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Promoting Lifespan Health and Well-Being Through the Autism Intervention Research Network

Alice A. Kuo, MD, PhD

In 2000, the prevalence of autism was 1 in 166. Today it is 1 in 54 (1.8%), reflecting an increase of >300%, making this condition as common as red hair or green eyes in the world's population. With the recognition that a substantial proportion of the population experiences autism, a frameshift toward autism needs to occur. Similar to the growing recognition among researchers that the Latinx population is demographically diverse, autistic individuals are also diverse with unique sociocultural characteristics. These characteristics may contribute to differences in biological risk of co-occurring conditions such as cancer or cardiovascular disease across the life course. Treating all Latinx as a "pan-ethnic group" does not take into account cultural and behavioral differences among subgroups (ie, Puerto Ricans, Cubans, Mexicans, Hondurans, etc). We must begin to recognize the diversity of subgroups within autistic populations in research. We are adopting this frameshift (presented in the current supplement) in the Autism Intervention Research Network on Physical Health (AIR-P).

The AIR-P, recently retooled under University of California, Los Angeles leadership, includes partnerships with the AJ Drexel Autism Institute at Drexel University, Kaiser Permanente, and the Association of University Centers on Disabilities to promote research on the health of autistic individuals through the life course. Most notably, in the AIR-P, we created the first ever Autistic Researchers Review Board. Composed of 8 investigators who all have the lived experience of autism as well as research expertise, the Autistic Researchers Review Board is active in all aspects of the network and ensures that our contributions promote neurodiversity, avoid ableist language and concepts, and support equity in all intersectional identities with autism (eg, autism and race/ethnicity and autism and sexual/gender identity). The current supplement reflects this developing infrastructure composed of diverse collaborators via node-specific and intersectional commentaries, original autism research articles, and original neurodiversity research articles.

The research node commentaries from our 6 research nodes in the AIR-P represent the most pressing areas of needed research on the physical health throughout the lifespan of autistic individuals. The primary care services and quality node examines the ways in which the quality of primary care, as well as the overall primary care experience, can be optimized to support the health needs of autistic individuals, with interventions such as

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Departments of Medicine and Pediatrics, University of California, Los Angeles, Los Angeles, California

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Address correspondence to Alice Kuo, MD, PhD, 911 Broxton Avenue, Los Angeles, CA 90024. E-mail: Akuo@mednet.ucla.edu

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immunizations, cancer and cardiovascular screenings, and a consistent medical home. The community-based lifestyle interventions node focuses on promoting health behaviors that directly impact the quality of life of autistic individuals, such as nutrition, physical activity, and sleep. The health systems and services node addresses the development of autistic children into autistic adults, recognizing the substantial challenges for them and their families during this period because of barriers within the health care system, including service fragmentation and physician training. The gender, sexuality, and reproductive health node recognizes the importance of these biologic processes in autistic individuals and searches for improved education and intervention to support the experience of sexual debut, sexual or gender identity formation, and pregnancy. The neurology node examines common neurologic conditions that autistic individuals have, with the goal of promoting agency and self-determination for managing these conditions, and the genetics node focuses on improving access to genetic screening among autistic individuals, with the goal of empowering autistic individuals and their families to apply genetic findings to their lives.

We also present several intersectional commentaries that highlight important issues in autism and physical health and overlap with the priorities outlined across the node commentaries. These include commentaries presenting issues such as the impact of the coronavirus disease 2019 pandemic on autistic individuals, training the next generation of researchers and scientists, and how higher education can support the health and academic success of autistic individuals.

The AIR-P is poised to be highly successful on the basis of our partnership with the Association of University Centers on Disabilities and its network of 133 university centers that are now members of the AIR-P network. Our goal is to eventually create a national registry for autism, starting with smaller registries for those with genetic syndromes, to have better estimates of prevalence and support new and emerging multisite research collaborations, which will amplify the current state of research on physical health.

To lay the foundation for these research activities, the next section of our supplement presents original autism research articles. These articles reflect the developing research within the network that aligns with priorities outlined in the commentaries. These include studies on health care and services (eg, hospital inpatient stays, emergency department visits, and family perceptions on services), previously underexplored areas in the physical health of autistic individuals, including substance use and reproductive health, and studies of co-occurring health conditions among autistic individuals.

We also made a concerted effort to ensure our research reflects our theoretical orientation toward autism research. In disability communities, one is often asked whether they subscribe to a “medical model” or a “social model” of disability. A medical model is one in which the disability is pathologized (and often overpathologized) as sickness and focuses on what is wrong with the patient. A social model states that disability results from the way society is organized (eg, lack of accessibility). In AIR-P, we subscribe to a public health model of disability. In this model, public health activities, including surveillance, epidemiology, health promotion, and prevention, should serve all individuals and, in turn, autistic individuals must be regarded as part of the general population.[1] Research using the public health model considers the entire population and examines the influence of multiple determinants, including but not limited to autism status, on health outcomes.[1] By applying a public health model to autism, we recognize the challenges of impairment that can occur at the individual level and the opportunities to address the barriers to success at the population level. This model is particularly fitting to our work given that our funder is the federal public health agency, the Health Services and Resources Administration.

The public health model of disability is reflected in several of our original neurodiversity research articles that seek to promote health in all individuals. In this supplement, these efforts focus on the transition to adulthood, a developmental period of both heightened vulnerability and opportunity for intervention. For example, we present the development of 2 potential approaches to promote the health of all young adults: a needs assessment to inform a health-promoting, college-based intervention and a qualitative assessment to inform health care transition-related curricula in residency programs. We also include 2 nationally representative studies of young adults in college with conditions that frequently co-occur among autistic individuals: ADD/ADHD and mental health diagnoses.

This supplement presents our vision for autism research and our emerging efforts to move this vision forward. We look forward to advancing health promotion for autistic individuals through the emerging collaborations, research, and infrastructure building presented in this supplement.

ABBREVIATION

AIR-P: Autism Intervention Research Network on Physical Health

REFERENCE

1. Krahn G, Campbell VA. Evolving views of disability and public health: the roles of advocacy and public health. *Disabil Health J.* 2011;4(1):12–18

The Autism Intervention Research Network on Physical Health (AIR-P) Charter

Alice A. Kuo, MD, PhD,[a,b,c] Emily Hotez, PhD,[a] Kashia A. Rosenau, PhD,[c] Candace Gragnani, MD, MPH,[b] Priyanka Fernandes, MBBS, MPH,[a] Madeline Haley, BS[a]; on behalf of the AIR-P NATIONAL COORDINATING CENTER, Dawn Rudolph, MSEd,[d] Lisa A. Croen, PhD,[e] Maria L. Massolo, PhD,[e] Laura Graham Holmes, PhD,[f] Paul Shattuck, PhD,[g] Lindsay Shea, MS, DrPH,[h] Rujuta Wilson, MD,[a] Julian A. Martinez-Agosto, MD, PhD, FACMG, FAAP[a]; on behalf of the AIR-P STEERING COMMITTEE, Heather M. Brown, PhD, MEd,[i] Patrick S. R. Dwyer, MA,[j,k] Dena L. Gassner, MSW,[l,m] Steven K. Kapp, PhD,[n] Ari Ne'eman, BA,[o] Jacalyn G. Ryan, MA, CPA, CMA,[p] TC Waisman, EdD,[q] Zachary J. Williams, BS[r,s,t,u]; on behalf of the AUTISTIC RESEARCHER REVIEW BOARD, Jessica N. DiBari, PhD, MHS,[v] Dana M. Foney, PhD,[v] Lauren R. Ramos, MPH,[w] Michael D. Kogan, PhD[v], on behalf of the HEALTH RESOURCES AND SERVICES ADMINISTRATION MATERNAL AND CHILD HEALTH BUREAU

BACKGROUND

In the United States, autistic individuals experience disparate physical- and mental-health-related quality of life across the lifespan relative to non-autistic individuals. In recognition of these disparities, the Autism Intervention Research Network on Physical Health (AIR-P) seeks to establish and maintain a research network to enhance the health and well-being across the lifespan of autistic individuals, particularly for underserved and vulnerable populations. This charter serves as the initial charter for the AIR-P; as a network, we plan to continue to revise and elaborate on the contents of this charter as our research advances and as we continue to forge new partnerships and collaborations.

PURPOSE

The purpose of the AIR-P is to support innovative life course intervention research that promotes optimal health and well-being across the lifespan of autistic individuals in 6 key areas: (1) primary care services and quality, (2) community-based lifestyle interventions, (3) gender, sexuality, and reproductive health, (4) health systems and

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Departments of [a]Medicine and [b]Pediatrics, and [c]Graduate School of Education and Information Studies, University of California, Los Angeles, Los Angeles, California; [d]Association of University Centers on Disabilities, Silver Spring, Maryland; [e]Kaiser Permanente Northern California, Los Angeles, California; [f]Boston University School of Public Health, Boston, Massachusetts; [g]Mathematica Policy Research, Princeton, New Jersey; [h]AJ Drexel Autism Institute, Philadelphia, Pennsylvania; [i]Department of Educational Psychology, Faculty of Education, University of Alberta, Edmonton, Alberta, Canada; [j]Center for Mind and Brain and [k]Department of Psychology, University of California Davis, Davis, California; [l]School of Social Work, Adelphi University, Garden City, New York; [m]Department of Health Sciences, Towson University, Towson, Maryland; [n]Department of Psychology, University of Portsmouth, Portsmouth, United Kingdom; [o]Harvard University, Cambridge, Massachusetts; [p]Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada; [q]University of Calgary, Calgary, Alberta, Canada; [r]Medical Scientist Training Program, Vanderbilt University School of Medicine, Nashville, Tennessee; [s]Department of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville, Tennessee; [t]Vanderbilt Brain Institute, Vanderbilt University, Nashville, Tennessee; [u]Frist Center for Autism and Innovation, Vanderbilt University, Nashville, Tennessee; [v]Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland; and [w]Division of MCH Workforce Development, Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland

Drs Kuo, Hotez, Rosenau, Gragnani, Fernandes, and Ms Haley conceptualized the theoretical framework and methodology in this study and led the development of this manuscript; Ms Rudolph, Drs Croen, Massolo, Graham Holmes, Shattuck, Shea, Wilson, and Martinez-Agosto provided subject matter consultation and guidance on the manuscript; Dr Brown, Mr Dwyer, Ms Gassner, Dr Kapp, Mr Ne'eman, Ms Ryan, Dr Waisman, and Mr Williams provided expert guidance and consultation from research expertise and lived experience; Drs DiBari and Foney, Ms Ramos, and Dr Kogan provided technical assistance, expert consultation and feedback, and additional insight on all aspects of the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Emily Hotez, PhD, 911 Broxton Avenue, Los Angeles, CA 90024. E-mail: ehotez@mednet.ucla.edu

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services, (5) neurology, and (6) genetics. The network will establish and maintain an interdisciplinary, multicenter research network for scientific collaboration and infrastructure to increase the life expectancy and quality of life for autistic individuals, with a focus on underserved populations.

GUIDING PRINCIPLES

A Neurodiversity Orientation to Health

As a network, the AIR-P aligns with the neurodiversity movement and views autism as an identity akin to gender and race, not a condition that requires a cure. This is reflected in our approach to promoting the health and well-being of autistic individuals.

A Stakeholder-Driven Approach

All research supported within the network will be vetted and/or codeveloped by the Autistic Researcher Review Board, caregivers and family members of autistic individuals, and other stakeholders.

Inclusivity

The network will create an infrastructure for anyone, including early-career investigators and investigators seeking to begin a program of research in autism and physical health, to conduct research related to the physical health of autistic individuals. Any individual or organization may join the network, as well as access and contribute to the robust research infrastructure we are developing and maintaining.

Health Promotion

Our network seeks to advance research on physical health beyond a medical model and deficit-oriented approach toward promoting the multidimensional health, well-being, and thriving of autistic individuals and their families.

Equity

The network seeks to address disparities in the access, quality, and utilization of health-promoting services and supports for autistic individuals, particularly for underserved or marginalized populations. The network will aim to ensure that all research supported within the network benefits participants representative of low-income, racial or ethnic minority, immigrant, female, Indigenous, geographically remote, gender identity minority, and sexual orientation minority populations. This may require modifications to usual recruitment, data collection, and analytic methods that mitigate barriers to participation.

High-Quality Research Across the Lifespan

The AIR-P seeks to advance the evidence base of high-quality research across the lifespan for autistic individuals and their families. Areas in which there is currently no existing evidence base, the AIR-P seeks to spur innovative research and engage experts across the United States to guide policy and clinical practice in these areas.

MISSION

The mission of the AIR-P is to develop a robust research infrastructure that will foster measurable improvements in optimal physical health and well-being across the lifespan of autistic individuals and their families.

VISION

The AIR-P envisions a future in which autistic individuals experience optimal multidimensional health and well-being.

VALUES

The following values are central to all of our activities:

- Respect, integration, and equitable access to supports and services that promote optimal health and well-being for autistic individuals
- Self-determination and integration of autistic individuals in all facets of the network
- Individualized and culturally appropriate health care
- Diversity within the network, programs, and society
- Stewardship of public resources and measurable accountability
- A commitment to helping individuals by strengthening communities and systems

FIVE PRIMARY GOALS

1. Establish an interdisciplinary AIR-P Network that will lead, promote, and coordinate national research activities to improve physical health and well-being across the lifespan for autistic individuals;
2. Advance the evidence base for autistic individuals and their families by designing a portfolio of multisite research in 6 key areas: (1) primary care services and quality, (2) community-based lifestyle interventions, (3) gender, sexuality, and reproductive health, (4) health systems and services, (5) neurology, and (6) genetics;
3. Collaborate with autistic individuals in developing and carrying out research that addresses their needs, experiences, and priorities and fill the current gaps in research, practice, and policy;
4. Implement a pilot and feasibility funding program and corresponding scholars program to facilitate the research training and mentorship of diverse new investigators and launch the

next generation of researchers in autism and physical health; and
5. Coordinate and facilitate the dissemination of research findings by publishing an annual research supplement, presenting at annual AIR-P, Health Resources and Services Administration, and Association of University Centers on Disabilities conferences, and developing resources for families, clinicians, and other stakeholders.

