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ORIGINAL PAPER

Mind the NIH-Funding Gap: Structural Discrimination in Physical Health–Related Research for Cognitively Able Autistic Adults

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Abstract
Autistic adults experience disparities in physical health and health care access. A major barrier to addressing these disparities is a lack of federal funding for research on this topic. In seeking funding from the National Institutes of Health (NIH), we discovered nodes that contribute to structural discrimination in physical health–related research for autistic adults. To examine this structural discrimination, we systematically searched funded research on all physical health–disparity conditions in autistic adults using NIH RePORTER. Among 61 unique studies, none focused on improving the relevant physical health condition through intervention, programs, or services for autistic adults. Thus, we need updated policies and procedures that support research on physical health disparities in populations with developmental or mental health conditions.

Keywords Autism · Discrimination · Physical health · Health care disparities · Neurodiversity

Introduction

Autistic adults face disparities in physical health and health care access. Compared to the general population, they have a higher risk of nearly every chronic physical health condition (Croen et al., 2015; Sala et al., 2020). By age 8 years, about 85% of autistic children have at least one co-occurring condition (Levy et al., 2010). Unfortunately, much research on co-occurring conditions in autism assumes autism is causative, or the primary disease that affects the development of co-occurring conditions. But these assumptions are likely incorrect (McDonald, 2021; Sala et al., 2020). Regardless of the primary cause, the co-occurring physical health conditions experienced disparately by cognitively able autistic adults (see Table 1 for important key terms) leads to unnecessary pain, decreased quality of life, and mortality in this population (Sala et al., 2020). Thus, we need research in cognitively able autistic adults that examines the causes of these co-occurring conditions, effective treatments to manage these conditions, and disparities in health care access (Cervantes et al., 2021; Mason et al., 2019; Nicolaidis et al., 2015; Raymaker et al., 2017).

In autism research, topics of physical health disparities can be conflated with eugenics-related research. But these two research objectives are distinct. In autism, eugenics-related research focuses on the cause, cure, prevention, and treatment of autism as a disease. Thus, some health conditions are conceptualized as "risk factors" for autism, such as genetic disorders, epilepsy, gut microbiome, and other prenatal, perinatal, and postnatal factors. Although eugenics-related research in autism is commonly funded (Cervantes et al., 2021; Hisle-Gorman et al., 2018; Wang et al., 2017), cognitively able autistic adults oppose this type of research (J. P. Baker & Lang, 2017). Instead, they want research on physical health disparities (Interagency Autism Coordinating Committee, 2020), which focuses on conditions that occur at a higher rate (health disparities) in people with autism versus the general population (Sala et al., 2020). Such physical health disparities in autism, like other marginalized groups, may derive from several factors, including social, environmental, lifestyle, biological, and other factors (National Academies of Sciences et al., 2017a; Sala et al., 2020). Thus, research on physical health disparities focuses on reducing the burden of co-occurring physical health conditions on quality of life, *not* on reducing autistic traits, the prevalence of autism, or other eugenics aims.

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Table 1 Key terms

Term	Definition
Cognitively able:	People who do not have an intellectual disability defined as two-standard deviations below average intelligence.
Disease:	The encyclopedia Britannica defines disease as "any harmful deviation from the normal structural or functional state of an organism, generally associated with certain signs and symptoms and differing in nature from physical injury. A diseased organism commonly exhibits signs or symptoms indicative of its abnormal state. Thus, the normal condition of an organism must be understood in order to recognize the hallmarks of disease" (W. Burrows & Scarpelli, n.d. 2021). However, human conditions that fit this definition constantly flux, as diversity is common in the human conditions, and "harm" is often a social value. For example, 'homosexuality' was historically considered a disturbance in the endocrine system, a neurological disorder, and other physical functioning disturbances. However, as social values relating to "harm" changed over time, medical and societal perceptions of "homosexuality" changed from disease to a protected class of citizens who face health disparities (Scully, 2004).
Eugenics:	The social movement and practice of creating a "better" race in which the conditions of what constitutes "better'" depends on the values of the society members and/or its leaders (J. P. Baker & Lang, 2017; Brown, 2019; Swenson, 2019). Historically, eugenics research sought to study "undesirable traits" in large human families to identify genetic causes and enable the removal of genes associated with the traits from the population (Norrgard, 2008). For example, NIH Project Number 4R01DA031833-05, Control of Synapse Formation and Maturation by Astrocytes includes the following passage in its Public Health Relevance Statement: "The proposed study aims to advance our understanding of astrocyte-neuron interactions that orchestrate central nervous system development and function. Understanding how synaptogenesis is regulated is crucial for understanding how our brains are sculpted during development, and how we learn and remember as adults. In addition, knowledge on how synaptogenesis can go awry is *required for development of new prevention and treatment strategies against disorders that stem from dysregulated synapse formation such as* [emphasis added] Alzheimer's disease, epilepsy, *autism* [emphasis added] and drug addiction" (https://reporter.nih.gov/search/dcVcWI9_qUCwOIbey9i02Q/project-details/9056466).
Health disparities:	The NIH defines health disparities as "differences that exist among specific population groups in the United States in the attainment of full health potential that can be measured by differences in incidence, prevalence, mortality, burden of disease, and other adverse health conditions" (National Academies of Sciences et al., 2017b).
Institutional discrimination:	Social institutions with embedded and enacted discrimination typically carried out by a dominant group over a minority group (Pincus, 1996).
Primary disease:	The initial cause of disease that is considered to "lie within the individual organism itself" (W. Burrows & Scarpelli, n.d. 2021).
Protected class:	Groups protected by federal law. Members from disability, race, ethnicity, sex, familial status, and religious groups are all protected from discrimination by U.S. Federal laws (*About The Division*, 2015).
Structural discrimination:	The negative outcomes for a minority group that result from policies and actions of institutions, despite institutions' intention to be bias-neutral (Pincus, 1996).
U.S. National Institutes of Health:	U.S. federal agency within the U.S. Department of Health and Human Services charged with overseeing federally funding medical research in the United States.

