosophical foundation for the activism of the neurodiversity movement. Its central claims are that autism and other neurodivergent conditions are not disorders because they are not intrinsically harmful and that they are valuable, natural, and normal parts of human neurocognitive variation. This paper: (a) identifies the non-disorder claim as the most central of these, based on its prominence in the literature and connections with the practical policy claims that the paradigm is supposed to support; (b) describes the heterogeneity of autism at the behavioral and causal levels, and argues that at the behavioral level this encompasses ways of being autistic that are harmful in ways that cannot be not wholly attributed to discrimination or unjust social arrangements, challenging the claim that autism is not a disorder; (c) considers and rejects responses to this challenge based on separation of high and low-functioning autism, separation of autism from co-occurring conditions, and viewing autism as part of an individual's identity. Two of these responses fail for reasons that are themselves connected with the behavioural and/or causal heterogeneity of autism.(Abstract from authors)

Reference:

Hughes, J. A. (2020) Does the heterogeneity of autism undermine the neurodiversity paradigm? *Bioethics*, 35(1), 47-60. DOI: <u>https://doi.org/10.1111/bioe.12780</u>

Title: *Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges*

https://dsq-sds.org/article/view/1069/1234#top

Summary: This article examines challenges to the quality of life experienced by autistic adults. The author, who is an autistic researcher, first shares how a neurodiversity perspective offers an important alternative to the deficit model of autism. Whereas the deficit model portrays autistic people as ill, broken, and in need of fixing, the neurodiversity perspective portrays it as a form of human diversity with associated strengths and difficulties. The article's discussion then shifts to presenting Schalock's (2000) quality of life framework as a neurodiversity-compatible lens through which domains of quality of life can be viewed. The article analyzes in detail these core domains in relation to the lives of autistic adults. The author suggests that a collaborative approach between professionals/researchers and autistic adults is needed to develop meaningful solutions to these challenges, and he presents possibilities for collaboration.(Abstract from authors)

Reference:

Robertson, S. M. (2010) Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenged *Disability Studies Quarterly*, 30(1) DOI: <u>https://dsq-sds.org/article/view/1069/1234#top</u>

Real-Life Experiences

Title:Navigating neurodiversity in the workplace

Summary:As organizations continue to ramp their DEI programs, they must also recognize and account for differences in cognitive functioning.(Abstract from authors)

Reference:

Rolack, W. T., Sr, & Gonggrijp-Bello, M. (2021). Navigating neurodiversity in the workplace. *BenefitsPRO.* <u>https://www.proquest.com/trade-journals/navigating-neurodiversity-workplace/docview/2536056</u> <u>937/se-2</u>

Neurodiversity in the Workplace

Title:Does it matter what your reasons are when deciding to disclose (or not disclose) a disability at work? The association of workers' approach and avoidance goals with perceived positive and negative workplace outcomes

• https://link.springer.com/article/10.1007/s10926-020-09956-1

Summary: Deciding whether to disclose a disability to others at work is complex. Many chronic mental and physical health conditions are associated with episodic disability and include times of relative wellness punctuated by intermittent periods of activity limitations. This research draws on the disclosure processes model to examine approach and avoidance disclosure and non-disclosure goals and their association with perceived positive and negative workplace outcomes. Participants were 896 employed individuals (57.7% women) living with a chronic physical or mental health/cognitive condition. They were recruited from an existing national panel and completed an online, cross-sectional survey. Participants were asked about disclosure decisions, reasons for disclosure/non-disclosure, demographic, work context and perceived positive and negative disclosure decision outcomes (e.g., support, stress, lost opportunities). About half the sample (51.2%) had disclosed a disability to their supervisor. Decisions included both approach and avoidance goals. Approach goals (e.g., desire support, want to build trust, maintain the status guo at work) were significantly associated with perceived positive work outcomes regardless of whether a participant disclosed or did not disclose a disability at work, while avoidance goals (e.g., concerns about losing one's job, feeling forced to disclose because others notice a problem) were associated with perceived negative work outcomes. The findings highlight benefits and challenges that workers perceive arise when they choose to disclose or not disclose personal health information. By better understanding disclosure decisions, we can inform organizational health privacy and support gaps to help sustain the employment of people living with disabilities. (Abstract from author)