ABBREVIATION

AIR-P: Autism Intervention Research Network on Physical Health

The Autism Intervention Research Network on Physical Health (AIR-P) Research Agenda

Alice A. Kuo, MD, PhD,[a,b,c] Emily Hotez, PhD,[a] Kashia A. Rosenau, PhD,[c] Candace Gragnani, MD, MPH,[b] Priyanka Fernandes, MBBS, MPH,[a] Madeline Haley, BS,[a] on behalf of the AIR-P NATIONAL COORDINATING CENTER; Dawn Rudolph, MSEd,[d] Lisa A. Croen, PhD,[e] Maria L. Massolo, PhD,[e] Laura Graham Holmes, PhD,[f] Paul Shattuck, PhD,[g] Lindsay Shea, MS, DrPH,[h] Rujuta Wilson, MD,[a] Julian A. Martinez-Agosto, MD, PhD, FACMG, FAAP,[a] on behalf of the AIR-P STEERING COMMITTEE; Heather M. Brown, PhD, MEd,[i] Patrick S.R. Dwyer, MA,[k,l] Dena L. Gassner, MSW,[m,n] Steven K. Kapp, PhD,[o] Ari Ne′eman, BA,[p] Jacalyn G. Ryan, MA, CPA, CMA,[j] TC Waisman, EdD,[q] Zachary J. Williams, BS,[r,s,t,u] on behalf of the AUTISTIC RESEARCHER REVIEW BOARD; Jessica N. DiBari, PhD, MHS,[w] Dana M. Foney, PhD,[w] Lauren R. Ramos, MPH,[v] Michael D. Kogan, PhD[w] on behalf of the HEALTH RESOURCES AND SERVICES ADMINISTRATION MATERNAL AND CHILD HEALTH BUREAU

abstract

OBJECTIVES: In the United States, autistic individuals experience disproportionate physical and mental health challenges relative to non-autistic individuals, including higher rates of co-occurring and chronic conditions and lower physical, social, and psychological health-related quality of life. The Autism Intervention Research Network on Physical Health (AIR-P) is an interdisciplinary, multicenter research network for scientific collaboration and infrastructure that aims to increase the life expectancy and quality of life for autistic individuals, with a focus on underserved or vulnerable populations. The current paper describes the development of the AIR-P Research Agenda.

METHODS: Development of the research agenda involved an iterative and collaborative process between the AIR-P Advisory Board, Steering Committee, and Autistic Researcher Review Board. The methodology consisted of 3 phases: (1) ideation and design, (2) literature review and synthesis; and (3) network engagement.

RESULTS: Six core research priorities related to the health of autistic individuals were identified: (1) primary care services and quality, (2) community-based lifestyle interventions, (3) health systems and services, (4) gender, sexuality, and reproductive health, (5) neurology, and (6) genetics. Specific topics within each of these priorities were identified. Four cross-cutting research priorities were also identified: (1) neurodiversity-oriented care, (2) facilitating developmental transitions, (3) methodologically rigorous intervention studies, and (4) addressing health disparities.

CONCLUSIONS: The AIR-P Research Agenda represents an important step forward for enacting large-scale health-promotion efforts for autistic individuals across the lifespan. This agenda will catalyze autism research in historically underrepresented topic areas while adopting a neurodiversity-oriented approach to health-promotion.

Departments of [a]Medicine and [b]Pediatrics, and [c]Graduate School of Education and Information Studies, University of California, Los Angeles, Los Angeles, California; [d]Association of University Centers on Disabilities, Silver Spring, Maryland; [e]Kaiser Permanente Northern California, Los Angeles, California; [f]Boston University School of Public Health, Boston, Massachusetts; [g]Mathematica Policy Research, Princeton, New Jersey; [h]AJ Drexel Autism Institute, Philadelphia, Pennsylvania; [i]Faculty of Education, Department of Educational Psychology, and [j]Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada; [k]Center for Mind and Brain, and [l]Department of Psychology, University of California Davis, Davis, California; [m]School of Social Work, Adelphi University, Garden City, New York; [n]Department of Health Sciences, Towson University, Towson, Maryland; [o]Department of Psychology, University of Portsmouth, Portsmouth, United Kingdom; [p]Harvard University, Cambridge, Massachusetts; [q]University of Calgary, Calgary, Alberta, Canada; [r]Medical Scientist Training Program, Vanderbilt University School of Medicine, Nashville, Tennessee; [s]Department of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville, Tennessee; [t]Vanderbilt Brain Institute, and [u]Frist Center for Autism and Innovation, Vanderbilt University, Nashville, Tennessee; and [v]Division of MCH Workforce Development, [w]Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland

WHAT'S KNOWN ON THE SUBJECT: In the United States, autistic individuals experience disproportionate physical and mental health challenges relative to non-autistic individuals, including higher rates of co-occurring and chronic conditions and lower physical, social, and psychological health-related quality of life.

WHAT THIS STUDY ADDS: This research agenda represents an important step forward for enacting large-scale health-promotion efforts for autistic individuals across the lifespan. This agenda will catalyze autism research in historically underrepresented topic areas while adopting a neurodiversity-oriented approach to health-promotion.

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The Autism Intervention Research Network on Physical Health National Coordinating Center and the Steering Committee created a targeted annotated bibliography of quantitative and

In the United States, autistic individuals experience disproportionate physical and mental health challenges relative to non-autistic individuals, including higher rates of co-occurring and chronic conditions and lower physical, social, and psychological health-related quality of life.[1–5] Funded by the Health Resources and Services Administration, Maternal and Child Health Bureau, the Autism Intervention Research Network on Physical Health (AIR-P) seeks to establish and maintain a research network to enhance the physical health and well-being of autistic children, adolescents, and adults, particularly for underserved and vulnerable populations. The current paper describes the AIR-P Research Agenda, developed through collaborations with researchers, practitioners, stakeholders, and autistic individuals; literature reviews; and consensus-building. This research agenda will be iteratively revised as the field continues to advance to ensure that ongoing efforts within the network reflect state-of-the-art research, priorities, and practice.

METHODS

Sample

The research agenda development process involved a collaborative process among the AIR-P Advisory Board ($n = 33$), Steering Committee ($n = 14$), and Autistic Researcher Review Board (ARRB) ($n = 8$). The Advisory Board is composed of researchers and practitioners across the United States who have expertise in autism and support research efforts within the network. The Steering Committee is composed of interdisciplinary researchers, practitioners, and other stakeholders with professional expertise, as well as personal experience working with or caring for autistic individuals across the lifespan. The ARRB is composed of autistic researchers and scholars in the United States, United Kingdom, and Canada who leverage their unique personal experiences to inform research that seeks to enhance the lives of autistic individuals. The network engagement phase of the methodology (described below) included a subsample ($n = 24$) from the Advisory Board ($n = 13$; 54%), Steering Committee ($n = 6$; 25%), and ARRB ($n = 5$; 21%). This subsample included individuals with diverse levels of training and education (PhD: $n = 10$, 41%; MD/PhD: $n = 5$; 21%; MD: $n = 4$, 17%; students and residents: $n = 3$, 13%; and master's level: $n = 2$, 8%). The sample also included those who identified as autistic ($n = 5$; 21%), those with an autistic family member or close friend ($n = 12$; 50%), and caregivers ($n = 5$; 21%).

Methodology

The methodology consisted of 3 phases:

1. Ideation and design: through a series of planning meetings, the Steering Committee identified preliminary priority domains based on their areas of expertise and background knowledge of the literature;

2. Literature review and synthesis: the Steering Committee created a targeted annotated bibliography of quantitative and qualitative research in the identified domains and synthesized the findings in a literature review to refine the domains; and

3. Network engagement: experts across the network ($n = 24$) engaged in a 2-step process via Qualtrics surveys to identify priority research topics within each domain.

In the first step, the sample provided open-ended responses regarding the highest-priority research topics within each of the research domains identified during the series of planning meetings and review of the literature. The open-ended responses were organized utilizing Dedoose coding software[6] and coalesced into 6 to 10 priority research areas within each domain. In the second step, participants were asked to participate in a follow-up survey to identify the top 3 priority research areas from the options within each domain, with consideration of the following criteria:

1. Need/urgency (ie, the influence of the research topic on the physical health and well-being of autistic individuals; severity of consequences [eg, number of autistic individuals affected by the issue]; and presence of critical gaps in knowledge);

2. Research impact (ie, the ability of the knowledge gained from this research topic to translate to meaningful progress in 5 to 10 years and the potential to lead to improvements in physical health status, quality of care, public health, or policy over the longer term); and

3. Person/family-centeredness (ie, how well the research topic reflects the experiences and priorities of autistic individuals and their families).

The research topics most frequently endorsed in participants' top 3 rankings across all categories were identified. Cross-cutting research domains—that is, research areas that apply to all domains and topic areas—emerged throughout all steps of the process.

RESULTS

The AIR-P Research Agenda, along with the highest-ranking research topic areas identified in the network engagement phase, are outlined in Table 1. The research agenda

TABLE 1 The Autism Intervention Research Network on Physical Health (AIR-P) Year 1 Research Agenda

Research Priority/Top 3 Research Topics[a]	*n* (%)[b]
Primary care services and quality: research that enhances primary care models that support autistic individuals across the lifespan	
Autistic individuals' self-determination (ie, capacity for autonomy, self-efficacy, and decision-making) in health care	19 (79)
Primary care provider training and specialized protocols for working with autistic individuals	18 (72)
Care and management around stress, anxiety, and/or suicidal ideation; referrals for psychiatric care	14 (58)
Community-based lifestyle interventions: research that enhances lifestyle interventions that support autistic individuals across the lifespan	
Lifestyle interventions that engage communities, families, children, and peers to promote social connectedness and enhance relationships	17 (71)
Lifestyle interventions that build self-advocacy capacities and important skills for development and independence	16 (67)
Engaging families and individuals in physical activity and nutrition, increasing community supports, and strengthening the evidence base for lifestyle interventions	12 (50)
Health systems and services: research that facilitates health care services and systems, particularly transitions and care coordination for autistic individuals	
Health care navigation for adolescents and adults and models of effective transition practices	16 (67)
Training primary care providers in the adult health care system to serve autistic individuals	14 (58)
Educating families and individuals about transitions and adult care	14 (58)
Gender, sexuality, and reproductive health: research that promotes sexual health among autistic individuals and addresses systemic barriers for women and gender nonconforming autistic individuals	
Developing sexual health curricula for autistic individuals and promoting awareness and knowledge	17 (71)
Understanding and addressing individual, caregiver, and family education and needs pertaining to sexual health	14 (58)
Understanding and supporting youth in areas related to intersectionality, LGBTQ+ issues, and gender and sexual identity	12 (50)
Self-determination around sexual behavior	12 (50)
Neurology: research that develops and tests the neurologic and developmental outcomes of motor-based interventions for autistic individuals	
Co-occurring conditions, (eg, motor dysfunction, sensory issues, seizures, and sleep) and corresponding accommodations, supports, and interventions	18 (75)
Understanding developmental neurologic trajectories and adult outcomes	12 (50)
Neurologic care coordination with other health care providers	12 (50)
Genetics: research that facilitates access to genetic testing as a means to enhance physical health among autistic individuals and their families	
Genetics counseling and physician–patient communication	15 (63)
Identifying genes linked to co-occurring conditions or treatment responses	13 (54)
Addressing the autistic community's concerns about genetics research and moving away from cure/cause research toward increasing quality of life	12 (50)

[a] Research topics reflect topics that were identified in the top 3 individual rankings. Rankings were obtained separately for need or urgency, research impact, and person or family-centeredness, and the topics with the highest rankings across all categories are displayed.

[b] This column reflects the number and percentage of experts across the network ($n = 24$) who ranked each research topic in their top 3 rankings of either need or urgency, research impact, or person or family-centeredness.

consists of 6 core research priority domains, each with critical implications for autistic individuals' physical health, and 4 cross-cutting priorities that applied across all domains.

Core Research Priorities Identified

Primary Care Services and Quality

Relative to their non-autistic counterparts, autistic children and adults have significantly more physician visits and medications prescribed and higher medical costs and total expenditures per treated patient.[7–10] Nonetheless, they create a smaller burden on health insurers because of their relatively low receipt of necessary treatment and services.[11–14] In addition, there are pronounced racial, ethnic, and gender health inequities in access to quality medical services.[13,14]

Of particular concern, only half of autistic individuals receive comprehensive primary care consistent with the medical home model as recommended by the American Academy of Pediatrics. This model is defined as care from a personal provider that is preventive, family-centered, compassionate, culturally appropriate, accessible, comprehensive, and coordinated.[15] A range of patient, provider, and systemic obstacles to an optimal medical home for autistic individuals has been cited in the literature.[16–19] These obstacles perpetuate unmet health care needs related to physical and mental health, prescription medications, and preventive care, and increase emergency service utilization.[20] Specific research priorities that emerged included promoting autistic individuals' self-determination (ie, capacity for autonomy, self-efficacy, and decision-making) in health care ($n = 19$, 79%), enhancing primary care provider training ($n = 18$, 72%), and mental health and psychiatric care ($n = 14$, 58%).

Community-Based Lifestyle Interventions

Although many autistic individuals experience challenges related to lifestyle, including nutrition, gastrointestinal issues, food selectivity,[21] obesity and associated chronic health conditions,[16,22, physical activity and motor performance,[23] sleep,[24–26] stress and anxiety,[27,28] social connectedness,[29,30] and substance use,[31] these challenges are variable in the autistic population. In addition, findings on the effectiveness of interventions have been inconclusive because of reliance on small sample sizes and subsequent failure to obtain robust effect sizes on physical health outcomes.[22,25] Research priorities that emerged included lifestyle interventions that promote social connectedness ($n = 17$, 71%), build self-advocacy capacities ($n = 16$, 67%), and engage families and communities ($n = 12$, 50%).

Health Systems and Services

Although health systems and services emerged as an important priority, a focus on transitions and coordination appeared to be particularly salient. Autistic individuals and their families characterize their experiences as a "lifetime of difficult transitions." They report difficulty using services, lack of source of care, inadequate insurance coverage, and lack of shared decision-making and care coordination. There are also a limited number of specialized service providers and resources that are often highly fragmented and governed by stringent and restrictive program and funding criteria.[32–35] Further, autistic individuals frequently encounter a poor person–environment fit in health care and service settings and uncertainty about the roles of parents in facilitating transitions.[34,35] Transition challenges are heightened for Black and low-income youth and those with comorbid conditions.[36,37] Access to a medical home is an important predictor of receiving health care transition services because autistic youth with a medical home are almost 3 times as likely to receive health care transition services as youth without a medical home.[38] Specific research priorities that emerged included supporting health care navigation and models of transition practices ($n = 16$, 67%), training primary care providers in the adult health system ($n = 14$, 58%), and educating individuals and families about transition care ($n = 14$, 58%). In recognition of the need for further research on health care transitions, the Maternal and Child Health Bureau has prioritized research, performance measurement, and data analysis around transitions. As an example, they invested in the Autism Transitions Research Project for Youth and Young Adults with Autism Spectrum Disorders. The AIR-P will collaborate with the Autism Transitions Research Project over the course of the grant.