Federal Funding for Autism Research

To support autism research, the U.S. Autism CARES act of 2019 provides federal funding that supports the entire lifespan of autistic people, with an emphasis on health and well-being for this population (Autism CARES Act of 2019 | IACC, n.d.). To support the CARES act, the Office of Autism Research Coordination manages the Interagency Autism Coordinating Committee (IACC). The IACC coordinates autism-related activities and policies, including research and research funding (About OARC | IACC, n.d.), across the U.S. Department of Health and Human Services. Within the U.S. Department of Health and Human Services lies the National Institutes of Health (NIH), the primary federal agency that oversees federally funded medical research in the United States.

Although the NIH is empowered with funding autism research, the institutes fund little research on lifespan issues or services in autism (Cervantes et al., 2021). The NIH also funds mostly eugenics-related research (Cervantes et al., 2021; Hisle-Gorman et al., 2018; Wang et al., 2017), which is opposed by autistic adults and researchers. And of the 9.1% of NIH funds allocated to services research in autism, only 4% was allocated for autistic adults (Cervantes et al.,

2021). Thus, the NIH is not adequately supporting research to address the needs of autistic adults.

The NIH comprises 27 separate institutes that each focus on specific domains of research (e.g., diseases, body systems) (Institutes at NIH, n.d.). These institutes were designed to have independent priorities for research funding that aim to prevent overlap between research institutes. However, these independent priorities can also create gaps that block funding for certain areas of research or specific populations of people. These gaps can contribute to structural discrimination that results in negative outcomes for minority groups, despite an institution's intention to be bias-neutral. But regardless of intention, federal agencies are prohibited from discriminating against people with disabilities (https://www.ada.gov/pubs/adastatute08.htm#12132).

Process Nodes Potentially Restricting Access to Physical Health Research

Structural discrimination can occur at various points, or nodes, within the processes of an institution (e.g., policies, practices). These process nodes can limit or bias access to institutional services by a population or members of a population (Geneviève et al., 2020).

Between 2018 and 2021, we discovered process nodes that block grant proposals related to physical health for cognitively able autistic adults. During this time, we drafted and submitted specific aims for grants from different NIH institutes. These specific aims centered on the topic of adapting the delivery (implementation science) of Cognitive Behavioral Therapy for Insomnia (CBT-I; the front-line treatment of insomnia; Trauer et al., 2015; Tsiachristas et al., 2018) to better meet the social-communication and information-processing needs of autistic adults. In the general population, disturbed sleep is linked to greater mortality, cardiovascular disease, diabetes, obesity, accidents, anxiety, and depression, as well as low physical activity (Grandner et al., 2016; Riemann et al., 2015). In the autistic population, these conditions and insomnia are health-disparity conditions (E. K. Baker & Richdale, 2015, 2017; Croen et al., 2015). Thus, targeting sleep disorders in autism with interventions such as CBT-I may help reduce these disparities.

Although the IACC identifies sleep disturbances in autism as a priority research area (Interagency Autism Coordinating Committee, 2020), we found three process nodes that block the review of CBT-I research for the autistic population and, likely, physical health research more broadly. The first two nodes are intertwined and include (1) gaps between NIH-funding priorities and (2) program officers serving as gatekeepers with "inside" information about the match between an NIH institute's funding priorities and the proposed research. The third node includes multiple stakeholders who can influence the career trajectory of early career researchers.

Intertwining Process Nodes Create Gaps and Gatekeepers that Contribute to Structural Discrimination

As we submitted our specific aims to different NIH institutes, we uncovered two process nodes that block funding for physical health–related research, namely CBT-I research, for cognitively able autistic adults. These intertwined nodes include gaps in NIH-funding priorities and program officers serving as gatekeepers with "inside" information on those funding priorities. Below, we outline our experience illustrating the intertwining relationship of these nodes.

National Heart Lung and Blood Institute

The National Heart Lung and Blood Institute (NHLBI) prioritizes research on sleep and outcomes related to disturbed sleep (e.g., cardiovascular disease, diabetes, obesity). This priority suggests that the NHLBI is the most appropriate NIH institute to support CBT-I adaptation research. However, program officers assert that the NHLBI views autism as the "primary disease" (personal correspondence) and, therefore, is not an appropriate institute for this research. Program officers suggest contacting other NIH institutes, such as the National Institute of Mental Health (NIMH), National Institute on Child and Human Development (NICHD), National Institute of Neurological Disorders and Stroke (NINDS), or National Institute of Minority Health Disparities (NIMHD) (personal correspondence).

National Institute on Child and Human Development

The NICHD prioritizes research on "what causes autism, how best to detect signs of autism, how best to treat autism and its symptoms, and other topics" (Eunice Kennedy Shriver National Institute of Child Health and Human Development, n.d.-a). This institute prioritizes research "[c]ontributing to the overall health and well-being of people with autism throughout the lifespan" and "[u]nderstanding the prevention, etiology, and treatment of conditions and diseases that are commonly comorbid with ASD [autism spectrum disorder]" (Eunice Kennedy Shriver National Institute of Child Health and Human Development, n.d.-b).

These priorities suggest that the NICHD is an appropriate NIH institute to support CBT-I adaptation research. However, program officers assert that because the NICHD is flooded with applications, the institute prioritizes three main populations: children, adolescents, and people with

intellectual disabilities (with or without autism). Program officers specifically stated that research focused solely on cognitively able autistic adults, regardless of the context of research (e.g., sleep, physical health treatments) would not be appropriate for the NICHD. They suggest contacting other NIH institutes, such as the NHLBI, NINDS, NIMH, or NIMHD (personal correspondence).