Reference:

Gignac, M. A., Jetha, A., Ginis, K. A., & Ibrahim, S. (2021). Does it matter what your reasons are when deciding to disclose (or not disclose) a disability at work? The Association of Workers' approach and avoidance goals with perceived positive and negative workplace outcomes. *Journal of Occupational Rehabilitation*, *31*, 638–651. <u>https://doi.org/10.1007/s10926-020-09956-1</u>

Title:Neurodiversity at work: a biopsychosocial model and the impact on working adults

• <u>https://academic.oup.com/bmb/article/135/1/108/5913187</u>

Summary: Neurodiversity Introduction: The term neurodiversity is defined and discussed from the perspectives of neuroscience, psychology and campaigners with lived experience, illustrating the development of aetiological theories for included neurodevelopmental disorders. The emerging discourse is discussed with relevance to adults, social inclusion, occupational performance and the legislative obligations of organizations. Sources of date: Literature is reviewed from medicine, psychiatry, psychology, sociology and popular press. No new data are presented in this article. Areas of agreement: There is consensus regarding some neurodevelopmental conditions being classed as neurominorities, with a 'spiky profile' of executive functions difficulties juxtaposed against neurocognitive strengths as a defining characteristic. Areas of controversy: The developing nomenclature is debated and the application of disability status versus naturally occurring difference. Diagnosis and legal protections vary geographically, resulting in heretofore unclear guidance for practitioners and employers.Growing points:The evolutionary critique of the medical model, recognizing and updating clinical approaches considering the emerging consensus and paradigmatic shift. Areas timely for developing research: It is recommended that research addresses more functional, occupational concerns and includes the experiences of stakeholders in research development, moving away from diagnosis and deficit towards multi-disciplinary collaboration within a biopsychosocial model.at work: a biopsychosocial model and the impact on working adults.(Abstract from authors)

Reference:

Doyle, N. (2020). Neurodiversity at work: A biopsychosocial model and the impact on working adults. *British Medical Bulletin*, *135*(1), 108–125. <u>https://doi.org/10.1093/bmb/ldaa021</u>

Title: Getting Hired:Successfully Employed People with Disabilities Offer Advice on Disclosure, Interviewing, and Job Search

https://link.springer.com/article/10.1007/s10926-011-9336-y

Summary:*Introduction* Many people with disabilities want to work, but face employment barriers that have resulted in dismal employment rates. Successfully employed people with disabilities have valuable experience that can help others seeking employment, yet research literature provides little information about their strategies for discussing disabilities with employers and negotiating the hiring process. *Method* In five focus groups, 41 people competitively employed for at least 5 years discussed employment experiences related to their varied disabilities. The sample excluded people in disability-related jobs or self-employed. Data were coded and

analyzed using a grounded theory method. *Results* Disclosure and discussion decisions were influenced by the nature of disability (visible, hidden, stigmatized, multiple), whether and when people needed accommodations, and the perceived "disability-friendliness" of organizations. Qualitative data analysis suggested guidelines for whether, when, and how to discuss disability, while acknowledging the complexity of decision-making depending on workplace culture and personal choices. Interview strategies included ways to emphasize strengths, gather information about duties and work environment, handle inappropriate questions, and address unspoken employer concerns. Participants gave disability-specific advice to help job-seekers balance their abilities and interests, and use networking and other approaches to find favorable opportunities. Concluding that people with disabilities must work harder than others to get a job, they described approaches and tools to help others achieve success. *Conclusions* Findings suggest approaches to assist job-seekers to make decisions about disclosing or discussing their disability, present themselves in a straight-forward, disability-positive manner, and find satisfying work based on their skills and interests. (Abstract from author)

Reference:

Jans, L. H., Kaye, H. S., & Jones, E. C. (2012). Getting hired: Successfully employed people with disabilities offer advice on disclosure, interviewing, and job search. *Journal of Occupational Rehabilitation*, 22(2), 155–165. https://doi.org/10.1007/s10926-011-9336-y

Title: Getting hired: Successfully employed people with disabilities offer advice on disclosure, interviewing, and job search

https://link.springer.com/article/10.1007/s10926-011-9336-y

Summary: Many people with disabilities want to work, but face employment barriers that have resulted in dismal employment rates. Successfully employed people with disabilities have valuable experience that can help others seeking employment, yet research literature provides little information about their strategies for discussing disabilities with employers and negotiating the hiring process. Method In five focus groups, 41 people competitively employed for at least 5 years discussed employment experiences related to their varied disabilities. The sample excluded people in disability-related jobs or self-employed. Data were coded and analyzed using a grounded theory method. Results Disclosure and discussion decisions were influenced by the nature of disability (visible, hidden, stigmatized, multiple), whether and when people needed accommodations, and the perceived "disability-friendliness" of organizations. Qualitative data analysis suggested guidelines for whether, when, and how to discuss disability, while acknowledging the complexity of decision-making depending on workplace culture and personal choices. Interview strategies included ways to emphasize strengths, gather information about duties and work environment, handle inappropriate guestions, and address unspoken employer concerns. Participants gave disability-specific advice to help job-seekers balance their abilities and interests, and use networking and other approaches to find favorable opportunities. Concluding that people with disabilities must work harder than others to get a job, they described approaches and tools to help others achieve success. Conclusions Findings suggest approaches to assist job-seekers to make decisions about disclosing or discussing their

disability, present themselves in a straight-forward, disability-positive manner, and find satisfying work based on their skills and interests.(Abstract from authors)

Reference:

Jans, L. H., Kaye, H. S., & Jones, E. C. (2012). Getting hired: Successfully employed people with disabilities offer advice on disclosure, interviewing, and job search. *Journal of Occupational Rehabilitation*, 22(2), 155–165. <u>https://doi.org/10.1007/s10926-011-9336-y</u>

Title: Does it matter what your reasons are when deciding to disclose (or not disclose) a disability at work? The Association of Workers' approach and avoidance goals with perceived positive and negative workplace outcomes

• https://link.springer.com/article/10.1007/s10926-020-09956-1

Summary: Deciding whether to disclose a disability to others at work is complex. Many chronic mental and physical health conditions are associated with episodic disability and include times of relative wellness punctuated by intermittent periods of activity limitations. This research draws on the disclosure processes model to examine approach and avoidance disclosure and non-disclosure goals and their association with perceived positive and negative workplace outcomes. Participants were 896 employed individuals (57.7% women) living with a chronic physical or mental health/cognitive condition. They were recruited from an existing national panel and completed an online, cross-sectional survey. Participants were asked about disclosure decisions, reasons for disclosure/non-disclosure, demographic, work context and perceived positive and negative disclosure decision outcomes (e.g., support, stress, lost opportunities). About half the sample (51.2%) had disclosed a disability to their supervisor. Decisions included both approach and avoidance goals. Approach goals (e.g., desire support, want to build trust, maintain the status guo at work) were significantly associated with perceived positive work outcomes regardless of whether a participant disclosed or did not disclose a disability at work, while avoidance goals (e.g., concerns about losing one's job, feeling forced to disclose because others notice a problem) were associated with perceived negative work outcomes. The findings highlight benefits and challenges that workers perceive arise when they choose to disclose or not disclose personal health information. By better understanding disclosure decisions, we can inform organizational health privacy and support gaps to help sustain the employment of people living with disabilities. (Abstract from authors)

Reference:

Gignac, M. A., Jetha, A., Ginis, K. A., & Ibrahim, S. (2021). Does it matter what your reasons are when deciding to disclose (or not disclose) a disability at work? The Association of Workers' approach and avoidance goals with perceived positive and negative workplace outcomes. *Journal of Occupational Rehabilitation*, *31*, 638–651. <u>https://doi.org/10.1007/s10926-020-09956-1</u>

Title: Neurodiversity at work: A biopsychosocial model and the impact on working adults.