Gender, Sexuality, and Reproductive Health

Mounting evidence suggests that gender-biased diagnostic and clinical criteria, along with actual sex and gender differences, may lead to the delayed recognition of autism in females.[39] Barriers to service access for autistic women may continue into adulthood, particularly for health services related to reproductive health and pregnancy.[40] Autistic adults are less likely to be gender-conforming than non-autistic adults. Belonging to a sexual or gender minority group is associated with higher rates of unmet health care needs among autistic people and, in turn, poorer physical health.[41] Indeed, autistic individuals often receive insufficient support regarding their sexuality and gender identity.[42,43] Further compounding these challenges, autistic individuals are at higher risk of sexual victimization and abuse compared with non-autistic people. These experiences are associated with suicidal or self-injurious behavior and psychiatric hospitalizations.[44] Autistic adults report less perceived and actual sexual knowledge, which may increase the risk of sexual victimization.[45] Specific research priorities that emerged included developing sexual health curricula for autistic individuals ($n = 17$, 71%), promoting sexual health education among individuals and families ($n = 14$, 58%), understanding intersectional identity issues ($n = 12$, 50%), and promoting self-determination ($n = 12$, 50%).

Neurology

Although autistic individuals have been found to experience motor impairments, including impairments related to gross and fine motor, postural control, and imitation and praxis, such impairments are not universal nor specific to autism.[46,47] The current research base surrounding motor-based interventions has shown some promising results, but is largely based on case studies and individuals without intellectual disability, or have yielded small-effect sizes.[48–50] Rigorous studies that include autistic individuals with heterogeneous behavioral and intellectual abilities are needed to objectively evaluate (1) motor dysfunction, and (2) motor-based interventions that target fundamental motor skills, social communication, and proprioceptive awareness.[51–53] Specific research priorities that emerged were understanding and addressing co-occurring neurologic conditions ($n = 18$, 75%) and neurologic developmental trajectories and adult outcomes ($n = 12$, 50%), as well as coordinating neurologic care ($n = 12$, 50%).

Genetics

Although autism has been found to be highly heritable,[54] genotyping is particularly complex due to frequently co-occurring conditions. Although a proportion of autism is attributable to common variants, rare copy-number variants and protein-disrupting, single-nucleotide variants have also been shown to significantly contribute to the etiology.[55] The diagnostic relevance of genomewide small common and rare copy-number variants continues to provide evidence of the high diagnostic yield of microarray for genetic testing in autistic children.[56] These findings support the utility of enhancing access to genetic testing for autistic individuals. Research priorities that emerged were genetic counseling (n = 15, 63%), identifying genes linked to co-occurring conditions or treatment responses (n = 13, 54%), and addressing the autistic community's concerns about genetics research and moving away from cure and cause research toward increasing quality of life (n = 12, 50%).

Cross-Cutting Research Priorities Identified

Neurodiversity-Oriented Care

The neurodiversity movement challenges deficit-oriented conceptualizations of disability, reframing the disability as a valuable minority identity that does not require corrective treatment.[57] The neurodiversity movement has proliferated in recent decades, primarily across college campuses, as a means to promote the success of diverse learners. However, the majority of literature on neurodiversity has been largely conceptual, with limited efforts to adapt a neurodiversity approach to health care.[58] This perspective encourages the promotion of self-determination, advocacy, and decision-making among autistic individuals and is informed by autistic individuals themselves.

Facilitating Developmental Transitions

Research with nationally representative samples of autistic youth reveal profound developmental, educational, and health-related struggles in the transition to adulthood[38,59] As previously mentioned, these challenges are often because of, in part, systemic factors that impede their capacity to succeed and thrive.[60] Transition-related challenges occur across the lifespan for autistic individuals and represent important opportunities for intervention and support.

Methodologically Rigorous Intervention Studies

Our review of the literature revealed that translating research on physical health for autistic individuals into interventions is constrained by several factors. These include research with small samples, a limited quantity of existing interventions that target physical health promotion, and a lack of measurement strategies that capture multidimensional developmental outcomes.[46,61]

Addressing Health Disparities

There is a well-established research base regarding the need for research and interventions that address health and health care disparities among marginalized and underserved autistic populations.[7,14,36] This includes a range of populations, including women, racial and ethnic minorities, and individuals from low socioeconomic backgrounds.

DISCUSSION

This paper presents the development of the AIR-P Research Agenda. Our agenda catalyzes autism research in currently underrepresented topic areas (eg, gender, sexuality, and reproductive health), particularly for autistic populations that experience disproportionate disparities. Our agenda adopts a neurodiversity orientation to health promotion for autistic individuals. This model contrasts with the traditional deficit-oriented medical model that emphasizes identifying a cure or pinpointing the etiology of autism at the expense of promoting well-being and thriving among autistic individuals in accordance with their self-reported needs, experiences, and priorities.

This agenda lays the foundation for research conducted within the AIR-P Network. Moving forward, the ARRB will collaborate with the Steering Committee in the continuous development and refinement of the overall research domains. In addition, there will be systematic efforts to catalog research that emerged during the first year of the AIR-P to ensure that priorities are representative of the current research and emerging trends. There will also be continuous consensus-building efforts to ensure alignment within the network.

CONCLUSION

The AIR-P Research Agenda represents an important step forward for enacting large-scale health-promotion efforts for autistic individuals across the lifespan. The AIR-P looks forward to addressing these critical research priorities and continuing to advance this research agenda as the network spurs research and innovation.

ABBREVIATIONS

AIR-P: Autism Intervention Research Network on Physical Health
ARRB: Autistic Researcher Review Board

qualitative research in identified domains and drafted the initial manuscript; the National Coordinating Center, Steering Committee, and Autistic Researcher Review Board participated in the qualitative research and reviewed and revised the manuscript; the Health Resources & Services Administration Maternal and Child Health Bureau contributed to the conception and design of the work, participated in revising the manuscript, and provided guidance and overarching feedback to this work; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Emily Hotez, PhD, University of California, Los Angeles, 911 Broxton Ave, Los Angeles, CA 90024. E-mail: ehotez@mednet.ucla.edu

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The Autism Intervention Research Network on Physical Health Autistic Researcher Review Board

Heather M. Brown, PhD, MEd,[a] Patrick S. R. Dwyer, MA,[b,c] Dena L. Gassner, MSW,[d,e] Steven K. Kapp, PhD,[f] Ari Ne'eman, BA,[g] Jacalyn G. Ryan, MA, CPA, CMA,[h] TC Waisman, EdD,[i] Zachary J. Williams, BS[j,k,l,m]

To increase the involvement of stakeholders in the autism research process, a committee of autistic researchers known as the Autistic Researcher Review Board (ARRB) has been established within the Autism Intervention Research Network on Physical Health (AIR-P). The ARRB includes a multinational group of academics, lecturers, and autistic consultants spanning a wide range of educational backgrounds and career stages. By harnessing the unique perspectives of ARRB members as both researchers and lived experience experts, this organization aims to ensure that the diverse perspectives of autistic individuals are appropriately considered during the conceptualization, conduction, and communication of research findings in the area of autism and physical health. The present commentary provides an introduction to the ARRB, as well as an overview of its guiding principles, research priorities, and goals for the future.

INTRODUCING THE AUTISTIC RESEARCHER REVIEW BOARD OF THE AUTISM PHYSICAL HEALTH RESEARCH NETWORK

Engagement of autistic individuals in the research process is crucial to ensure that autism research ultimately serves to improve the overall well-being of autistic individuals, as defined by autistic individuals.[1,2] To this end, patient-oriented research[3] and community-based participatory research paradigms have recently emerged. However, Pellicano et al[4] suggest that autism researchers have been reluctant to engage the autistic community in research.

The ARRB has been established as part of the AIR-P to serve as an innovative model for how autism researchers and autistic voices can effectively work together. The ARRB consists of a group of autistic researchers at various career points as academics, lecturers, and consultants. This gives the unique perspective as both scientists and lived-experience experts, with which to assess the merit of the proposed research projects and their relevance to improve the lives of autistic people. Our mission is to ensure that

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[a]Department of Educational Psychology, Faculty of Education, and [h]Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada; [b]Center for Mind and Brain, and [c]Department of Psychology, University of California Davis, Davis, California; [d]School of Social Work, Adelphi University, Garden City, New York; [e]Department of Health Sciences, Towson University, Towson, Maryland; [f]Department of Psychology, University of Portsmouth, Portsmouth, United Kingdom; [g]Harvard University, Cambridge, Massachusetts; [i]University of Calgary, Calgary, Alberta, Canada; [j]Medical Scientist Training Program, Vanderbilt University School of Medicine, Nashville, Tennessee; [k]Department of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville, Tennessee; and [l]Vanderbilt Brain Institute, and [m]Frist Center for Autism and Innovation, Vanderbilt University, Nashville, Tennessee

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Address correspondence to Zachary J. Williams, 1215 21st Avenue South, Medical Center East, Room 8310, Nashville, TN 37232. E-mail: Zachary.j.williams@vanderbilt.edu

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research conducted by the AIR-P:

1. Includes the voices of autistic individuals from across the lifespan; and
2. Ultimately aims to improve the health and well-being of autistic people as defined by them.

We will guide our decisions using the values of neurodiversity, well-being, and a study of physical health that reflects a deeper understanding of issues at the patient, provider, systems, and population levels and autistic individuals subjective experiences.

WHY IS NEURODIVERSITY ONE OF OUR KEY VALUES?

Neurodiversity has multiple definitions. As a descriptive term, "neurodiversity" refers to the simple fact that all brains are different[5] and highlights that the diversity of human brains is "every bit as crucial for the human race as biodiversity is for life in general".[6] As such, neurodiversity encompasses both "neurodivergent" and "neurotypical" people.[7] However, neurodiversity refers also to a political movement with distinct social and political goals.

The neurodiversity movement has its roots in the autistic community's efforts to push back against dominant autism narratives, beginning in the early 1990s with Jim Sinclair and Autism Network International.[8] While the meaning of neurodiversity continues to evolve through dialogue,[7,9–12] in general, the neurodiversity movement opposes attempts to find a "cure" for autism along with interventions that promote "indistinguishability from peers," instead advocating for greater acceptance and support of neurologic differences and adoption of more person-centered goals consistent with the preferences of autistic people.[5,12]

Having said this, neurodiversity advocates make clear that the movement does support improving adaptive functioning and addressing the various medical problems that commonly occur in neurodivergent individuals (such as forms of epilepsy), which may inherently threaten their quality of life.[13] They also support the need for caregivers, allies, and professionals to provide services and strategies that allow autistic individuals to better adapt to the world around them,[13,14] consistent with protecting the rights of and promoting social inclusion for neurodivergent people.[7] The neurodiversity framework's emphasis on helping autistic individuals achieve greater quality of life as the endpoint of autism advocacy ensures that we retain a practical focus on promoting happiness and wellness, rather than 'normalization,' as the indication of our success.[14] Autistic neurodiversity advocates have built an increasingly broad coalition with other disability groups, including many parents of non-autistic children and professional advocates.[15]

WHAT DOES IT MEAN TO BE WELL?

The ARRB aims to ensure that research conducted by the AIR-P is poised to make a positive contribution to the well-being of autistic people. To achieve this aim, we have chosen to operationalize well-being for individuals on the autism spectrum within the framework of Seligman's Positive Emotions, Engagement, Relationships, Meaning, and Accomplishment (PERMA) theory of well-being.[16] Notably, this model was developed to describe and promote well-being among neurotypicals without considering how these definitions of "idealized personhood" may look different for autistic people. Unfortunately, in practice, "well-being" is often conflated with the outcomes valued by neurotypical researchers, professionals, and society,[17] and there continues to be very little research that specifically identifies what autistic people themselves would consider a good quality of life.[18]

Keeping these caveats in mind, Seligman's PERMA model suggests that there are 5 pillars to human flourishing[16]: (1) Positive emotions or a subjective sense of well-being; (2) engagement, which refers to Csikszentmihalyi's[19] notion of "flow" or "intense concentration, absorption and focus" and is highly relevant given the special interests of autistic people[20]; (3) positive relationships can be defined as having "a strong sense of connection with others in the community,"[21] but this may be operationalized differently among people on the spectrum (eg, prioritizing the development of a few close friendships); (4) meaning refers to having a sense that one's life has direction, purpose, and value[22]; and (5) accomplishment, which is similar to Ryan and Deci's Self-Determination Theory,[23] which states that a feeling of 'competence' or 'working to achieve mastery' is a core basic human need.

The multidimensional approach of Seligman's model is important because autistic people often struggle a great deal in some areas while also experiencing high levels of well-being on other dimensions.[24] The ARRB aims to use the PERMA model to guide our decisions about whether AIR-P research ultimately serves the well-being of autistic individuals, such that each research project must ultimately have the potential to meaningfully improve the lives of autistic people in at least 1 of the 5 domains of well-being.

WHAT ARE OUR PRIORITIES IN PHYSICAL HEALTH RESEARCH?

Within the PERMA framework, the physical health of the autistic population is a particularly important area of research, and interventions targeting co-occurring medical conditions have the potential to greatly improve the well-being of many autistic children and adults. Most prior work on physical health in autism has specifically focused on a small number of disorders that are prevalent in autistic children, including epilepsy, gastrointestinal issues, and sleep disorders.[25] Research in the areas of health services and medical anthropology has also begun to identify a number of barriers at the patient, provider, and systems levels that prevent autistic people from accessing quality medical care, as well as the ways in which autism-related health disparities are compounded by other factors such as race, ethnicity, sex, gender, and socioeconomic status.[26–28] However, far less research has been conducted on the physical health of autistic adults or adult-onset medical conditions,[29] and there is a substantial lack of information regarding the health of older adults on the autism spectrum.[30] Moreover, even in cases where the co-occurrence of autism and certain medical conditions is firmly established (eg, epilepsy), it remains unclear whether any of these conditions share an etiologic origin with autism or result from autism-related health disparities.[31] Thus, to develop effective interventions for physical health conditions in the autistic population, research in this area must move beyond simply describing the overlap of autism with other medical conditions and instead focus on developing a deeper understanding of the mechanisms of these cooccurrences at the patient, provider, systems, and population levels.

Furthermore, when we consider the physical health of individuals on the autism spectrum, it is important to understand the ways in which autism itself can impact an individual's subjective experience of their illness. In particular, differences in interoceptive sensory processing in the autistic population[32] may alter the ways in which symptoms are perceived, potentially reducing the effectiveness of standard diagnostic and treatment modalities for many common conditions. While there has been relatively little research to date assessing the adequacy of standard-of-care medical treatments in the autistic population, we believe that such work can highlight the areas in which autistic people people may not benefit sufficiently from interventions established in the general population.

WHAT DO WE HOPE TO ACCOMPLISH?