National Institute of Minority Health Disparities

The NIMHD acknowledges the health disparities faced by people with disabilities: "Many populations in America, whether defined by race, ethnicity, immigrant status, *disability* [emphasis added], sex, gender, or geography, experience higher rates of certain diseases and more deaths and suffering from them compared with the general population" (National Institute on Minority Health and Health Disparities, 2021). Because autistic people are a disability population, this statement suggests that the NIMHD is an appropriate institute for CBT-I adaptation research. However, the NIMHD only designates "Blacks/African Americans, Hispanics/Latinos, American Indians/Alaska Natives, Asian Americans, Native Hawaiians and other Pacific Islanders, socioeconomically disadvantaged populations, underserved rural populations, and sexual and gender minorities" for disparity research in health and health care access (NIMHD, 2020). Disability populations are notably absent from this list, and the NIMHD does not clarify why it excludes disability populations from this list of designated populations.

Program officers assert that cognitively able autistic adults are not included within the groups designated by the NIMHD for health disparities research. They also assert that unless the research focuses on a designated intersectional population (e.g., women, racial and ethnic groups, rural populations), the NIMHD would not consider the research (personal correspondence). Although autistic adults comprise 2% of the adult population, diagnosed people are primarily Non-Hispanic, White males (Aylward et al., 2021; Burrows et al., 2022; Lai & Baron-Cohen, 2015). Although this proportion likely represents racial, ethnic, and gender disparities in diagnostic processes (Aylward et al., 2021; Burrows et al., 2022; Lai & Baron-Cohen, 2015), it also means that the diagnosed population of women and racial and ethnic minorities with autism is very small. This small population makes CBT-I adaptation research unfeasible in intersectional populations. Program officers suggested contacting other NIH institutes, such as the NHLBI, NIMH, NICHD, or NINDS (personal correspondence).

National Institute of Mental Health

The NIMH prioritizes autism research. However, program officers assert that, although the NIMH is the primary "home" for autism research at the NIH, the NIMH is not interested in research on physical health outcomes (e.g., insomnia, sleep), physical health disparities, or treatments to improve physical health. They stated that the NIMH is "solely interested in mental health" (personal correspondence), such as reducing anxiety, depression, bipolar disorder, and autism spectrum disorder. Also, NIMH prioritizes research that improves postsecondary transition outcomes (e.g., education, employment, independent living). They also devote most of their research funding for autism to the cause, cure, prevention, and treatment of autism as a disease (topics viewed as eugenics by autistic adults). And the NIMH prioritizes "objective" biological markers (e.g., cortisol levels) as target outcomes. Program officers suggest contacting other NIH institutes, such as the NHLBI, NICHD, NINDS, or NIMHD (personal correspondence).

National Institute of Neurological Disorders and Stroke

The NINDS prioritizes autism research, primarily related to eugenics. In its most recent strategic report (2021–2026), the NINDS describes autism as an "affliction" that accounts for "premature death, disability, [and/or] suffering" (National Institute of Neurological Disorders and Stroke, n.d.). "The mission of NINDS is to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease" (National Institute of Neurological Disorders and Stroke, 2021). However, research on co-occurring neurological conditions (e.g., epilepsy) may be regarded as physical health–related research.

The program director (the NINDS version of a program officer) indicated that the NINDS does not have clear explicit or implicit research priorities for autistic adults. After the program officer sent out seven emails to other NIH institutes and discussed my specific aims with the Center for Scientific Review, it was determined that none of the other institutes besides NINDS would be appropriate for research on health in autistic adults. They indicated that the NINDS does not have clear guidelines for determining what research on physical health–disparity conditions would be appropriate for NINDS. Instead, they state that NINDS determines the relevance of the research on a case-by-case basis, with priorities and processes described as "very murky." This strategy is also true for measured outcomes of the research (e.g., acceptability and appropriateness of adaptation research, development and validation measures) for this population. When asked about the language of the NINDS website and

strategic goals, the program director indicated that NINDS plans to modify the language in the future and that their research priorities for autism are "in flux." However, the program director was not certain of whether the scope of the proposed research (insomnia or measured outcomes) would be appropriate for NINDS. The program director promised to follow up (personal correspondence).

To summarize, after contacting five NIH Institutes, we learned that none of institutes other than the NINDS would be appropriate for physical health–related research in cognitively able autistic adults. Even though the NINDS *might* fund such research, the lack of clear guidelines and strategies does not support an effective funding mechanism. This lack of clarity contributes to structural discrimination in research funding for this population.

Process Node Discourages Early Career Researchers from Pursuing Structural Discrimination

Another process node that contributes to structural discrimination involves stakeholders who have a powerful influence in steering the paths of early career researchers. These stakeholders include research mentors, principal investigators of training grants, center directors, and training representatives for NIH grant writing, including NIH affiliates (e.g., program officers) and non-affiliates. In our experience, multiple stakeholders across several institutions discouraged us from pursuing the resolution of structural discrimination. They expressed concerns about adverse outcomes, such as retaliations by the NIH through uncooperative program officers or poor reviews of research grant submissions (personal correspondence). Although we do not know if these concerns are warranted, they create a chilling effect that discourages whistleblowing structural discrimination within funding agencies. Also, because many stakeholders receive and pursue NIH funding, their advice to early career researchers may create a conflict of interest.

Many stakeholders argued that the first two process nodes (gaps in funding priorities and gatekeepers of inside information) are not due to structural discrimination. They dismissed these claims and suggested that the process nodes are due to specific situations (e.g., interactions with program officers) or a specific researcher's skills, behaviors, and/or research topic(s) (personal correspondence). They even suggested that early career researchers are not at a career stage to pursue changes in NIH policy (personal correspondence). However, researchers who are at the initial stages of their research career are most impacted by, and most likely to discover, structural discrimination.