• <u>https://doi.org/10.1093/bmb/ldaa021</u>

Summary: Introduction: The term neurodiversity is defined and discussed from the perspectives of neuroscience, psychology and campaigners with lived experience, illustrating the development of aetiological theories for included neurodevelopmental disorders. The emerging discourse is discussed with relevance to adults, social inclusion, occupational performance and the legislative obligations of organizations. Sources of data: Literature is reviewed from medicine, psychiatry, psychology, sociology and popular press. No new data are presented in this article. Areas of agreement: There is consensus regarding some neurodevelopmental conditions being classed as neurominorities, with a 'spiky profile' of executive functions difficulties juxtaposed against neurocognitive strengths as a defining characteristic. Areas of controversy: The developing nomenclature is debated and the application of disability status versus naturally occurring difference. Diagnosis and legal protections vary geographically, resulting in heretofore unclear guidance for practitioners and employers. Growing points: The evolutionary critique of the medical model, recognizing and updating clinical approaches considering the emerging consensus and paradigmatic shift. Areas timely for developing research: It is recommended that research addresses more functional, occupational concerns and includes the experiences of stakeholders in research development, moving away from diagnosis and deficit towards multi-disciplinary collaboration within a biopsychosocial model.(Abstract from authors)

References:

Doyle, N. (2020). Neurodiversity at work: A biopsychosocial model and the impact on working adults. *British Medical Bulletin*, *135*(1), 108–125. <u>https://doi.org/10.1093/bmb/ldaa021</u>

Title: Navigating neurodiversity in the workplace

 <u>https://www.proquest.com/docview/2536056937?parentSessionId=%2F%2FmCTqQ3Uc</u> <u>9P%2Fbn8f7huIz3hTQwBbtS5u%2FpOtNIZ6UY%3D</u>

Summary: Diversity and inclusion breed innovation – whether in the context of gender, race, sexual orientation, or cognitive functioning. The melding of a variety of backgrounds fuels unique perspectives and ideas to manifest, coming together to pave new paths and increase efficiency. The very definition of ND – diversity of thinking styles and abilities – is especially important for innovative decision-making. Hiring more neurodivergent individuals is one competitive advantage many companies have been missing. People on the spectrum often have a propensity to think outside the box and can be extremely creative. Their tendency to operate in a black and white manner lends itself to detail-oriented roles. For example, many ND individuals excel at jobs that require traits and skills that correlate with pattern recognition, strong attention to detail, and a direct and succinct communication style - such as computer programming and quality assurance. But it is also important to remember it is not one size fits all. There are many autistic and neuro-diverse workers who excel outside of these "typical" career paths in fields such as marketing, human resources, customer service, and sales. Actions speak louder than words Numerous organizations are unaware of how many neuro-diverse employees they have. Yet many ND individuals are afraid to disclose their status with the fear that others will think less of them, or opportunities for advancement will decrease. From fostering inclusion for those already within an organization, to recruiting and expanding

into new talent pools, here are three steps organizations can take now to embrace neurodiversity.(Abstract from authors)

Reference:

Rolack, W. T., Sr, & Gonggrijp-Bello, M. (2021). Navigating neurodiversity in the workplace. *BenefitsPRO.* <u>https://www.proquest.com/trade-journals/navigating-neurodiversity-workplace/docview/2</u> 536056937/se-2

Title: *Listening to neurodiverse voices in the workplace.*

• https://scholarworks.gvsu.edu/ought/vol3/iss2/11/

Abstract: This study found that neurodivergent individuals are impacted by the inaccurate stereotypes and assumptions from others at work, leading to a wide spectrum of issues such as the fear of disclosure, lack of career progression and negative emotions which can contribute towards poor mental health. Both, neurodivergent individuals and their organizations, need education to facilitate conversations, workplace accommodations and improve employees' experiences at work. Additionally, there is a need for more flexibility in the workplace and less standardization in the work environment to facilitate productivity and satisfaction. These findings can be used to facilitate greater understanding of Neurodiversity at work and build on foundational literature regarding the best workplace practices to empower neurodiverse talent. This research may be used as a starting point for the development of evidence-based organizational wide interventions which can seek to mitigate some of these perceived barriers and make the workplace more accessible to neurodivergent individuals. We sing with neurodiverse talent: let us teach employers to sing with us.