As a starting point for our work in supporting the AIR-P network, we have developed 5 primary goals for the ARRB:

1. To ensure that we use our dual perspectives as researchers and autistic people to guide AIR-P research and their development of health interventions and supports for autistic individuals. Although we recognize our privilege as researchers, we aim to attempt to accurately represent the voices of our peers on the autism spectrum, so that we can ultimately promote autistic people health and well-being.
2. To foster the development and growth of collaborations between AIR-P sites and autistic people, caregivers, and other community stakeholders.
3. To promote an evidence base that is scientifically rigorous, inclusive of heterogeneous populations with intersectional identities, and sensitive to community needs.
4. To ensure that results of AIR-P research are communicated respectfully and in a manner that is accessible to autistic people and other stakeholders. The ARRB will expect use of respectful terminology[33] in AIR-P research and publications and, for community dissemination, will encourage use of additional media and formats.
5. To inspire other research networks and organizations to use innovative models to increase collaboration with autistic people in all stages of research from conceptualization to dissemination.

CONCLUSION

In sum, we believe that the establishment of the ARRB represents a major step forward in improving stakeholder involvement in autism research. Our mission is to ensure that the diverse perspectives of autistic individuals are appropriately considered during the conceptualization, conduction, and communication of research findings in the area of autism and physical health. Furthermore, we embrace a neurodiversity perspective, which emphasizes the need to reconsider what constitutes "quality of life" for autistic people when determining whether an intervention is beneficial. We aim to promote research that is scientifically rigorous, clinically applicable, inclusive of heterogenous populations, and driven by community priorities, with specific emphasis on the notion that such research will ultimately improve the health and well-being of autistic people. Although the goals of the ARRB and its role within the AIR-P network may change over time, the inclusion of autistic collaborators in the network's research will help to ensure that such research is conducted and communicated in a way that maximizes its benefit for the population that it aims to serve.

ABBREVIATIONS

AIR-P: Autism Intervention Research Network on Physical Health
ARRB: Autistic Researcher Review Board
PERMA: positive emotions, engagement, positive relationships, meaning and accomplishment

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Meeting the Primary Care Needs of Autistic Individuals

Alice A. Kuo, MD, PhD,[a,b] Audrey Torrest, MD[a]

In 1996, the Institute of Medicine adopted the following definition of primary care: the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.[1] On the basis of our previous work in the Health Care Transitions Research Network, we know that young autistic adults and their families struggle to find adult primary care providers who understand their needs.[2,3] The overall goals of health and health care are to increase lifespan and maximize quality of life. Primary care for autistic adults needs to improve for them to attain these goals.

Autistic adults have a significantly higher prevalence of common chronic medical conditions, including dyslipidemia, hypertension, diabetes, obesity, and thyroid disease.[4] However, despite an increased need for health services in this population, autistic individuals are faced with health care barriers from childhood to adulthood, which limit their access to high-quality primary and preventive care* services throughout the life course.

Both autistic children and older youth have higher levels of health service use, including a higher percent of pediatrician visits, specialty care services, and inpatient hospitalizations, compared to non-autistic individuals. Interestingly, despite this increased contact with the health care system, autistic children are less likely to have received important preventive health services including immunizations for influenza and other vaccinations.[5] In addition to receiving fewer vaccines in childhood, autistic individuals continue to face barriers in access to care as adults. Autistic adults report significantly higher odds of unmet health care needs related to physical health and mental health, compared to non-autistic adults.[6] Furthermore, although autistic adults are as likely as non-autistic adults to have a primary care provider, they are less likely to have received a tetanus vaccine, and, if female, less likely to have received cervical cancer screening in the past 3 years. Beyond vaccination and cervical cancer screening, little is known about the use and access of autistic individuals to other routine guideline-driven preventive services such as colon cancer and breast cancer screening.

The deficit in primary and preventive care services faced by autistic individuals, as well as the increased prevalence of various chronic medical conditions is related to a

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*In this commentary and all of our Autism Intervention Research Network on Physical Health related materials, the terms preventive care, preventive health, and preventive medicine all specify the prevention of acute infections or chronic diseases such as cardiovascular disease or cancer. They will never be meant to prevent the condition of autism.

Departments of [a]Medicine and [b]Pediatrics, University of California, Los Angeles, Los Angeles, California

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Address correspondence to Alice Kuo, MD, PhD, 911 Broxton Ave, Los Angeles, CA 90024. E-mail: Akuo@mednet.ucla.edu

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combination of both provider discomfort with treating autistic individuals as well as autism-specific barriers such as communication deficits, which pose a challenge for delivery of care through conventional models of medical practice. In a study on the patient experience, autistic patients experienced heightened anxiety when communicating with the physician, during the physical exam, and while in the waiting room. These difficulties could be alleviated by preplanning individualized accommodations to overcome environmental and process barriers such as rooming the patient immediately and not performing vital signs at the time of intake.[7] Such interventions may help improve clinic visits as well as the patient-doctor interaction.

Further interventions are needed to bridge the existing gaps in primary and preventive care and to address the increased prevalence of chronic health conditions in autistic individuals. Future directions should include research on differences in access to routine guideline-driven preventive health services such as colon and breast cancer screening, as well as further evaluation of the origin of the disparities in access to care faced by autistic individuals. Care for autistic individuals should incorporate guideline-driven practices provided to the general population in addition to personalized accommodations to improve delivery of care.

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Promoting Healthy Lifestyles and Well-Being in Autistic Youth

Candace M. Gragnani, MD, MPH, Priyanka Fernandes, MBBS, MPH

According to data from the National Health and Examination Survey, ~40% of adults and 19% of youth in the United States were obese in 2015 and 2016, with a disproportionate burden seen in non-Hispanic Black and Hispanic youth when compared with non-Hispanic White and non-Hispanic Asian youth.[1] The etiology of the obesity epidemic is complex and multifaceted, spanning physiologic, behavioral, genetic, social–emotional, political, and economic factors. As the epidemiology of morbidity and mortality has shifted from infectious to chronic and, most often, preventable diseases, the importance of healthy lifestyle behaviors for all families, including autistic individuals, could not be more pressing.

Autistic children and adolescents are at disproportionate risk for unhealthy weight status and represent just one of many communities with unique considerations when it comes to tailoring interventions designed to improve nutrition and physical activity.[2,3] Restrictive eating behaviors, sensory issues, specialized diets, social and behavioral impairments, motor impairments, and family factors are key considerations in addressing barriers to optimal nutrition and physical activity in autistic children.[4–6] For American Black and Hispanic/Latinx families with autistic children, a history of structural racism and the generation of limiting social structures further complicate efforts at healthier living via the disproportionate burden of food insecurity, food deserts, and safe built environments they share. Multifaceted interventions offering touchpoints in multiple social arenas (ie school, church, home, community center) that are tailored to the needs and strengths of diverse communities will be required for meaningful and effective change for families with autistic individuals.[7]

Lifestyle medicine focuses on 6 key tenets of health: (1) whole food, plant-based diet, (2) regular physical activity, (3) restorative sleep, (4) stress management, (5) social connectedness, and (6) avoiding risky substance use. When optimized, these 6 tenets can prevent and even help reverse chronic diseases such as cardiovascular disease, diabetes, and cancer. Our goal is to pursue interventions that, first and foremost, use the local autistic community's input to guide the development and implementation of interventions aimed at improving the lifestyle of autistic individuals and their families. By prioritizing creative educational delivery methods such as a virtual teaching kitchen that promotes social engagement, sensory exposure to a variety of foods, and meal preparation skills that promote self-care and independent living skills, we aim to promote whole-person growth and wellness.

The coronavirus disease 2019 pandemic has undoubtedly altered

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Department of Medicine, University of California, Los Angeles, Los Angeles, California

Drs Fernandes and Gragnani conceptualized, drafted, reviewed, and revised the manuscript and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Candace M. Gragnani, MD, MPH, 911 Broxton Avenue, Los Angeles, CA 90024. E-mail: CGragnani@mednet.ucla.edu

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every family's life in deep and meaningful ways. It has also spurred and required innovative solutions, including the explosive growth of virtual meeting platforms, whose use will require continued input from autistic youth and their families for the development of best practices. Virtual platforms provide expansive virtual reach to autistic youth and families in a variety of historically underserved settings such as rural and urban underserved areas. By funding small-scale pilots, enabling researchers to engage with a network of collaborating research entities, and providing a centralized data infrastructure, the lifestyle node of the Autism Intervention Research Network on Physical Health is poised to scale and more robustly evaluate novel interventions.

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Improving Care and Service Delivery for Autistic Youths Transitioning to Adulthood

Paul Shattuck, PhD,[a] Lindsay Shea, DrPH, MS[b]

Approximately 100 000 autistic youths turn 18 each year, a rough approximation for the number entering adulthood. Population outcomes among autistic young adults are poor across indicators of physical health, mental health, employment, postsecondary education, community participation, independence, financial security, and access to needed community services. There is little evidence that we have moved the needle on these population-level outcomes over the past 15 years, despite growing attention to the needs of this group and an outpouring of investment in the development of patient-level clinical interventions. The focus on developing evidence-based treatments has not yet been matched by a corresponding investment in implementing interventions at a scale that can reach this growing population or in systems-level strategies for improving policy and program performance.[1]

Historically, autism was conceptualized as a pervasive developmental disorder because difficulties typically manifest pervasively across domains of physical and behavioral health, motor and speech development, and social and emotional development. Thus, delivery of physical health care and health care transition in this population are almost always inextricably intertwined with other developmental domains and a need for communication and coordination with the patient, his or her family, and a myriad of other health and community service providers.[2]

Recommendations for improving care coordination are commonplace in this field and targets for research and practice. However, few specific measures of care coordination exist beyond general questions asked of parents in health care surveys. Implementing continuous improvement practices is impossible without clear metrics to measure progress. A promising direction for measuring care coordination in a way that could inform iterative improvement cycles is the adaptation of social network measures.[3] This is a priority of the Autism Intervention Research Network on Physical Health (AIR-P) research node at Drexel University.

Medicaid plays a key role in the coordination of care and delivery of services. Poor employment prospects among autistic youth result in Medicaid being among the only potential insurers for this group. Hallmark Medicaid programs, including Section 1115 waivers and other programs that vary by state, can deliver a robust service array to eligible autistic youth. However, a thorough, population-level understanding of the pathways needed to navigate Medicaid during the transition of these youths to adulthood has not

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[a] *Mathematica, Washington, DC; and* [b] *AJ Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania*

Drs Shattuck and Shea conceptualized the commentary and drafted and revised the manuscript, and both authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Paul Shattuck, PhD, Mathematica, 1100 First St NE, 12th Floor, Washington, DC 20002. E-mail: pshattuck@mathematica-mpr.com

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been established. There may be specific and modifiable aspects of Medicaid eligibility criteria that differentially affect access for aging autistic youth. The identification of Medicaid services used by enrolled autistic young adults will be a substantial advancement for AIR-P and may reveal avenues to boost the efficiency and effectiveness of service delivery.

Across insurers, new service models for transition-aged youth with mental health and chronic health conditions, including peer support and service navigation, are being pilot tested. The adaptation of these innovative models to help autistic youth will be a key goal for AIR-P. Furthermore, among the most critical advancements needed to improve care delivered to autistic youth is reworking the connections between research and practice so that they are both more bidirectional (research informs practice and vice versa) and more efficient (innovation to scalable implementation cycles are faster). Robust networks that foster close connections among researchers, practitioners, and policymakers from the outset of innovation are poised to make much-needed headway for developing and implementing this burgeoning evidence base in a timely manner to truly move the needle on population-level outcomes.

ABBREVIATION

AIR-P: Autism Intervention Research Network on Physical Health

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Improving the Sexual and Reproductive Health and Health Care of Autistic People

Laura Graham Holmes, PhD,[a] Jennifer L. Ames, MS, PhD,[b] Maria L. Massolo, PhD,[b] Denise M. Nunez, MD, MPH,[c] Lisa A. Croen, PhD[b]

The gender, sexuality, and reproductive health research node seeks to improve sexual and reproductive health care and outcomes for autistic people, with a focus on the lifespan of autistic women and lesbian, gay, bisexual, transgender, queer, intersex, and asexual individuals (LGBTQIA+). For most adults, sexuality and relationships are among the primary everyday contributors to life satisfaction, health, and well-being. Most people on the autism spectrum experience sexual attraction, and many adolescents and autistic adults are sexually active. All, including those who are not sexually active, benefit from sexual and reproductive health services. These services, which support self-determination, promote the ability to have safe, satisfying, noncoercive sexual experiences if desired and to make and implement informed decisions about reproduction. Although limited, research on sexual and reproductive health services for autistic people indicates an urgent need for investments, particularly in the areas of sexuality education; sexual violence; prenatal, perinatal, and postpartum care; and LGBTQIA+ health.

SEXUALITY EDUCATION AND SEXUAL AND REPRODUCTIVE HEALTH SERVICES

Autistic people often have complex medical and educational support needs that may affect puberty, sexuality development, autonomy, and personal identity. This means they may require adapted or specialized sexual and reproductive health services, including sexuality education. Despite this, half of families raising autistic adolescents report that no health care provider ever talked with them about puberty or sexuality, and autistic adolescents are the least likely to receive school-based sexuality education compared with other disability populations.[1] Service access disparities continue in adulthood, as multiple studies show autistic individuals are half as likely to receive basic sexual and reproductive health care, such as gynecology visits and cervical cancer screenings, compared with non-autistic individuals.[2]

SEXUAL VIOLENCE

Rates of parent-reported sexual victimization for autistic children and adolescents are significantly greater than rates among non-autistic youth, and autistic college students experience more unwanted sexual contact compared with their non-autistic peers.[3] For autistic youth, sexual abuse in childhood has been associated with running away from home, sexual acting out or offending, and suicide,[4] but there is limited

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[a]*Boston University School of Public Health, Boston, Massachusetts;* [b]*Kaiser Permanente Northern California, Oakland, California; and* [c]*University of California, Los Angeles, California*

All authors conceptualized and designed the commentary, drafted, reviewed, and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Dr Graham Holmes' current affiliation is Silberman School of Social Work at Hunter College, New York, NY.

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Address correspondence to Lisa Croen, PhD, Division of Research, Kaiser Permanente Northern California, 2000 Broadway, Oakland, CA. E-mail: lisa.a.croen@kp.org

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information about resulting physical, mental, or sexual and reproductive health sequelae across the lifespan.

PRENATAL, PERINATAL, AND POSTPARTUM CARE

Research on the obstetric health and prenatal care experiences of pregnant individuals on the autism spectrum is currently limited with a paucity of large epidemiologic studies. However, early evidence suggests that pregnant autistic people have elevated risks of several pregnancy complications and may experience exacerbations of anxiety, stress, and challenges with sensory processing as a result of the biological and social changes of pregnancy.[5] We do not yet know the reasons for these disparities. One issue raised by autistic people and health care providers is that adult care providers may not be aware of the needs of autistic patients.