What solutions do stakeholders suggest for early career researchers? Choose between a path in either research or advocacy, but not both. And when choosing a research path, select a research topic and study population that fit the agency's funding priorities (personal correspondence). But this approach is limiting for early career researchers. And these limitations can slow progress in the field and impact the population the researcher wishes to study.

Most importantly, these process nodes may prevent cognitively able autistic adults from receiving research on physical health–related disparity conditions that adults from other federally protected groups (e.g., Hispanic people, women) are receiving (see Table 2 for examples of funded research for designated health disparity groups). In this way, structural discrimination at the NIH would create funding gaps for physical health–related research for this population, contributing to needless pain, greater mortality, and decreased quality of life.

Purpose of Study

We reasoned that if the three process nodes were idiosyncratic to the experiences of an individual researcher, and do not contribute to structural discrimination, then we would find NIH-funded research addressing specific physical health–related issues for cognitively able autistic adults. In this study, we systematically investigated whether the NIH has funded physical health–related research that aims to address health-disparity conditions affecting cognitively able autistic adults.

Methods

We identified NIH-funded research on physical health disparities in cognitively able autistic adults using NIH RePORTER (https://reporter.nih.gov/) in 2021. This electronic database is publicly available to ensure transparency and accountability to the public, and it is searchable by keywords (https://report.nih.gov/faqs). We included all funded autism research since 1985 (https://reporter.nih.gov/search/VEZi8UCKP06bPySgc0XUiA/projects). To identify grants focused on addressing physical health disparities in autistic adults, we used the "Quick Search" tool in NIH RePORTER to search the key terms of "autism" and "adult" along with a specific health condition (e.g., cardiovascular disease). These conditions were based on physical health conditions identified by Croen et al. (2015) as occurring at higher rates in autistic adults (Table 3). We repeated the search process for each of these health conditions, resulting in 30 separate searches.

For each search, we recorded the funded grant's title, grant number, applying organization, funding institute, and related search terms. We then analyzed the abstracts and public health relevance statements to determine whether (1)

Table 2 Grants funded in sleep with other adult health disparity populations

Title	Grant #	Target population
My ESSENCE - mindfulness to reduce stress, improve sleep, and reduce cardiovascular risk in African-Americans with type 2 diabetes	5K01HL149775-03	African American people
American Indian CHronic disEase RIsk and Sleep Health (AI-CHERISH)	3R01MD014035-04S1	American Indian and Alaska Native people
DORMIR: Determinants, Outcomes, Responses and Markers of Insufficient sleep in Rural-urban settings	5R01HL152453-02	Rural communities; Latinx people
Sleep and health disparities among Asian Americans: roles of stressors and protective factors	5R01MD015186-02	Asian American people; people with disadvantages
Administrative supplement for sleep and cardiometabolic health disparities at the US/Mexico border: the Nogales Cardiometabolic Health and Sleep (NoCHeS) Study	3R01MD011600-02S1	Native Hawaiian and other Pacific Islander people
Lifecourse stressors and social disparities in cognitive aging: the roles of social networks and sleep disturbance	1F99AG068431-01	People who are socially disadvantaged; White, Black, Asian, Latinx people;
Diagnosis and treatment of sleep apnea in women veterans	5I01HX002300-04	Women
Sleep and Cardiometabolic Health Disparities at the US/Mexico Border: The Nogales Cardiometabolic Health and Sleep (NoCHeS) Study	5T32HD007414-28	Immigrants, Hispanic/Latinx people
Examining sleep health and adherence outcomes among older HIV-positive men	3R21AG060824-02S1	Gay and bisexual men
Sleep disturbance and inhibitory control as proximal predictors of suicidal ideation and behavior: a daily diary and actigraphy study of young adults	5R21MH124902-02	People who are economically disadvantaged

autism was identified as the target condition, (2) the research focused on human adults, and (3) the research aimed to better understand or improve physical health (versus mental or occupational health). Abstracts and public health relevance statements that mentioned autism or autistic traits as a consequence of another target condition (e.g., Angelman Syndrome increases risk of autism) were not considered to target autism. We also noted if the target population or subjects were not explicitly mentioned. If autistic adults were the target population and their cognitive ability was not specified, we assumed the population was cognitively abled. We coded grants into four major purpose categories: (1) grants focused on improving or reducing the specified health-disparity condition through intervention, programs, or services; (2) grants studying general physical health; (3) grants aimed at reducing traits and behaviors associated with autism, or that were not targeting physical health; and (4) all other grants.

Results

The 30 searches returned a total of 99 listed grants. Nearly half (14) of the searches did not return any grants (Table 3). A total of 61 unique grants appeared across all searches, with 26 grants appearing in the search results for multiple health conditions (Table 4).

Among the 61 grants, 43 grants did not meet the criteria for including cognitively able autistic adults in the target population (Table 5). Although many of these grants included the term "autism" in the abstract or public health relevance statement, autism was most often described as a consequence of a physical disease, rather than the population of interest. Six other grants (Table 6) did not clearly describe cognitively able autistic adults as part of their target population. These grants gave vague descriptions that did not specify age or exact diagnoses, or they stated that autistic adults would only be indirectly involved in the future. For example, a study of twins only specified "autistic" but not "adults" or "children." Three other grants target developmental disabilities or language disorders without directly mentioning autism. Another grant is an equipment request that mentions many conditions, including autism (age unspecified), but only in the context of future research that could be conducted with the equipment being requested. Finally, one grant is indirectly applicable to autistic adults. This grant describes training postdocs in neurorehabilitating children and adults with neurological disabilities, and it provides autism as an example.