Reference:

Burton, L., Carss, V., & Twumasi, R. (2022). Listening to neurodiverse voices in the workplace. *Ought: The Journal of Autistic Culture*, *3*(2), 11. <u>https://scholarworks.gvsu.edu/ought/vol3/iss2/11</u>

- **Title**: *Autism, attributions and accommodations:* Overcoming barriers and integrating a neurodiverse workforce.
 - https://www.emerald.com/insight/content/doi/10.1108/PR-04-2018-0116/full/html

Abstract: Purpose: Individuals with autism spectrum disorders (ASD) represent a growing segment of the population but face important obstacles in the workplace. Even for ASD individuals with the mildest form/highest-functioning type, unemployment is 80 percent, and many of those who work are underemployed. This in spite of the fact that these individuals are highly intelligent and capable of excellent work. The purpose of this paper is to present a model of the unique challenges that workers with ASD face in the modern workplace based on stigmas and discrimination surrounding mental health, attribution theory and the disconnect between behaviors common to neurodiverse individuals and some of the most researched theories in the field of organizational behavior. The goal of the paper is to encourage more empirical researched

focused specifically on ASD workers.Design/methodology/approach: A review of the literature on ASD in juxtaposed to evidence-based social psychology and management theories to demonstrate the difficulties faced by individuals with ASD. Findings: Recommendations for overcoming these barriers and using management theories to help integrate ASD workers are discussed. Originality/value: Workers with ASD are a growing population in the workforce, but have received scant research attention. This is the first paper to link several theories to ASD and the hope is that subsequent research will illuminate these relationships empirically.(Abstract from authors)

Reference:

Patton, E. (2019). *Autism, attributions and accommodations: Overcoming barriers and integrating a neurodiverse workforce*. Personnel Review. <u>https://www.emerald.com/insight/content/doi/10.1108/PR-04-2018-0116/full/html</u>

Living With Neurodiverse Conditions

Title: Shifting the Discourse on Disability: Moving to an Inclusive, Intersectional Focus

<u>https://psycnet.apa.org/fulltext/2023-11160-001.html</u>

Summary: Individuals with disabilities comprise one of the largest marginalized groups in the United States and experience systemic barriers in health care. In Westernized communities, disability has historically been conceptualized via the medical model, which considers disability an individual-level deficit in need of correction. Although other models of disability (e.g., social model) have been developed to address the medical model's ableist shortcomings, these fail to consistently acknowledge intersectionality. Specifically, these models fail to consider that (a) a disabled individual may hold other marginalized or oppressed identities and (b) these intersecting oppressions may exacerbate health inequities. Intersectionality, which originates from Black feminist literature, describes the ways that systems of power and oppression (e.g., racism, sexism) interact to form an individual's unique experience. To date, the intersection of disability and other marginalized identities has been neglected in psychology and related fields, leaving little guidance for how scholars, clinicians, and other stakeholders can address disability via an intersectional lens. The present article discusses how a *disability-affirmative*, intersectional approach can serve as a strategy for challenging and reforming oppressive systems across the field of psychology. We assert that, ultimately, this approach has the potential to optimize and expand access to equitable, inclusive mental health care, and we propose actionable steps psychologists can take in research, practice, training, and policy in pursuit of this aim.(Abstract from authors)

Reference:

Brinkman, A. H., Rea-Sandin, G., Lund, E. M., Fitzpatrick, O. M., Gusman, M. S., Boness, C. L., & Scholars for Elevating Equity and Diversity. (2022). Shifting the discourse on disability: Moving to an inclusive, intersectional focus. *American Journal* of Orthopsychiatry. <u>https://doi.org/10.1037/ort0000653</u> **Title**:Come as You Are: Examining Autistic Identity Development and the Neurodiversity Movement through an Intersectional Lens

 <u>https://karger.com/hde/article/66/2/93/828416/Come-as-You-Are-Examining-Autistic-Iden</u> <u>tity</u>

Summary: Singer intended for neurodiversity to be a new category of intersectionality. However, intersectionality has been neglected in autism research and practice. This paper aims to inform an intersectional approach to autism by exploring autistic identity development in relation to other marginalized identities. We reviewed literature about neurodiversity, intersectionality, discrimination, and the identity development of autistic people, racial/ethnic minorities, and gender and sexual minorities. We discuss minority stress and evidence that cultural traditions alleviate it. Autistic culture can reframe personal difficulties as a politicized struggle. While the stereotype of autism is one of withdrawal, the history of autistic people coming together for justice defies this notion. Intersectionality teaches us that we must understand differences *within* the autistic community if we wish to help all autistic people experience the dignity they deserve. Using an intersectional lens, we can become more flexible in our understanding of positive autistic identity development and strategies to promote it.(Abstract from authors)

Reference:

Botha, M., & Gillespie-Lynch, K. (2022). Come as you are: Examining autistic identity development and the neurodiversity movement through an intersectional lens. *Human Development*, 66(2), 93–112. <u>https://doi.org/10.1159/000524123</u>

Title: Reconceptualizing leadership from a neurodiverse perspective.

Summary: While scholarship has increased on the topic of neurodiversity in organizations, which refers to individuals with pervasive developmental disorders in the workforce, leadership theory and research has not yet integrated this perspective. Consistent with conventional conceptualizations of disability as an impairment, the few relevant leadership studies tend to approach these differences as special cases, rather than as a population to which theory may be generalized. As a result, management scholars have yet to develop theories and models that are inclusive of neurodiversity. Using the critical disability theory as a lens for reframing assumptions about leadership behavior as described in existing theory and research, we postulate that neurodiversity may serve as a cognitive strength from which leadership derives. We offer a conceptual model that articulates how cognitive characteristics associated with neurodiversity may lead to task-based leadership behavior, and we trace the influence of such behaviors on leader and follower outcomes. The model also includes enabling conditions that may positively influence the emergence and recognition of neurodiverse individuals as leaders. We conclude by proposing directions for future research to better integrate the neurodiversity and leadership literatures and reflecting on the associated practical implications. (Abstract from authors)

Reference:

Roberson, Q., Quigley, N. R., Vickers, K, & Bruck, I. (2021). Reconceptualizing leadership from a neurodiverse perspective. *Group & Organization Management, 46*(2), 399-423. https://doi.org/10.1177/1059601120987293

Title: Ataxia and me – living within a neurological hierarchy

• https://www.tandfonline.com/doi/pdf/10.1080/09687599.2022.2034110?needAccess=true

Summary: The author of this article discussed how neurodivergent conditions may exist on a hierarchy with autism being near the top since it's one of the most recognized neurodivergent conditions. The author mentioned how information being so readily available for more common neurodiverse conditions and not including information on less common neurodiverse conditions leads many neurodivergent individuals going unrecognized. Some neurodiverse individuals may have symptoms that are invisible to others and go undetected. The neurodiverse community seems to be limited to those with autism because of the lack of awareness of other conditions. People may belittle those with invisible conditions because of being unable to identify the difficulties they're having. The author also discussed their experience living with ataxia and stated "The anxiety I felt leading up to and after being diagnosed had to do with the thought that no one would understand my condition, no one could immediately tell why a healthy looking seventeen-year-old was walking so abnormally." Ataxia includes the loss of coordination from muscle weakness and may present symptoms like slurred speech, abnormal eye movements and poor proprioception. Ataxia has no cure yet. The author said her diagnosis has motivated her to study disability throughout college and she's developed an interest in labeling, stereotypes, and the effects they can have on those who aren't part of the conventional society. Some thoughts she feels about her condition included: "My concern is around whether these stereotypes and conventions also define me. Am I less valuable because I deviate from the orthodox aesthetically normal woman? I am a second-class citizen because I do not conform to the norm?" Since those with ataxia may struggle with speech, which society may misinterpret as them being drunk. This lack of awareness is harmful to individuals with ataxia who are stigmatized based on other's lack of awareness. The hierarchy of neurodiverse conditions from more known conditions being acknowledged and discussed leave those with uncommon disorders like ataxia feeling misunderstood and left out. Suggestions included more research of uncommon neurological conditions to assist with their understanding and early detection of conditions to lead to faster diagnosis and aid in implementation of treatments.(Abstract from authors)