SEXUAL AND GENDER MINORITIES

A substantial proportion of autistic adolescents and adults are LGBTQIA+. Autistic people are more likely to be transgender or gender nonconforming compared with non-autistic people, and findings from a recent autism registry study suggest that among autistic people able to self-report on a survey, up to 18% of men and 43% of women may be sexual minorities.[6] Examining the intersection of LGBTQIA+ identity and autism reveals compounded health disparities that have not been adequately addressed by insurers and service providers, particularly as individuals transition to the adult medical system. The National Survey on Health and Disability showed autistic LGBTQIA+ respondents had worse self-reported health and health care access compared with non-LGBTQIA+ autistic people, with 2 times the rate of psychiatric diagnoses, 10 times the rate of smoking, and 2 times the number of poor physical health days per month. Although most autistic LGBTQIA+ individuals in this study had health insurance, they still reported more unmet health care needs than autistic non-LGBTQIA+ individuals, and approximately one-third had been refused services by a provider.[7]

The gender, sexuality, and reproductive health priority research area will systematically address service gaps and health disparities for autistic individuals regarding sexuality education, sexual violence prevention, reproductive health and pregnancy, and LGBTQIA+ health. We will convene a stakeholder advisory group comprising people with relevant lived experiences and conduct a needs assessment to identify urgent knowledge gaps in autistic sexual and reproductive health, prioritize sexual and reproductive health research questions, and disseminate findings to our research networks. We will identify facilitators and barriers to gynecologic, obstetric, and primary health care for autistic women and LGBTQIA+ individuals. Finally, we will develop, implement, and evaluate interventions to improve access and utilization of sexual and reproductive health care and health status for this population. An important part of this priority research area's work will be training early career professionals in the sexual and reproductive health of autistic people and LGBTQIA+ health so that emerging priorities continue to be addressed well into the future.

ABBREVIATION

LGBTQIA+: lesbian, gay, bisexual, transgender, queer, intersex, and asexual individuals

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Improving Awareness, Identification, and Treatment of Motor Impairments in Autism

Rujuta B. Wilson, MD, MS

Autism represents a heterogenous group of neurodevelopmental disabilities characterized by the presence of social communication impairments and focused and repetitive behaviors.[1] Motor impairments are also a frequent co-occurring behavioral and neurologic condition in autistic individuals. These motor impairments include delayed motor milestones, atypical gait, poor visual motor coordination, and difficulties with balance and postural control.[2,3] Recent large-scale national cohort and database studies have estimated that motor impairments can affect 35% to 87% of autistic individuals across a lifespan.[4,5] Furthermore, motor impairments have been posited to be one of the earliest signs of atypical development in autism and can negatively impact the development of social communication, adaptive function, and participation in physical activity.[6–9] Thus, identification of and interventions for motor impairments can improve multiple neurodevelopmental and physical health outcomes. Despite their prevalence and pervasive nature, motor impairments remain under recognized and under screened by clinicians and researchers. One reason for this gap is that motor impairments are listed as an associated condition in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, with no standardized guidelines on how to evaluate or categorize these impairments. In addition, current standardized motor assessments are not tailored for autistic individuals and intellectual disability and do not capture the heterogenous nature of motor impairments that can be seen in autistic individuals.[10,11] There is a need for more objective motor measures that can evaluate autistic individuals across a life span with a range of intellectual abilities. These objective measures can improve our ability to characterize motor impairments in autism which, in turn, can improve: (1) screening guidelines for clinicians, (2) evaluation of outcomes of motor-based interventions, and (3) referral to more targeted motor interventions.

The Autism Intervention and Research Network (AIR-P) neurology node is uniquely positioned to address these gaps in the field. The neurology node aims to (1) use objective quantitative and qualitative motor measurement methods to improve motor phenotyping across the lifespan, (2) evaluate the benefits of motor-based physical activity interventions on motor skills, adaptive functioning, and physical health outcomes, and (3) disseminate evidence-based information to caregivers and clinicians to improve

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Semel Institute for Neuroscience and Human Behavior, David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, California; and UCLA Center for Autism Research and Treatment, Los Angeles, California

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Address correspondence to Rujuta Wilson, MD, MS, Department of Psychiatry and Pediatrics, 760 Westwood Plaza, Los Angeles, CA, 90095. E-mail: RBhatt@mednet.ucla.edu

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screening of motor impairments and referral to interventions.

Given the AIR-P's focus on physical health outcomes and well-being, it is also important to elaborate on the second aim of the neurology node, which includes evaluation of the benefits of motor-based physical activity interventions for autistic individuals. Motor impairments can pose a barrier to engagement in physical activity and organized physical activity programs (eg, soccer, dance, tennis, or yoga). It has been reported that only 14% of autistic youth meet the recommended 60 minutes of physical activity a day.[12] Decreased levels of physical activity can compound co-occurring medical conditions already prevalent in autism such as obesity, lower bone mineral density, and hyperlipidemia.[13] Engagement in organized physical activity also provides opportunities for developing peer relationships.[14] Barriers to engagement in sports represent missed opportunities for autistic individuals to benefit from these meaningful social experiences. Additional barriers to inclusion of autistic youth in organized physical activity programs include caregiver reports of lack of awareness and accessibility of these programs and limited training of staff to support autistic individuals.[9,12] The AIR-P neurology node will directly address these issues by conducting clinical intervention studies to evaluate the benefits of motor-based physical activity for autistic individuals. The first phase of this work is underway and is focused on evaluating the benefits of an expressive movement-based dance program on motor skills, physical activity level, social communication, quality of life, and adaptive function.[15] The goal of this work is to provide evidence-based recommendations to caregivers, clinicians, and community providers on how to refer and support autistic individuals in organized physical activity programs.

The AIR-P neurology node will use a multifaceted approach to address gaps in identification, awareness, and interventions for motor impairments in autism. Specifically, the node will use methods to improve motor phenotyping in autistic individuals, evaluate motor-based interventions, and disseminate this knowledge to the community at large. The data gathered from the neurology node can help inform other nodes and researchers engaged in the AIR-P network and ultimately build the evidence needed to improve the diagnostic and treatment approach for this prevalent co-occurring neurologic and behavioral condition in autism.

ABBREVIATIONS

AIR-P: Autism Intervention Research Network on Physical Health
OPA: organized physical activities

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The Role of Genetic Testing Among Autistic Individuals

Iram Shafqat, MD, Kashia A. Rosenau, PhD, Julian A. Martinez-Agosto, MD, PhD

Autism is estimated to have a heritability component of ~90%.[1] This estimate is based on the reported concordance rates of 70% to 90% between monozygotic twins compared with 10% concordance in dizygotic twins.[2,3] Furthermore, siblings of autistic individuals carry a >17 times higher likelihood of being on the autism spectrum compared with the general population.[3] Although a significant proportion of genetic and molecular mechanisms related to autism remain unclear, researchers have reported findings that suggest both rare Mendelian and polygenic, multifactorial patterns of inheritance. For example, chromosomal microarray testing may identify a genetic etiology in up to 20% of autistic individuals.[4,5]

Given this extent of genetic heritability, large-scale genetic testing and tracking within databases are beneficial in informing both research and clinical practice. The developers of these datasets aim to identify specific gene interactions and assess individual gene contributions while advancing the diagnostic yield of genetic testing.[6] The Autism Intervention Research Network on Physical Health genetics research node is poised to help to facilitate the creation of registries for rare and orphan diseases that commonly co-occur with autism. An aim of the Autism Intervention Research Network on Physical Health data repository is to collect this information through the use of data-gathering materials designed to ease the burden on families and support groups wanting to initiate new registries.

An important distinction to note is that genetic testing is not used to diagnose autism. An autism diagnosis is based on the presence of defined clinical characteristics. Although genetic test results may reveal the origin of autism in an individual or provide information about the statistical likelihood of being on the autism spectrum, they can also be used to improve the physical health and well-being of autistic individuals by identifying co-occurring medical conditions. Genetic testing may inform a specific diagnosis (eg, fragile X syndrome, Rett syndrome) that could ultimately establish a personalized roadmap for identifying syndrome-associated co-occurring conditions, instituting surveillance, and developing interventions or treatments specific to the genetic etiology. Furthermore, the individual diagnosis may lead to diagnosis-specific community support and help to guide family planning efforts.

Despite the American College of Medical Genetics and Genomics establishing fragile X and chromosomal microarray testing as standard-of-care, first-tier tests in the genetic evaluation of autistic individuals,[7,8] a surprisingly low number of autistic individuals receive these recommended genetics tests. One recent study with 1280 participants revealed that although 16.5% of participants had some genetic testing done, only 3% had

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David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, California

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Address correspondence to Iram Shafqat, MD, Surgery Education Office, UCSF Department of Surgery 513 Parnassus Avenue, S-321 San Francisco, CA 94143-0470. E-mail: iramshafqat@gmail.com

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received both recommended tests.[9] Moreover, well-documented racial and ethnic disparities exist in the timely identification and genetic screening of autistic individuals. Black, Hispanic/Latinx, and other children of color, particularly those with co-occurring intellectual disabilities, are more likely to have a missed or delayed diagnosis of autism.[10–12] Unfortunately, this inequality in the care of autistic individuals, and particularly for Black children, is also observed in the context of genetic screening and counseling.[13] Overall, approximately two-thirds of autistic children receive some form of genetic screening and/or counseling; however, Black children are much less likely than their White peers to be offered these services.[13] The majority of parents of autistic children actually favor the use of genetic screening and counseling because they believe that the increased knowledge empowers and helps them to intervene earlier than they might have otherwise.[14]

Our goal is to increase awareness regarding the importance and utility of genetic screening and counseling in the lives of autistic individuals and their families. Novel intervention strategies need to be implemented to improve access to such services so that autistic people can be empowered to make informed decisions surrounding the lifestyle interventions and care they wish to pursue.

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Addressing the Intersectionality of Race and Disability to Improve Autism Care

Elizabeth H. Morgan, PhD, EdM,[a,b] Rylin Rodgers, BA,[c] John Tschida, MPP[c]

"We must do the work that justice and equality calls us to do."– John Lewis.

We write this article to (1) summarize intersectionality, (2) consider implications of intersectionality for Black, Indigenous, people of color (BIPOC) autistic communities, and (3) provide a call to action for disability researchers and organizations to foster and maintain an intersectional lens. The authors, who identify as disabled persons and family members of autistic people, seek to show how intersectionality affects the work of researchers and disability organization leaders.

INTERSECTIONALITY OF RACE AND DISABILITY

Intersectionality, coined by Kimberlé Crenshaw, describes the complex and multidimensional social phenomenon of double oppression that Black women experience in the United States.[1] The term has expanded to include interlocking aspects of identity as it relates to race and disability. To have a Black, Brown, and disabled body in the United States is to be connected to a history saturated in oppressive and discriminatory treatment. The sociohistorical relationship between race and disability perpetuates inequalities that impact Black and Brown disabled people and thus lead to overrepresentation in disability categories associated with more restrictive environments.[2] Disparities in the diagnosis and treatment of autism in children in the BIPOC communities has resulted in later identification and higher misdiagnosis rates. Black and Brown children are less likely to be identified for autism spectrum disorder by either a qualified health or educational professional.[3,4]

In 2021, we see the conversation about race and its intersections with disability as overdue, dynamic, and urgent because of a failure to address systemic barriers to progress. We recognize the Civil Rights movement and the Women's Liberation movement as the inspiration for the Disability Rights movement. These distinct forces served as the foundation for the coalitions that supported the disability community's 1977 San Francisco Federal Building sit-ins, which led to the enactment of Section 504 regulations.[5] With current movements such as "Black Lives Matter" and "Say Her Name" demanding an end of police violence

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[a]*Center for Excellence in Developmental Disabilities at the UC Davis MIND Institute, University of California Davis, Davis, California;* [b]*College of Education, Doctorate in Educational Leadership Program, California State University Sacramento, Sacramento, California; and* [c]*Association of University Centers in Disabilities, Silver Springs, Maryland*

Dr Morgan served as the lead author and drafted and provided critical revisions of the article; Ms Rodgers wrote sections of the article and provided policy content knowledge for the development of the publication; Mr Tschida wrote sections of the article and helped with editing drafts of the document; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Elizabeth Holliday Morgan, University of California Davis, Center for Excellence in Developmental Disabilities at the MIND Institute, 2825 50th St, Sacramento, CA 95817. E-mail: emorgan@ucdavis.edu

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against Black and Brown bodies, we see the cyclical connection to progress as we see these movements growing to include the lives of autistic BIPOC.

CALL FOR ACTION

This is the time for continual improvement through the amelioration of research priorities, system design considerations, and for individual and group education inside and outside our laboratories and organizations. The work is not that of the affected communities alone. Racism and ableism harm all communities. However, the voices, needs, and wants of autistic BIPOC communities must be prioritized as we seek to move forward to create projects and programs that address complex issues associated with race and disability. We must use an intersectional paradigm to acknowledge the sociohistorical roots of race and disability and acknowledge our own contributions in perpetuating systems that have maintained unequal scales by taking the social justice steps need to undo harm in our work. This includes, but is not limited to, disability researchers and organizations elevating the voice of autistic BIPOC, which includes prioritizing funding for self-advocate researchers and leadership staff. This also includes the intentional incorporation and citation of autistic scholars and disabled scholars of color in all program design and research projects. The change will be incremental but will address health inequities and better support individuals and families from our autistic BIPOC communities.

ABBREVIATION

BIPOC: Black, Indigenous, people of color

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First Do No Harm: Suggestions Regarding Respectful Autism Language

Patrick Dwyer, MA,[a,b] Jacalyn G Ryan, MA, CPA, CMA,[c] Zachary J Williams, BS,[d,e,f,g] Dena L Gassner, MSW[h,i]

Nationally and internationally, efforts are ongoing to promote diversity, equity, and inclusion in healthcare and other fields. These efforts require consideration of ways in which language and assumptions impact individuals and communities. The autism and disability spheres are no exception. Indeed, the mental health of autistic people is predicted by the degree to which they feel society accepts them as autistic.[1] Thus, we believe discourse that disparages autism could be harmful to autistic people's well-being. Autistic individuals who face further stigma and discrimination due to other intersectional identities might be particularly vulnerable. Unfortunately, autism research and practice have traditionally used disparaging language grounded in the medical model.

Some might object that alternatives to traditional medical model terms are subjective or unscientific. However, we believe traditional terminology is heavily laden with subjective value judgements. For example, the traditional term "disorder" has a decidedly negative connotation. It also implies that individuals' own characteristics are responsible for their challenges, and it suggests a need to eliminate this disorder. In contrast, the more nuanced word "disability" allows both individual characteristics and societal or contextual barriers to contribute to challenges. The term disability thus appears to be both more scientifically appropriate and less stigmatizing toward a vulnerable population than disorder.