Table 3 Health disparities[a] used as search terms in NIH RePORTER and the corresponding number of returned grants

Search term	Total search returns
Allergy	1
Asthma	2
Autoimmune	2
Blindness	4
Cardiovascular disease	2
CNS diseases	21
Constipation	0
Diabetes	6
Diarrhea	0
Diseases of rectum and anus	0
Dyssomnia	0
Gastrointestinal	2
GERD	0
Hearing impairment	4
Hematology	0
Hepatic disease	0
Insomnia	0
Lower GI	0
Musculoskeletal	4
Nutrition	8
Obesity	11
Organic sleep apnea	0
Other disease of esophagus	0
Pituitary gland & hypothalamic control	5
Pulmonary	0
Renal disorders	2
Sleep disorders	6
Stroke	19
Thyroid disease	0
Upper GI motility	0

CNS, central nervous system; GERD, gastroesophageal reflux disease; GI, gastrointestinal. [a]Health disparity conditions were determined by Croen et al. 2015

Only 12 funded grants (Table 7) indicated inclusion of autistic adults. However, few of these studies explicitly designated the cognitive ability of the participants. Therefore, unless the grant explicitly indicated that the target population has intellectual disabilities, we assumed the population was cognitively able. Six of the 12 grants included autistic adults, but not exclusively. For example, they included autistic children/youth or people with other developmental disabilities.

After excluding studies that did not focus on physical health conditions (i.e., research focused on mental health conditions, the causes or prevention of autism, treatment of autistic traits, or other non-physical health characteristics), only four studies remained (Table 7, italics). Among these four studies, three are using electronic databases to better understand health conditions in autistic adults, and one is focused on better understanding age-related neuro-motor impairments in autistic adults. *None of the grants for cognitively able autistic adults focused on improving the relevant health-disparity condition through intervention, programs, or services.*

Discussion

Using data provided by the NIH, we sought to identify NIH-funded grants that support research on disparity conditions related to physical health. We found that in the past four decades, the NIH has not funded research for autistic adults that supports treatment, services, or programs *for any of the 30 physical health-disparity conditions identified by Croen (2015)*. This gap in funded research is deeply troubling, because autistic adults continue to experience adverse physical health outcomes and mortality (Bishop-Fitzpatrick & Kind, 2017; Croen et al., 2015; Hwang et al., 2019; Tregnago & Cheak-Zamora, 2012).

One way that researchers can bridge gaps in federal funding is to include the gap topic or population as a secondary aim in a proposal. In other words, they can submit research proposals on a topic or population that is a clear research priority for an institute and then, within the same proposal, include a secondary topic or population that falls within the funding gap. However, based on our results in this study, this approach has not been widely successful.

Without funding for research on physical health–disparity conditions, we cannot know whether treatments designed for the general population are effective or can be modified for autistic populations. For example, CBT-I for the general population is typically completed in six to eight face-to-face sessions (in-person or via telehealth) with a clinician, either individually or in groups (Simpson & Manber, 2021; Trauer et al., 2015). This format may not have the same benefits for autistic adults who have social-communication and information processing differences (Nicolaidis et al., 2015). However, given the described process nodes and their contribution to structural discrimination, researchers may not receive—or even be considered for—NIH funding to study whether CBT-I is effective for autistic adults in its current or an adapted form.

Structural discrimination can block research into the causes of health disparities for a federally protected population. This barrier is particularly concerning because marginalized groups are more likely to experience disparities in health conditions (Inzlicht & Schmader, 2011). For example, racism is a social determinant of health associated with poorer health outcomes (Paradies et al., 2015). Unfortunately, structural discrimination in research funding can prevent research on structural discrimination of physical