Reference:

Clark, T. (2022). Ataxia and me – living within a neurological hierarchy. *Disability & Society*, 37(6), 1054-1059. DOI: 10.1080/09687599.2022.2034110

Title:Helping a Child with Autism Spectrum Disorder Cope with Divorce

• <u>https://journals.lww.com/jrnldbp/Fulltext/2018/05000/Helping_a_Child_with_Autism_Spec</u> <u>trum_Disorder_Cope.10.aspx</u> **Summary**:Aaron is an 11-year-old boy with autism spectrum disorder (ASD), with cognitive and language skills in the above-average range, whose parents have recently separated. Aaron's mother initiated the separation when she learned that Aaron's father had maintained a relationship with a woman with whom he has a 10-year-old daughter. When Aaron's mother discovered this relationship, she demanded that Aaron's father leave their home. Aaron's father has moved in with his long-term girlfriend and keeps in contact with Aaron by calling once a day. Neither Aaron's father nor mother has discussed the reason for their separation with Aaron. So far, they have explained their separation by telling Aaron that they are "taking a break." Aaron's mother has been deeply hurt by Aaron's father's infidelity and does not want to reconcile with his son. He would also like Aaron to get to know his half-sister. Aaron's mother seeks guidance regarding how to talk to Aaron about the separation and his father's second family. Given Aaron's diagnosis of ASD, she is particularly concerned about his ability to cope with this unexpected change in circumstances. What is your advice?(Abstract from authors) **Reference**:

Reilly, M., Fogler, J., Bridgemohan, C., Wiley, M., Weitzman, C. & Augustyn, M. (2018). Helping a child with autism spectrum disorder cope with divorce. *Journal of Developmental & Behavioral Pediatrics*, 39(4), 345-347. <u>Https://Doi.Org/10.1097/DBP.000000000000570</u>

Title: Disclosing a disability: Do strategy type and onset controllability make a difference?

https://psycnet.apa.org/record/2017-17078-001

Summary: In hiring contexts, individuals with concealable disabilities make decisions about how they should disclose their disability to overcome observers' biases. Previous research has investigated the effectiveness of binary disclosure decisions—that is, to disclose or conceal a disability—but we know little about how, why, or under what conditions different types of disclosure strategies impact observers' hiring intentions. In this article, we examine disability onset controllability (i.e., whether the applicant is seen as responsible for their disability onset) as a boundary condition for how disclosure strategy type influences the affective reactions (i.e., pity, admiration) that underlie observers' hiring intentions. Across 2 experiments, we found that when applicants are seen as responsible for their disability (rather than embrace it) lower observers' hiring intentions by elevating their pity reactions. Thus, the effectiveness of different types of disability disclosure strategies differs as a function of onset controllability. We discuss implications for theory and practice for individuals with disabilities and organizations. (Abstract from authors)

Reference:

Lyons, B. J., Volpone, S. D., Wessel, J. L., & Alonso, N. M. (2017). Disclosing a disability: Do strategy type and onset controllability make a difference? *Journal of Applied Psychology*, *102*(9), 1375–1383. <u>https://doi.org/10.1037/apl0000230</u>