In Table 1, we list various traditional terms and concepts that we believe are problematic, along with suggested replacements. We also suggest that practitioners and researchers balance a focus on autistic individuals' challenges with discussion of their strengths and potential. This balanced approach may be especially important for families of young children whose futures may be unclear and a source of considerable anxiety to caregivers.

Furthermore, researchers and practitioners should be aware of an

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[a]Center for Mind and Brain, and [b]Department of Psychology, University of California Davis, Davis, California; [c]Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada; [d]Medical Scientist Training Program, Vanderbilt University School of Medicine, Nashville, Tennessee; [e]Department of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville, Tennessee; [f]Vanderbilt Brain Institute, and [g]Frist Center for Autism and Innovation, Vanderbilt University, Nashville, Tennessee; [h]School of Social Work, Adelphi University, Garden City, New York; and [i]Department of Health Sciences, Towson University, Towson, Maryland

Mr Dwyer contributed to the conception of the commentary and wrote an initial draft of this commentary; Ms Ryan, Mr Williams, and Ms Gassner contributed to the conception of the commentary, and reviewed, revised, and edited the manuscript; and all authors approved the final submitted text and agree to be accountable for all aspects of the work.

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Address correspondence to Patrick Dwyer, MA, 267 Cousteau Place, Davis, CA 95618. E-mail: psdwyer@ucdavis.edu

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TABLE 1 Traditional Terms, Concepts, and Ideas, Along With Suggested Alternatives.

Traditional Terms, Concepts, and Ideas	Suggested Alternatives
Disorder	Disability
Autism spectrum disorder	Autism, autism spectrum development, autism spectrum disability
Deficit	Area of challenge, difficulty
Autism symptoms	Autism characteristics, traits, features
Red flags for autism	Signs or indicators of possible autism
Problem behavior or challenging behavior	Distressed behavior, meltdown, more specific description of the behavior (e.g., self-injury, destruction of property)
Restricted interests	Focused, intense interests
Comorbid	Co-occurring
Risk[a]	Likelihood, probability
Risk factor[a]	Predictive factor, predictor, correlate
Healthy controls	Typically-developing or neurotypical (if screened for other diagnoses), non-autistic (if only autism ruled out), or general population (autism not ruled out, group not sampled with regard to autism status) controls
High-functioning or low-functioning autism, severe autism or severity of autism	Descriptions of relevant individual characteristics (eg, autistic person with or without intellectual disability or language impairment) Descriptions of support needs, grounded in specific contexts (as needs vary across contexts)
Prevention of autism; treatments focused on reducing autism symptoms and on promoting recovery, normalization, and "optimal outcomes"	Interventions and supports aimed at curing or preventing co-occurring medical problems (not autism itself), at teaching adaptive skills to individuals, at making environments accessible, and at promoting quality of life or well-being or thriving
Rigid, inflexible	Consider: in any particular instance, is it the autistic individual, the environment around them, or both that is or are inflexible?

[a] Only problematic when applied to autism; may be appropriate for many co-occurring conditions.

ongoing debate between supporters of identity-first ("autistic person") and person-first ("person with autism") language. Many autistic individuals support identity-first language[2,3] and some fear that person-first language reflects negative attitudes toward autism.[4] However, others endorse person-first language.[2,3] The term "person on the autism spectrum" is often the most preferred term among autistic individuals and other stakeholder groups,[2,3] and this verbiage is typically found to be acceptable by proponents of both person-first and identity-first language. Practitioners should ask about and respect the language preferences of individuals "on the spectrum" who can articulate their views.

Overall, in light of concerns that typically-developing people struggle to understand autistic perspectives,[5] we urge practitioners and researchers to strive to have empathy for how their language sounds to autistic people. We also suggest it can often be helpful to ask oneself if one would use similar phrasing with other marginalized communities. We feel that there needs to be a shift toward "cultural humility" and willingness to learn from autistic people about autistic identities and how to promote autistic well-being.

Practitioners and researchers interested in a more detailed discussion of appropriate autism terminology should refer to Bottema-Beutel and colleagues.[6] We provide definitions of neurodiversity terminology (eg, neurodiverse, neurodivergent) in Supplemental Table 2.

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Supplemental Information

SUPPLEMENTAL TABLE 2 Definitions of Neurodiversity Terms and Concepts

Term	Definition
Neurodiversity	Noun. The wide variety of different minds and brains found throughout the human population.
Neurodiverse	1. Adjective. Having a variety of different minds and brains. Can be applied to any group of people, including groups of neurotypical people, insofar as no two people have exactly the same mind and brain. Does not apply to individuals. 2. Adjective. Used as a synonym of "neurodivergent." This usage is widespread in the community but is not recommended by experts who point out a singular individual cannot be "diverse."[7,8]
Neurodivergent	Adjective. Having a mind or brain that differs from what is socioculturally normative in ways that can be associated with disability. Can be applied to individuals or groups. Not specific to autism (also includes intellectual disability, ADHD, etc.).
Neurotypical	1. Adjective. Typically-developing: having a mind or brain that falls within sociocultural standards of what is normal or normative and that is not associated with disability. Can be applied to individuals or groups. 2. Noun. An individual who is neurotypical.
Neurotype	Noun. A group or class of individuals whose minds and brains are sufficiently similar to be considered a category or type.
Neurominority	Noun. A neurotype whose members' minds or brains differ from what is socioculturally typical and normative in ways that are associated with disability. Autism is only one example (others are intellectual disability, ADHD, etc.).
Neurodivergence	Noun. The quality of being neurodivergent.
Neurodiversity movement	Noun. A political movement that opposes cures for and normalization of autism and various other neurominorities (but not neurominorities that are considered medical conditions or diseases, such as epilepsy). The movement advocates for acceptance, supports, and promotion of quality of life.
Neurodiversity approach or paradigm or framework	Noun. A perspective on neurodiversity that values variation in human minds/brains and does not privilege any one neurotype.

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Autism and COVID-19

Priyanka Fernandes, MBBS, MPH, Hannah Kwak, MD, MPH

The coronavirus disease 2019 (COVID-19) pandemic has widened existing inequities faced by autistic individuals. The unprecedented medical, social, educational, and economic upheaval has highlighted the diverse physical health needs of autistic individuals and the importance of addressing these with a life-course approach using multisectoral and policy solutions driven by advocates and self-advocates in the community.

Autistic individuals in congregate and group settings, with co-occurring medical conditions are at higher risk for contracting COVID-19 and poor health outcomes.[1,2] Wide variations in state vaccine prioritization plans exist, where high-risk disabled populations are not considered high priority.[3] Access to routine medical visits has been disrupted during surges in cases, leading to potential delays in accessing necessary diagnoses, treatments and services.[4] Emergency preparedness plans often overlook the needs of autistic individuals; for example, the use of the frailty scale to ration care, which unfairly disadvantages autistic individuals.[1]

Social isolation has negative effects on the well-being of autistic individuals who have lost their routine social interactions and support.[1] In children, loneliness has been associated with challenging behaviors, worsening mental health, and long-lasting effects into adulthood.[5]

The disruption to learning has been particularly concerning for children with special educational needs.[6] Families have reported greater difficulty accessing therapies and services for autistic children and regression in previously attained skills.[7] Because of lack of existing standards, the quality of remote therapies and learning is highly variable. Economically disadvantaged children face an additional burden of poor access to technology and stable internet.[6] Several autistic children and adults have consistently advocated for availability of virtual learning platforms but have only just benefitted now that these are widely available.[1]

Autistic adults and their families are vulnerable to economic instability and the downstream health implications brought about by the pandemic. Even before the pandemic, autistic adults had the lowest rate of employment among those with disabilities.[8] Due to remote schooling during the pandemic, parents may have to forgo their employment to care for their children.[1]

The COVID-19 pandemic has highlighted areas that need urgent attention in the community. Autistic individuals, particularly those at high-risk for COVID-19-related hospitalizations and deaths, should be prioritized to receive the COVID-19 vaccine.[9] In promoting equitable access to the vaccine, the focus must be on dissemination of accurate and timely information, creating easily navigable systems and ensuring vaccine confidence. Autistic individuals must be represented in infection control and emergency preparedness planning at multiple levels: for example, within schools, health care settings, residential facilities, etc. Prolonged and unexpected disruptions to

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Department of Medicine; University of California, Los Angeles, Los Angeles, California

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Address correspondence to Priyanka Fernandes, MBBS, MPH, 911 Broxton Avenue, Los Angeles, CA 90024. E-mail: pfernandes@mednet.ucla.edu

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health, educational, and behavioral service deliveries during occurrences such as the COVID-19 pandemic must be met with innovative solutions to maximize individual life-course trajectories. Leveraging the virtual environment may be beneficial to some (eg, telehealth and remote learning), while technological innovations (eg, mRNA vaccines and point-of-care testing) could safeguard in-person service delivery for others. Financial stability of affected individuals should be addressed through the provision of economic relief packages, uninterrupted health care and/or unemployment insurance. It is imperative we take immediate action to accommodate autistic children and adults at all levels in our society and close existing inequities.

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Promoting Interdisciplinary and Participatory Autism Research

Kashia A. Rosenau, PhD, Emily Hotez, PhD

The Autism Intervention Research Network on Physical Health (AIR-P) has a strong emphasis on cultivating the next generation of researchers committed to promoting the health and well-being of autistic individuals across the lifespan. As we begin our roles as scientists on this ambitious project, we are confronted with the tension between aspects of research culture that are both progressive and dynamic and outdated and static, particularly in the autism field. As we reflect on the current state of the field, we increasingly recognize the importance of conducting interdisciplinary research and using participatory methods to ensure that our research will enhance health outcomes for autistic individuals.

INTERDISCIPLINARY APPROACHES IN AUTISM RESEARCH

Throughout our short careers, it has become readily apparent that the research community recognizes, at least in name, the value of working on diverse interdisciplinary teams, particularly with respect to addressing complex public health issues.[1] We are acutely aware, however, of traditional research culture wherein mentors have historically encouraged trainees to master a single focal area and protect it as their own.[2] In effect, we continuously experience conflicting messages. On one hand, we are urged to identify a narrow area of expertise, pursue it with fervor, and work to establish our independence as researchers. On the other hand, our experience in autism research requires us to approach complex problems from multiple angles, cultivate a vast array of methodological and theoretical tools, and cull together diverse teams.

We believe that an interdisciplinary approach to research is an asset to early-career investigators' professional development and to the field. We urge mentors to encourage early-career investigators to learn from peers in other fields, even those that do not, at face value, appear complementary. In practice, autism researchers would collaborate with physicians and clinicians, social justice advocates, educators, and other leaders and stakeholders. We believe that these collaborations will promote out-of-the-box thinking and dismantle antiquated models that do not further the development of innovative, health-promoting research for autistic individuals.

PARTICIPATORY METHODS IN AUTISM RESEARCH

Researchers underscore the critical role of participatory methods for autistic individuals.[3] However, a pervasive undervaluing of the role of lived experiences still exists in shaping research questions and methodologies, which translates into an additive approach wherein the stakeholder perspective is layered on top of the empirical research study rather than sought out at the beginning to inform the research process in a meaningful way. When participatory methodologies are secondary to the research study, researchers often position those

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David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, California

Dr Rosenau led the development of this commentary; Dr Hotez contributed to the conceptual development and drafting of this commentary; and both authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Kashia A. Rosenau, PhD, University of California Los Angeles, 911 Broxton Avenue, Los Angeles, CA 90024. E-mail: k.rose@ucla.edu

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with lived experience in tokenistic roles that do an injustice to their perspectives in the research process.

One of the earliest developments within the AIR-P is the Autistic Researcher Review Board. This group of international autistic researchers is tasked with reviewing all studies that will be supported within the AIR-P and developing collaborative theoretical articles and empirical research studies that will advance the field. As the neurodiversity movement continues to gain traction and individuals with neurodivergence continue to serve as self-advocates and assume prominent leadership positions, we hope that participatory research becomes the status quo in autism research.

FUTURE DIRECTIONS

We call on our peers, early-career investigators, as well as colleagues steeped in traditional research culture, to join us in placing a precedent on moving the field of autism research forward through interdisciplinary and participatory approaches. We look forward to collaborating with novices and experts across disciplines in developing and implementing research that is directly responsive to lived experiences in an effort to address our broader goal of having a robust impact on the health and well-being of autistic individuals across the lifespan.

ABBREVIATION

AIR-P: Autism Intervention Research Network on Physical Health

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Barriers to Inclusive Learning for Autistic Individuals

TC Waisman, EdD,[a] Laura A. Alba, MS, MA,[b] Shulamite A. Green, PhD[c]

Elementary and higher education policies developed by autistic experts and founded on research can fundamentally enhance the accessibility of the learning environment for autistic students throughout their educational career. Although autistic students have the potential to perform successfully academically, one major barrier to their success is that the educational environment is filled with anxiety-provoking sensory input. We call on educational institutions to do more to positively affect the outcomes for autistic students and those with sensory modulation challenges by reducing sensory-related barriers to learning in higher education. In particular, we call on higher education institutions to consider the myriad barriers that autistic students encounter at this stage of their education and the sudden, inherent lack of support and understanding once they leave the secondary education environment. Sensory modulation challenges experienced in primary and secondary education environments do not disappear in tertiary education settings.

Sensory modulation challenges are commonly associated with autism and are an important barrier to quality of life.[1] Recently, hypo- and hyper-reactivity to sensory stimuli have been outlined in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, criteria for autism and have brought increased attention to the individual sensory challenges in this population.[2] Researchers have begun to provide insight into the biological mechanisms underlying sensory modulation challenges, with a focus on sensory hyper-responsivity. Neuroimaging studies have shown that during exposure to aversive sensory stimulation, sensory hyper-responsivity in autistic youth is associated with reduced habituation in brain regions associated with attention, salience, and threat response.[3,4] Autistic youth with lower hyper-responsivity also show atypically high prefrontal downregulation of the amygdala, which suggests that they are exerting extra effort to avoid behavioral sensory responses, including irritability, meltdowns, and covering ears.[3,4] Elevated physiologic responses, such as heart rate, to aversive sensory stimuli have also been found among autistic individuals,[5] indicating that heightened arousal may explain the high co-occurrence between anxiety and sensory hyper-responsivity.[6] Thus, emerging understanding about the biological mechanisms underlying sensory modulation challenges supports the idea that sensory hyper-responsivity is distracting, exhausting, and anxiety provoking.