Table 4 All unique funded grants returned in searches

Title	Grant #
A hybrid effectiveness-implementation trial of a school based executive function treatment for transition age youth with autism	1R01MH124772-01
A neuroimaging study of twin pairs with autism	5R01MH083972-05
Accents, focus, and syntactic attachment	2R15HD072713-02
Arizona Surveillance and Research Center for Developmental Disabilities	5U01DD000691-02
Autoimmunity against novel antigens in neuropsychiatric dysfunction	5R01MH094741-04
Birth defects: Moebius syndrome and related facial weakness disorders	1U01HD079068-01
brain abnormalities and neurobehavioral deficits in hypoplastic left heart syndrome	5F30HD097967-03
Brain microstructure & behavior in newly-diagnosed toddlers/preschoolers with ASD	5R21MH105822-02
California Monitoring of Early Childhood Autism (CA-MECA)	5U01DD000305-04
Cerebellar and basal ganglia markers underlie neuromotor impairments in adults with autism spectrum disorder (ASD)	1R01NS121120-01
Clinical and genetic characterization of myotonic dystrophy	5P01NS058901-11
Cognitive enhancement therapy for adult autism spectrum disorder	5R01MH106450-05
Control of synapse formation and maturation by astrocytes	4R01DA031833-05
Correlates of physical activity in adolescents with intellectual disabilities	5R21HD059100-02
Exploring a potential role for epigenetics in tuberous sclerosis complex	5R21NS095187-02
Gait and communication growth in typical development and autism spectrum disorder	5F31MH123033-02
Gene dosage imbalance in neurodevelopmental disorders	5R01MH074090-15
Harnessing electronic health records to identify participants and to study health outcomes in transition-age youth and adults with autism spectrum disorder	5K18MH122755-02
High-density, MR-compatible functional near-infrared spectroscopy system for advancing clinical neuroscience and cognitive brain research in infants, children, adolescents, and adults	1S10OD026925-01
How connectivity determines function in the mature and developing human brain	5F32HD079169-03
Human subjects core	5P50ES026049-04
In vivo ultra-high field anatomical evidence of cortical abnormalities in ASD	5R21MH115306-02
Investigating the phenomenology and physiologic underpinnings of decreased sound tolerance in adults with autism spectrum disorder	1F30DC019510-01
Longitudinal study of adverse driving outcomes among adolescents with ADHD	5R01HD079398-03
Manipulating temporal and spacial CaMKII activity in Angelman syndrome	5R21NS072785-02
Mechanisms of bone loss from administration of the second-generation antipsychotic	5F32AR061932-03
Mechanisms of RNA-mediated CNS pathogenesis in myotonic dystophy	5P01NS058901-11
Metabolomic profiling for discovery of biomarkers of neurocognitive impairment in children with chronic kidney disease	5R21AT009752-02
Modulation of KCC2 activity and the postnatal development of synaptic inhibition	5R01NS101888-05
Mouse models to define critical periods and molecular targets in FXTAS	5R01NS079775-05
MRI-based biomarkers for regional brain abnormalities in autism spectrum disorder: from newborns to young adults	5R21MH118739-02
Multimodal imaging of early neural signature in autism spectrum disorder	5R01MH107802-05
Multiscale genetic connectivity of primate social circuits	5R01MH100635-05
Netrin5 in mammalian neurodevelopment	5R03NS085285-02
Neural bases of phonological working memory in developmental language disorders	5R03DC014045-03
Neural systems for the dynamic use of memory	5R00NS069788-05
Neurophysiologic investigation of somatosensory dysfunction in autism spectrum disorders	1R21MH120438-01A1
Oral health status and its correlates in adults with developmental disabilities	5RC1DE020396-02
Pathogenesis of neurological disability in primary diseases of myelin	5R35NS097303-04
Perineuronal nets, hippocampal plasticity and autism spectrum disorder	5R01MH118631-03
Pharmacogenetic prediction of antipsychotic induced weight gain	5R21MH099868-02
Preclinical imaging of adolescent cannabidiol on brain structure and functional connectivity	5R03DA042971-02
Probing receptor structures with unnatural amino acids	4R01NS034407-21
Proteolytic regulation of inhibitory circuits to gate cortical plasticity	3R01EY026053-03S1
Rehabilitation for emotion recognition impairments after stroke: building a scientific basis	5R21HD095273-02
Relational memory as a model of behavioral (dys)function in adults with traumatic brain injury	5R01NS110661-02
Research training in rehabilitation for brain injury and neurological disability	5T32HD007414-25
Risk and resiliency for youth with autism during the transition to adulthood	5K01MH092598-04
Small molecule approaches to targeting the DNA and RNA in myotonic dystrophy	5R01AR069645-05
Social determinants of child development and mental health	1ZIAHD008976-01

Table 4 (continued)

Title	Grant #
Social motivation in adults	1F32MH102024-01A1
Socially assistive robotic architecture for elder care	3R21AG050483-02S1
Spatial transcriptomics mapping of basal ganglia to understand critical periods for sensorimotor learning	1R21NS123763-01A1
The Autistic brain over 45: the anatomic, functional, and cognitive phenotype	2R01MH103494-06A1
The effects of oxytocin on complex social cognition in autism spectrum disorders	5R21HD065276-02
The gut microbiome in autism	5R01MH112356-05
The Kentucky ECHO Pediatric IDeA Research Center (KE-PIRC)	5UG1OD024954-04
The Kentucky pediatric clinical trials rural/urban partnership	1UG1HD090904-01
Unravelling the mechanisms of epilepsy - depression comorbidity in a genetic mouse model of temporal lobe epilepsy	5K08NS110924-03
Weight management for adolescents with IDD	5R01HD079642-05
Women with autism spectrum disorders during adolescence and adulthood: unique and common vulnerabilities	5R03MH112783

CNS, central nervous system

health–related disparities in autistic adults—thus, creating a circular problem. To examine the effects, and remediation, of ableism in health care and the broader societal structure, we need funded research to determine their impact on physical health disparities in autism.

In addition to structural discrimination, we need to understand how research marginalization influences funded research involving autistic populations. We have already uncovered other populations who have experienced, and rejected, eugenics research. For example, the United States historically used legitimized scientific and health care efforts to reduce the population of racial minorities (Farber, 2008) and people with intellectual disabilities (Ilyes, 2020) through involuntary sterilization and other methods. Also, the Public Health Service (the predecessor agency of the NIH) supported the Study of Untreated Syphilis in the Male Negro (1932–1972) (also known as the Tuskegee Syphilis Experiment), an infamous study of racism and dehumanization in research (Lombardo & Dorr, 2006). Further, members of the lesbian, gay, bisexual, transgender, queer, intersex, asexual, plus community have been historically pathologized by the medical and psychiatric communities. They have been targeted for research on preventions or cures, including conditioning, hormone treatments, and castration (Institute of Medicine et al., 2011).

We are concerned that autistic people face similar societal and medical marginalization. Both autists and autism researchers expressed concern about unintended application of genetics research to further eugenics research aimed at reducing autism in the population (Sanderson, 2021). Many autistic adults believe autism is a neurobiological difference that should be accepted by society (J. P. Baker & Lang, 2017), and they oppose research aimed to prevent, cure, or treat autism as a disease or disorder (J. P. Baker & Lang, 2017). These views shut down the UK Spectrum 10 K study, a large-scale genetic study aimed at better understanding mental and physical health in autists (Sanderson, 2021).

Societal and medical marginalization also fuels distrust of research (Institute of Medicine et al., 2011; Scharff et al., 2010). This distrust hinders participation in research, which can lead to less effective treatments, programs, and services that can result in needless pain, suffering, and mortality. To understand and mitigate distrust in research by the autistic community, we need funding for health disparities research.