Higher education environments are composed of competing sensory inputs, including bright lights, the classroom layout, loud gathering areas, and bombardment of smells. Autistic and non-autistic college students report heightened sensory reactivity to higher education environments.[7] However, autistic students report that the lack of respite from sensory input is a barrier to learning that often triggers stress and anxiety and even leads to

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[a]University of Calgary, Calgary, Alberta, Canada; [b]Graduate School of Education, University of California, Riverside, Riverside, California; and [c]University of California, Los Angeles, Los Angeles, California

Dr Waisman wrote the initial manuscript on the basis of their area of expertise; Ms Alba and Dr Green provided input on the basis of their areas of expertise and edited the initial manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to TC Waisman, EdD, University of Calgary, Calgary, Alberta, Canada. E-mail: teresia.waisman@ucalgary.ca

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an inability to continue pursuing higher education.[7] In response, a recent study with autistic participants in Canadian universities showed that 78% who completed interviews and 87% who completed questionnaires reported experiencing sensory barriers in their classrooms, hallways, and campus grounds that directly affected their learning.[8] Researchers, faculty, and staff have reported recognizing that sensory barriers have an impact on students' educational outcomes and understanding the importance of accommodating the physical environment to provide accessible learning.[7,9] Although faculty, staff, and students in higher education generally agree on the importance of reducing disabling sensory barriers to learning for autistic students, more needs to be done to improve the sensory environment and promote inclusivity. An added effect of an improved sensory environment in tertiary education is the development of innovations for the elementary and secondary school environments. For example, Bellevue College's Neurodiversity Navigators aim to create inclusive environments for autistic students and neurodivergence by providing resources for them and educating faculty about supporting these students' neurologic differences. Similarly, Landmark College is specifically designed to create a space for autistic and neurodivergent students that provides therapeutic supports, including service animals that respond to sensory barriers affecting students' learning.

Autistic experts and sensory processing researchers can help to inform simple, cost-effective policies to remedy these challenges, such as offering various sensory choices in classrooms, routinely dimming or turning off lights in designated areas, and allowing autistic students to reserve seats where there are fewer sensory challenges. Outside the classroom, universities and colleges can offer areas of respite on campus, such as quiet zones. They can also educate the student body and faculty about supporting the learning of students with sensory processing challenges. Colleges and universities have the opportunity to be innovative in their policies and practices and include autistic students and sensory challenges in creating evidenced-based, inclusive environments that support learning with reduced anxiety and feelings of sensory overload.

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Hospital Inpatient Stays for Autistic Youth and Youth With Other Disabilities

Jessica E. Rast, MPH,[a] Anne M. Roux, MPH, MA,[a] Sherira J. Fernandes, PhD, NCSP,[a] Vera D'Silva, BSN, RN-BC,[b] Lindsay L. Shea, DrPH, MS[a]

abstract

BACKGROUND: Addressing health care needs is complex in autistic youth for many reasons. Increased inpatient care that has been noted in this population, particularly for ambulatory care sensitive conditions (ACSCs), may be a marker of inadequate primary and outpatient care.

METHODS: This study used data from hospital inpatient discharges from the National Inpatient Sample 2017. The prevalence, average length of stay, and the average cost per day of the 10 most common principal diagnoses for index stay were calculated for autistic youth and youth with mental, behavioral, and other neurodevelopmental disabilities (MBND), ages 0 to 17.

RESULTS: Of every 1000 inpatient stays, 7.3 were for autistic youth and 65.2 for youth with MBND. The rate varied by US region and zip code-level household income. The most common diagnosis associated with stays in autistic youth was mood disorders, as in youth with MBND. Nearly all top 10 principal diagnoses for autistic youth were for ACSCs. The highest average cost per day for autistic youth was for physical injuries ($4320 per day), and the longest stays were for schizophrenia (14 days).

CONCLUSIONS: High occurrence of ACSCs in autistic youth suggests that primary care may not adequately address health and mental health needs. Clinical complexity and autism characteristics may be impacting care received in the hospital. Additional considerations need to explore and examine care complexity, racial and ethnic disparities, and the large portion of Medicaid-covered youth. Strategies for the provision of care to these vulnerable populations are of great concern.

[a]AJ Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania; and [b]Robert Wood Johnson Barnabas Health Monmouth Medical Center, Children's Crisis Intervention Services, Long Branch, New Jersey

Ms Rast conceptualized and designed the study, drafted the manuscript, conducted analysis, and finalized the manuscript; Ms Roux contributed to the manuscript preparation and revisions; Drs Fernandes and Shea and Ms D'Silva contributed content expertise for interpretation and discussion of the findings and contributed to revisions; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Jessica Rast, MPH, AJ Drexel Autism Institute, Drexel University, 3020 Market Street, Suite 560, Philadelphia, PA 19104. E-mail: jer336@drexel.edu

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WHAT'S KNOWN ON THIS SUBJECT Autistic youth may have more and longer inpatient hospitalizations than their peers. Limited existing evidence suggests more expensive care for autistic youth and more hospitalizations for mental health or neurologic conditions than their peers.

WHAT THIS STUDY ADDS Mental health and other ambulatory care sensitive conditions were among the most common reasons for hospitalization in autistic youth. Stays for mental health conditions were among the longest. Comprehensive primary and outpatient care may reduce hospitalizations for these conditions.

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SUPPLEMENT ARTICLE

Health is an integral component of quality of life, yet optimal health and adequate health care are difficult to attain in autistic youth. Addressing health care needs is complex in autistic youth because the co-occurrence of health and mental health conditions is common.[1] This is compounded by emergent psychiatric diagnoses in early adult years, the need to see multiple providers for multiple conditions, the use of polypharmacy, and the need for mental health services and supports.[2,3] The complexity of care makes health and mental health crises that require emergency care more likely. This is evidenced by more inpatient hospitalizations in autistic youth than their same-age peers and stays that are longer, more expensive, and more likely related to mental health or neurologic conditions.[4,5]

Enhanced usage of inpatient care is a marker of inadequate primary care and management of autism and other conditions,[6] particularly hospitalizations for conditions that can be prevented or treated in primary or outpatient care, referred to as ambulatory care sensitive conditions (ACSCs). Hospitalizations for ACSCs can be reduced or avoided by comprehensive primary care addressing prevention and management. ACSCs include diabetes and related complications, hypertension, urinary tract infections, asthma, and epilepsy. Increasingly, mental health conditions are considered ACSCs.[7,8] Specific aspects of autism may impact the complexity of delivering adequate care, including communication challenges, difficulties with executive functioning that impact care schedules, sensory challenges in care settings, and communication of emotion or sensation. The willingness and ability of practices to provide accommodations for neurodivergent patients impact care quality.

The goal of this study is to examine characteristics of inpatient hospital stays for autistic youth and compare them with youth with other mental, behavioral, or neurodevelopmental disabilities (MBND). The aims are to (1) present demographic and inpatient stay characteristics of autistic youth and MBND youth, (2) examine the most common reasons for inpatient hospitalizations, and (3) describe the cost and length of inpatient stays among autistic youth and MBND youth. This research builds on existing literature to underscore the need to prioritize policies and programs that incentivize treatment of ACSCs to prevent unnecessary hospitalizations.

METHODS

This study used data from hospital inpatient discharges from the Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality National Inpatient Sample (NIS) 2017.[9] The NIS is a representative sample of an all-payer database of US hospital inpatient stays. NIS 2017 captured >7 million stays from 47 states plus the District of Columbia, covering 97% of the US population, excluding rehabilitation and long-term acute care hospitals.

Study Population

Patients ages 0 to 17 were included in this study. Index stays may record up to 40 diagnostic codes by using the *International Classification of Diseases, 10th Revision, Clinical Modification* (ICD-10-CM). Autistic youth were captured by codes F84.0, F84.5, or F84.9 in any position in the record. Patient demographic characteristics including age, race, and sex are captured by administrative hospital data. The inclusion of race is important in acknowledging and addressing racial and ethnic health disparities.

The MBND comparison group was created by using Clinical Classifications Software Refined (CCSR) for ICD-10-CM-coded diagnoses version 2020.3, housed and curated by HCUP. CCSR aggregates ICD-10-CM diagnosis codes into smaller, clinically meaningful categories that generally align with ICD-10-CM diagnosis chapters. The CCSR body system for MBNDs includes 32 subcategories, 1 of which includes autism. The MBND comparison group was created by using all 32 subcategories, excluding stays with autism in any diagnosis position, which generally correspond to ICD-10-CM codes beginning with "F."

Charge and Cost

The NIS contains information on the total charge for each stay. Costs were calculated by using hospital-specific charge-to-cost ratios provided by HCUP generated on the basis of information collected by the Centers for Medicare and Medicaid Services. Costs were then evaluated for outliers and Winsorization was used to censor the distribution at the first and 99th percentiles to reduce variability at the ends of the distribution.

Statistical Analysis

Index stay demographic and stay characteristics were compared between autistic youth and youth with MBND. Significant differences between groups were assessed by using logistic regression, as appropriate for complex survey data. The principal diagnosis is often considered the primary reason for hospitalization. The prevalence of the 10 most common principal diagnoses for index stay, categorized by using the CCSR taxonomy, were calculated for autistic youth and MBND youth.

When appropriate for interpretation, CCSR categories were combined to create categories such as mood disorders, physical injury, stomach or intestinal diseases, and pregnancy. For the 10 most common principal diagnoses in the autism group, the average length of stay and cost per day were calculated in the autism and MBND groups. Analysis was conducted by using Stata 16 to account for the complex survey design.

RESULTS

In 2017, autistic youth had 40 000 inpatient stays and MBND youth had 350 000. Autistic youth were younger, more often male, White, from zip codes with higher median household incomes, and from the Northeast (Table 1). The mean cost per day was $400 higher in autistic youth than youth with MBND although the total cost per stay was $900 lower.

Of every 1000 stays, 7.3 were for autistic youth and 65.2 were for youth with MBND. The rate of autism stays was higher in zip codes with higher median household incomes: 6.7 per 1000 in zip codes in the 0 to 25th percentile compared to 7.9 per 1000 in zip codes in the 76th to 100th percentile. This was a reverse of the trend for MBND: 66.2 per 1000 in zip codes in the 0 to 25th percentile compared to 62.5 per 1000 in zip codes in the 76th to 100th percentile. Rates differed by region for autistic youth, with higher rates in the Northeast (10.1 per 1000) and Midwest (8.3) than the South (6.9) and West (5.3). The highest rates of MBND stays were in the Midwest (88.5 per 1000), versus Northeast (66.5), South (63.5), and West (45.6).

TABLE 1 Patient Demographic Characteristics and Stay Characteristics for Autistic Youth and MBND Youth

	Autism, *n* = 7890	MBND, *n* = 70 150
Weighted number of stays	39 450	350 760
Patient demographic characteristics		
Age at admission, mean (SE)	10.8 (0.1)	12.2 (0.1)**
Male, % (SE)	75.8 (0.5)	43.0 (0.4)**
Race, % (SE)		
White	61.8 (1.4)	56.4 (1.2)**
Black	13.7 (0.7)	17.8 (0.7)**
Hispanic	16.4 (1.2)	17.6 (1.2)
Asian or Pacific Islander	2.5 (0.3)	2.3 (0.2)
Native American	0.4 (0.1)	1.1 (0.2)**
Other	5.1 (0.5)	4.9 (0.3)
Median household income for patient's ZIP code, based on current year, % (SE)		
0 to 25th percentile	26.7 (1.0)	29.8 (1.0)**
26th to 50th percentile (median)	27.0 (0.8)	26.3 (0.6)
51st to 75th percentile	23.6 (0.7)	23.7 (0.5)
76th to 100th percentile	22.8 (1.1)	20.2 (0.9)**
Region, % (SE)	—	—
Northeast	22.5 (2.4)	16.6 (1.7)**
Midwest	24.4 (2.7)	29.4 (2.5)**
South	36.4 (2.8)	37.7 (2.6)
West	16.7 (2.4)	16.3 (2.0)
Stay characteristics		
Mean length of stay, d (SE)	5.6 (0.2)	6.5 (0.2)
Mean cost per stay, $ (SE)	10 910 (420)	11 800 (480)*
Mean cost per day, $ (SE)	2810 (110)	2380 (90)**
Emergency department use either via admission or during stay, % (SE)	49.6 (1.4)	47.6 (1.4)
Weekend admission, % (SE)	18.2 (0.5)	17.8 (0.2)
Elective admission, % (SE)	23.0 (1.3)	18.0 (1.0)**
Primary expected payer, % (SE)		
Medicare	0.3 (0.1)	0.3 (0.0)
Medicaid	54.3 (1.1)	54.5 (0.9)
Private insurance	39.8 (1.0)	39.7 (0.9)
Other	5.6 (0.6)	5.6 (0.4)
Number of ICD 10 codes entered into stay record, mean (SD)	7.8 (0.1)	8.0 (0.2)
Disposition at discharge, % (SE)		
Routine	92.4 (0.5)	88.0 (0.5)**
Transfer to short-term or other care	4.9 (0.4)	8.5 (0.4)**
Other, home health care, against medical advice, died, discharge destination unknown	2.8 (0.3)	3.5 (0.2)*

Regions are composed of the following states: Northeast ME, NH, VT, MA, RI, CT, NY, NJ, and PA; Midwest OH, IN, IL, MI, WI, MN, IA, MO, ND, SD, NE, and KS; South DE, MD, DC, VA, WV, NC, SC, GA, FL, KY, TN, AL, MS, AR, LA, OK, and TX; and West MT, ID, WY, CO, NM, AZ, UT, NV, WA, OR, CA, AK, and HI.

*$P > .01$; **$P > .001$.

The most common principal diagnosis in autistic youth was mood disorders, as in youth with MBND (Table 2). All top 10 principal diagnoses for autistic youth were ACSCs with exception of physical injuries. Three non-ACSC conditions were on the top 10 list for MBND: physical injury, pregnancy, and antineoplastic therapies.

Figure 1 examines the cost per day and length of stay for the 10 most common principal diagnoses in autistic youth compared with youth with MBND. Many conditions were similar in cost and length of stay for autistic youth and MBND youth. Physical injuries resulted in longer stays for youth with MDNB, whereas schizophrenia resulted in longer stays for autistic youth. The highest average cost per day for autistic

TABLE 2 Prevalence of the Most Common Principal Diagnoses for Index Stay for Autistic Youth and MBND Youth

Principal diagnosis	Percentage	SE
Autism		
Mood disorders	15.5	1.2
Epilepsy; convulsions	13.2	0.8
Autism spectrum disorder	7.3	0.7
Stomach or intestinal diseases (excludes appendicitis and hepatic diseases)	6.7	0.3
Disruptive, impulse-control, and conduct disorders	4.3	0.7
Physical injury	4.0	0.2
Asthma	3.1	0.3
Fluid and electrolyte disorders	2.4	0.2
Pneumonia (except that caused by tuberculosis)	2.1	0.2
Schizophrenia spectrum and other psychotic disorders	1.7	0.2
MBND		
Mood disorders	34.8	1.8
Suicidal ideation/attempt/intentional self-harm	5.1	0.2
Epilepsy; convulsions	5.0	0.3
Physical injury	4.8	0.2
Trauma- and stressor-related disorders	3.7	0.3
Stomach or intestinal diseases (excludes appendicitis and hepatic diseases)	2.9	0.1
Disruptive, impulse-control, and conduct disorders	2.6	0.3
Pregnancy, childbirth, and the puerperium	1.9	0.1
Encounter for antineoplastic therapies (anticancer)	1.6	0.1
Diabetes mellitus with and without complications	1.6	0.1

youth was for physical injuries ($4320 per day) followed by epilepsy ($3480 per day).