Herein, we described potential process nodes that block sleep research focused on cognitively able autistic adults. Although we did not assess process nodes or funding patterns for other developmental (e.g., cerebral palsy) or mental health populations (e.g., schizophrenia), these populations likely experience similar disparities in physical health or health care access. To remediate process nodes that block potential funding, the NIH needs to develop and implement clear policy changes that do not explicitly exclude disability populations from receiving access to research available for other civil groups.

To support research related to physical health disparities with cognitively able autistic adults, we can consider the model provided by the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project. The INCLUDE Project launched in June 2018 in response to a FY2018 Omnibus Appropriation's Congressional directive calling for "a new trans-NIH research initiative on critical health and quality-of-life needs for individuals with Down syndrome (Baumer et al., 2022). INCLUDE…investigate[s] conditions that affect individuals with Down syndrome and the general population, such as Alzheimer's disease/dementia, autism, cataracts, celiac disease, congenital heart disease and diabetes." (National Institute of Health, n.d.). The INCLUDE Project removed barriers to funding streams across the NIH institutes that previously excluded physical health–related research for the population of people with Down syndrome. It also removed barriers that excluded people with Down syndrome from participating in health-related research.

Table 5 Grants in which the target population did not include cognitively able autistic adults

Title	Grant #	Population
A hybrid effectiveness-implementation trial of a school based executive function treatment for transition age youth with autism	1R01MH124772-02	Autistic youth
Accents, focus, and syntactic attachment	2R15HD072713-02	Unimpaired adults
Arizona Surveillance and Research Center for Developmental Disabilities	5U01DD000691-02	Spina bifida
Birth defects: Moebius syndrome and related facial weakness disorders	1U01HD079068-03	Moebius syndrome
Brain abnormalities and neurobehavioral deficits in hypoplastic left heart syndrome	5F30HD097967-03	Hypoplastic left heart syndrome mice
Brain microstructure & behavior in newly-diagnosed toddlers/preschoolers with ASD	5R21MH105822-02	Autistic children
California Monitoring of Early Childhood Autism (CA-MECA)	5U01DD000305-04	Autistic children
Clinical and genetic characterization of myotonic dystrophy	5P01NS058901-11	Myotonic dystrophy
Control of synapse formation and maturation by astrocytes	4R01DA031833-05	Unspecified
Correlates of physical activity in adolescents with intellectual disabilities	5R21HD059100-02	ID Adolescents with intellectual disabilities
Exploring a potential role for epigenetics in tuberous sclerosis complex	5R21NS095187-02	Unspecified
Gait and communication growth in typical development and autism spectrum disorder	5F31MH123033-02	Autistic children
How connectivity determines function in the mature and developing human brain	5F32HD079169-03	Typically developing children, adults?
Human subjects core	5P50ES026049-04S1	Infants
Longitudinal study of adverse driving outcomes among adolescents with ADHD	5R01HD079398-04	Adolescents with attention deficit hyperactivity disorder
Manipulating temporal and spacial CaMKII activity in Angelman syndrome	5R21NS072785-02	Mice (Angelman syndrome)
Mechanisms of bone loss from administration of the second-generation antipsychoti	5F32AR061932-03	Mice (Testing second generation antipsychotic medication)
Mechanisms of RNA-mediated CNS pathogenesis in myotonic dystophy	5P01NS058901-11	MBNL2 knockout mice (Myotonic dystrophy)
Metabolomic profiling for discovery of biomarkers of neurocognitive impairment in children with chronic kidney disease	5R21AT009752-02	Children with kidney disease
Modulation of KCC2 activity and the postnatal development of synaptic inhibition	5R01NS101888-05	Unspecified
Mouse models to define critical periods and molecular targets in FXTAS	5R01NS079775-05	Mice
Multimodal imaging of early neural signature in autism spectrum disorder	5R01MH107802-05S1	Autistic children
Multiscale genetic connectivity of primate social circuits	5R01MH100635-05	Macaque monkeys
Netrin5 in mammalian neurodevelopment	5R03NS085285-02	Mice
Neural systems for the dynamic use of memory	5R00NS069788-05	Older adults
Pathogenesis of neurological disability in primary diseases of myelin	5R35NS097303-04	Unspecified
Perineuronal nets, hippocampal plasticity and autism spectrum disorder	5R01MH118631-03	Mice (ASD Model)
Pharmacogenetic prediction of antipsychotic induced weight gain	5R21MH099868-02	Genome-wide association data on SGA-treated patients
Preclinical imaging of adolescent cannabidiol on brain structure and functional connectivity	5R03DA042971-02	Valproic acid model rats
Probing receptor structures with unnatural amino acids	4R01NS034407-21	Unspecified
Proteolytic regulation of inhibitory circuits to gate cortical plasticity	3R01EY026053-03S1	Unspecified
Rehabilitation for emotion recognition impairments after stroke: building a scientific basis	5R21HD095273-02	Patients who experienced stroke
Relational memory as a model of behavioral (dys)function in adults with traumatic brain injury	5R01NS110661-02	Patients with traumatic brain injury
Small molecule approaches to targeting the DNA and RNA in myotonic dystrophy	5R01AR069645-05	Cellular assays, *Drosophila*, mice (Myotonic dystrophy)
Social determinants of child development and mental health	1ZIAHD008976-04	Mothers and children
Social motivation in adults	1F32MH102024-01A1	(Non-autistic) adults
Socially assistive robotic architecture for elder care	3R21AG050483-02S1	Older adults with and without cognitive impairment
Spatial transcriptomics mapping of basal ganglia to understand critical periods for sensorimotor learning	1R21NS123763-01A1	Zebra finch

Table 5 (continued)

Title	Grant #	Population
The gut microbiome in autism	5R01MH112356-05	Genetic data, mice
The Kentucky ECHO Pediatric IDeA Research Center (KE-PIRC)	5UG1OD024954-04	Children and adults in Kentucky
The Kentucky pediatric clinical trials rural/urban partnership	1UG1HD090904-01	Children and adults in Kentucky
Unravelling the mechanisms of epilepsy - depression comorbidity in a genetic mouse model of temporal lobe epilepsy	5K08NS110924-03	Mice (epilepsy)
Weight management for adolescents with IDD	5R01HD079642-05	Adolescents with intellectual and/or developmental disabilities

ASD, autism spectrum disorder; MBLN2, muscleblind like splicing regulator 2

Table 6 Grants in which the target population was unclear about including autistic adults

Title	Grant #	Target population & reason unclear
A neuroimaging study of twin pairs with autism	5R01MH083972-05	Autistic twins, age unspecified
Autoimmunity against novel antigens in neuropsychiatric dysfunction	5R01MH094741-04	Patients with rapidly progressive neuropsychiatric disorders with catatonic features
High-density, MR-compatible functional near-infrared spectroscopy system for advancing clinical neuroscience and cognitive brain research in infants, children, adolescents, and adults	1S10OD026925-01	Equipment request for future NIH research grant submissions, including potential future study of "sleep-disordered breathing" in autism
Oral health status and its correlates in adults with developmental disabilities	5RC1DE020396-02	Adults with developmental disabilities, autism not specified
Neural bases of phonological working memory in developmental language disorders	5R03DC014045-03	Adults with typical language development, adults and children with developmental language disorders
Research training in rehabilitation for brain injury and neurological disability	5T32HD007414-28	Postdoctoral researchers

Regardless of whether the U.S. Congress creates directives, the NIH is responsible for preventing discrimination within its policies. By blocking physical health–related research solely due to the target population being a specific disability group, NIH institutes are discriminating in the same way as blocking physical health–related research for a target population of any other federally protected group (e.g., women, Hispanic people, lesbians). Additionally, people with other developmental disabilities (e.g., cerebral palsy) or mental health conditions (e.g., schizophrenia) also experience physical health conditions. These populations need access to research that addresses health disparities and physical health–related interventions and services. Future research should study whether other populations are affected by structural discrimination that blocks NIH funding for physical health–related research.

This study has several limitations. First, due to the limited information available in NIH RePORTER, we could not access all details about the population, target conditions, and/or other methods in the grants. The full details of successfully funded research proposals are not publicly available, likely due to the competitive process for obtaining research funding from the NIH. Second, the NIH RePORTER only includes successful grants, which comprise only about 18% of submitted research proposals (Rockey, 2015). And the NIH is not transparent about the frequency and types of research applications that are rejected (Cervantes et al., 2021). Thus, we do not know the number and nature of proposed grants that are rejected by (1) NIH program officers for not aligning with specific—and nuanced—funding priorities and (2) reviewers for the same or other reasons that may contribute to structural discrimination.

Conclusion

In this study, we describe process nodes that likely contribute to structural discrimination in physical health disparities research for cognitively able autistic adults. Similar structural discrimination likely exists for physical health disparities in other populations with developmental or mental health conditions. Such structural discrimination limits—even blocks—research funding for addressing these disparities. To correct this structural discrimination, we can look to the INCLUDE Project as a model to change policies and procedures within government agencies, including the NIH.

Table 7 Grants in which the target population included autistic adults

Title	Grant #	Search terms used	Topic[a]
Cerebellar and basal ganglia markers underlie neuromotor impairments in adults with autism spectrum disorder (ASD)	*1R01NS121120-01*	*Musculoskeletal, Stroke*	*Understanding comorbid neuromotor impairments*
Cognitive enhancement therapy for adult autism spectrum disorder	5R01MH106450-05	CNS	Mental/Occupational health
Gene dosage imbalance in neurodevelopmental disorders[b]	5R01MH074090-15	CNS	Causes of autism, developmental brain disorders
Harnessing electronic health records to identify participants and to study health outcomes in transition-age youth and adults with autism spectrum disorder[b,c]	*5K18MH122755-02*	*Obesity*	*General Health in ASD (Database)*
In vivo ultra-high field anatomical evidence of cortical abnormalities in ASD[b]	5R21MH115306-02	CNS	Causes of autism
Investigating the phenomenology and physiologic underpinnings of decreased sound tolerance in adults with autism spectrum disorder	1F30DC019510-01	Hearing Impairment	Mental/Occupational health
MRI-based biomarkers for regional brain abnormalities in autism spectrum disorder: From newborns to young adults[b]	5R21MH118739-02	CNS	Causes of autism
Neurophysiologic investigation of somatosensory dysfunction in autism spectrum disorders	1R21MH120438-01A1	Allergy, CNS	Mental/Occupational health
Risk and resiliency for youth with autism during the transition to adulthood[b]	*5K01MH092598-04*	*Pituitary/Hypothalamic control*	*General health (database)*
The autistic brain over 45: the anatomic, functional, and cognitive phenotype	2R01MH103494-06A1	CNS	Mental/Occupational health
The effects of oxytocin on complex social cognition in autism spectrum disorders	5R21HD065276-02	CNS	Mental/Occupational health
Women with autism spectrum disorders during adolescence and adulthood: unique and common vulnerabilities[b]	*5R03MH112783-02*	*Diabetes*	*Mental/Occupational health*

[a]Italicized grants focus on physical health conditions but do not directly treat these conditions

[b]Includes autistic children and adults

[c]Includes adults with developmental disabilities other than ASD

These efforts will better support research that addresses disparities in physical health or health care access for populations with developmental or mental health conditions.

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Data Availability All data are included in the manuscript. Raw data files may be available by request from the corresponding author.

Declarations

Conflict of interest The authors declare that they have no known competing financial interests or personal relationships that could appear to influence the work reported in the paper.

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