DISCUSSION

This study found a high rate of admissions for ACSCs for autistic youth. ASCSs were some of the longest (schizophrenia) and most expensive (epilepsy) stays. The high rates of ASCSs suggest that primary and specialty outpatient care may not currently adequately address the health and mental health needs of autistic youth. More than half of the ACSCs identified in autistic youth were related to mental health concerns. Escalation of health and mental health concerns are likely impacted by the management of mental health issues.

The long length of stay for schizophrenia, disruptive, impulse-control and conduct disorders, and mood disorders is also of note. Clinical complexity and high rates of condition cooccurrence are likely drivers of this finding. We lack evidence for effectively treating many disabilities when they cooccur, especially for autistic youth. In addition, the natural course of the development and experience of co-occurring conditions may result in changing levels of service needs over time. Although this study begins to describe cooccurrence of diagnoses in autistic youth, more research is needed to understand the rate and mechanisms of cooccurrence with the ultimate goal of expediting bench-to-bedside practice to improve care. Autism characteristics may also be related to longer stays; acclimation to a new setting, disruptions of routine, and lack of familiarity may result in emotional or violent behavior, adding complexity to the stay that results in additional days and even use of restraints. Hospital settings and staff that do not understand or accommodate neurodivergent patients will be limited in the quality of care they can provide. The difference in admission rates by region and income also highlight areas of concern for adequate treatment of ACSCs within primary care settings.

Two other considerations are illuminated by these findings. First, racial and ethnic disparities need to be investigated further, as does the higher rate of Black MBND versus Black autistic youth admissions. Racial and ethnic minority autistic youth are more often misdiagnosed and underdiagnosed than White youth, and behaviors associated with autism may be misinterpreted.[10] Concerns of misattribution of autism characteristics may lead to more use of restraint, longer stays, and more inaccurate diagnoses associated with behavioral issues such as violence in autistic Black children. Second, Medicaid was the majority primary expected payer in autistic youth inpatient stays. This group likely faces multiple contributing factors that exacerbate health issues and barriers to getting needed care, including poverty and disability among other social determinants of health, including race. How care is provided to these vulnerable populations is of great concern.

Although the NIS provides a national snapshot of inpatient hospitalizations in a given year, the following limitations are important to consider. The use of principal diagnosis allows for a convenient way to study the reason for admission, but it likely differs by diagnosis, location, provider, and insurer, as diagnostic coding influences reimbursement. We also did not explore the clustering of diagnoses that might be related to certain reasons for admission, nor variation by race, ethnicity, sex, or other important social determinants of health. However, the NIS provides an unparalleled opportunity to examine all-payer inpatient hospitalizations in autistic youth in the United States. These findings provide new insight into the health care of this population,

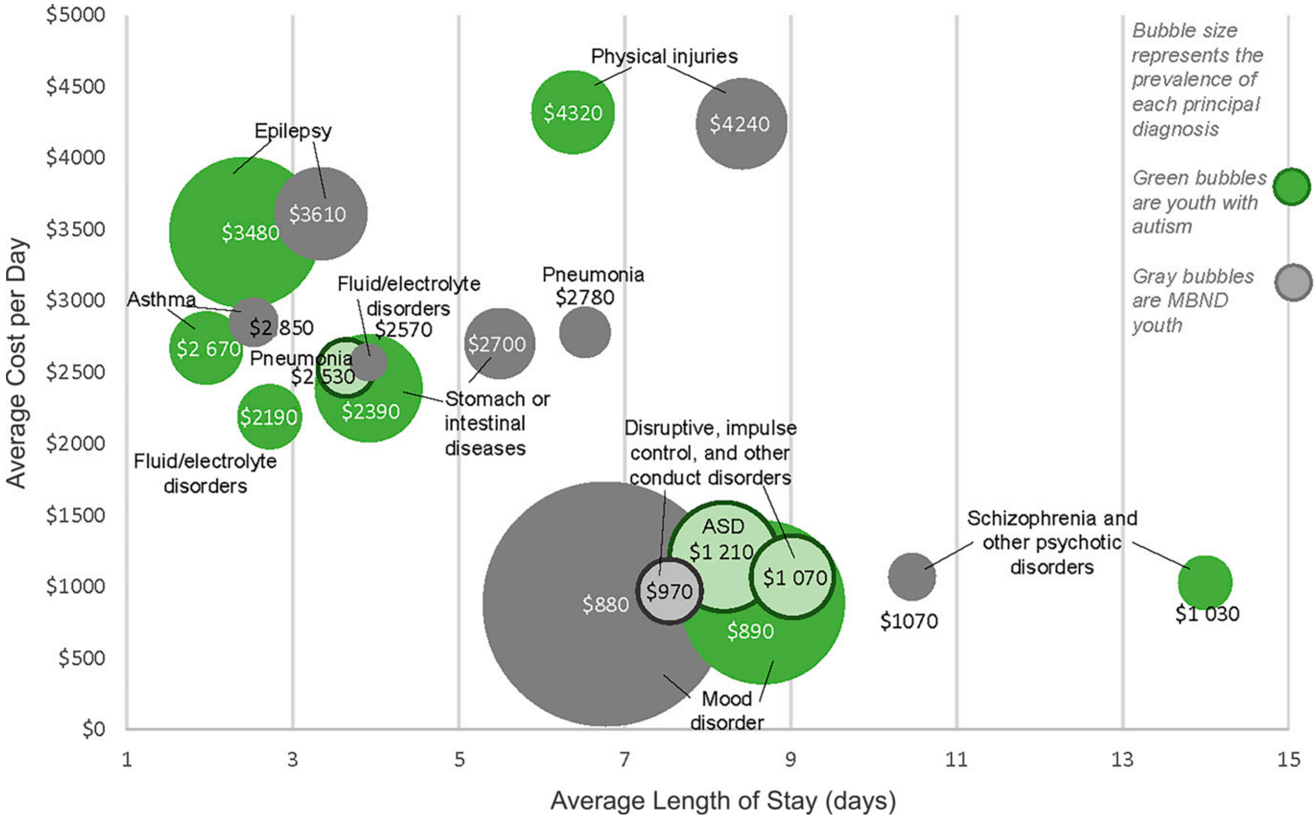

FIGURE 1

Graph of the average cost per day compared with the average length of stay for the 10 most common principal diagnoses in autistic youth. Green bubble size shows the prevalence of each principal diagnosis in autistic youth. Gray bubble size shows the prevalence of each principal diagnosis in MBND youth.

examining inpatient stays while highlighting the need for more comprehensive preventive and maintenance care.

ABBREVIATIONS

ACSC: ambulatory care sensitive conditions
CCSR: Clinical Classifications Software Refined
HCUP: Healthcare Cost and Utilization Project
ICD-10-CM: *International Classification of Diseases, 10th Revision, Clinical Modification*
MBND: mental, behavioral or neurodevelopmental disabilities
NIS: National Inpatient Sample

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Family Perceptions of Health Care Access for Autistic Young Adults Receiving Disability Services

Anne M. Roux, MPH, Jessica E. Rast, MPH, Lindsay L. Shea, DrPH

abstract

BACKGROUND: Autistic young adults (YAs) often live with family and present with complex health needs. Adults with developmental disabilities (DDs) who live with family are the least likely to receive preventive health care compared with residents of other settings. No published studies have examined intersectionality between age, race or ethnicity, household income, and health needs in health care access for autistic YA. This study explored health care access among autistic YAs receiving state DD services compared with other age and disability groups.

METHODS: We analyzed data from the National Core Indicator's Adult Family Survey of families of DD service users ages 18 and older who lived in the respondent's home. We used bivariate analyses and multivariable logistic regression to examine family-reported access to health care providers when needed, the role of sociodemographics, and the complexity of health care needs in predicting consistent care.

RESULTS: Approximately 70% of autistic YAs had consistent access to health care when needed, similar to autistic adults but at lower rates than those with other disabilities. Odds of consistent health care access were higher among autistic YAs who were Black or lived in a rural area and lower among those with co-occurring health conditions or who needed extensive personal care support.

CONCLUSIONS: Nearly one-third of autistic YAs who lived with family and receive state DD services had difficulty consistently accessing needed health care. Improved surveillance of health care services in this population is needed in addition to innovations in Medicaid waivers, which fund DD services, to address health needs and support families in accessing care.

AJ Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania

Ms Roux conceptualized and designed the study, drafted the manuscript, and finalized the manuscript; Ms Rast conducted initial analyses and contributed to the methods and manuscript revisions; Dr Shea contributed content expertise for interpretation and discussion of the findings and contributed to revisions; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Anne Roux, AJ Drexel Autism Institute, Drexel University, 3020 Market Street, Suite 560, Philadelphia, PA 19104. E-mail: amr376@drexel.edu

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WHAT'S KNOWN ON THIS SUBJECT Autistic young adults often live with family and present with complex health needs. Adults with developmental disabilities, such as autism, who live with family are the least likely to receive preventive health care compared with residents of other settings.

WHAT THIS STUDY ADDS Nearly one-third of autistic young adults receiving disability services and living at home had difficulty accessing health care (lower than peers with other disabilities). Odds of access were lower among those who had co-occurring health conditions or needed personal care.

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SUPPLEMENT ARTICLE

Preventive health care services are vital for autistic young adults (YAs) given frequent co-occurring health and psychiatric conditions and early mortality.[1,2] Few national datasets, however, allow for disability-specific surveillance of health care within populations of adults with mental, behavioral, or developmental disabilities (MBDDs), including autism.[3] Family members of individuals with disabilities are a valuable source of health data; however, there is little published research regarding family perceptions on health care for autistic adults.

Approximately 87% of autistic YAs live with family, which is a higher rate than their peers with other types of disabilities.[4] Adults with developmental disabilities (DDs) who live with family are the least likely to receive preventive health care visits compared with adults with DDs in other settings.[5] Families often must navigate service systems on their own with inadequate health care transition planning and difficulty locating health professionals who understand autism.[6,7]

Overall, there is limited understanding of health care experiences of autistic YAs who reside with family and receive state DD services. No published studies have examined the intersectionality between age, gender, race or ethnicity, household income, and health care needs in regard to health care access for this group. Among a cross-disability group of DD service users, African American and Hispanic adults were more likely to live with family and less likely to have an annual physical examination, whereas older age and a higher degree of intellectual disability predicted receipt of physicals.[5]

PURPOSE OF THIS STUDY

This study used survey data from families of adults who used state DD services. We explored 3 research questions:

1. How do the sociodemographic, health characteristics, and support needs of autistic YAs and autistic adults compare with those of their same-age peers with other MBDDs? How do the sociodemographic and support needs of the family members of autistic YAs and autistic adults compare with the family members of YAs and adults with MBDDs?
2. How do family perceptions of health care differ between families with YAs and autistic adults compared with families of YAs and adults with other MBDDs?
3. What are the associations between family-reported consistency of health care, sociodemographics of autistic individuals and their families, and the complexity of health care needs?

METHODS

Measures

We analyzed data from The National Core Indicators (NCI) Adult Family Survey (AFS). NCI collects and disseminates indicators data for use in improving DD systems performance of member states. The AFS gathers annual input by mail or online format from family members of adult DD service users via a nonprobability sample of those who live at home and use at least 1 direct service in addition to service coordination. Of 46 member states, 12 participated in the 2018 to 2019 AFS. Survey responses were not representative of the state's entire served population. We examined data for autistic YAs ages 18 to 25 years ($n = 700$) and autistic adults ages 26 and older ($n = 851$) per diagnoses reported by the family respondent versus YAs ($n = 682$) and adults ($n = 2514$) with other MBDDs (see Table 1 footnote) who did not have autism.

Variables

We used "always having access to a health care provider when needed" as a proxy for consistent health care. The dependent variable was assessed with the question, "Can your family member see health professionals when needed? (For example, doctor, dentist, or psychologist)." We also examined family perceptions of whether primary care doctors understood needs related to the family member's disability.

Independent variables (IVs) characterizing adults were all reported by the respondent and included sex, race or ethnicity, level of education, co-occurring health and psychiatric conditions, means of communication, level of support needed for managing behavior (self-injurious, disruptive, and/or destructive), personal care activities (eg, bathing, dressing, and eating), and daily activities (eg, managing money, shopping, and scheduling), guardianship, and whether the family used self-directed services, such as allowing them to hire or fire support workers and/or control the individual's budget, which we considered to be an indicator of capability in systems navigation. We included race or ethnicity in our model because of previous evidence of reduced health care access among minoritized autistic individuals.[8,9] IVs characterizing family respondents and their households included level of education, urbanicity, and household income.

Analysis

The distribution of variables was examined within each group and compared between autistic adults and those with MBDD by using

TABLE 1 Sociodemographics, Health Conditions, and Support Needs of DD Service Users Who Live in the Family Home by Age and Disability Type

	YAs 18–25 y			Adults ≥ 26 y		
	Autism, *n* (%)	MBDD,[a] *n* (%)	*P*	Autism, *n* (%)	MBDD,[a] *n* (%)	*P*
Sex			<.001			<.001
Male	501 (73.0)	366 (54.1)		583 (69.1)	1303 (52.4)	
Female	185 (27.0)	311 (45.9)		261 (30.9)	1185 (47.6)	
Race			.54			.036
White	516 (77.6)	507 (78.0)		617 (75.0)	1902 (79.3)	
Black/African American	93 (14.0)	98 (15.1)		138 (16.8)	329 (13.7)	
Other or multiple	56 (8.4)	45 (6.9)		68 (8.3)	169 (7.0)	
Hispanic or Latino	44 (6.4)	49 (7.3)	.52	37 (4.4)	114 (4.6)	.82
Highest level of education			.29			.023
In high school	112 (16.4)	100 (15.1)		0 (0.0)	2 (0.1)	
Less than high school	48 (7.0)	44 (6.6)		119 (14.4)	439 (18.6)	
High school certificate, no diploma or GED	209 (30.6)	232 (35.0)		337 (40.8)	848 (36.0)	
High school diploma or GED	226 (33.1)	222 (33.5)		281 (34.1)	790 (33.5)	
Postsecondary	87 (12.8)	65 (9.8)		88 (10.7)	276 (11.7)	
Co-occurring MBDD						
Intellectual disability	414 (59.1)	502 (73.6)	<.001	552 (64.9)	1876 (74.6)	<.001
Mood or psychiatric disorder	238 (34.0)	127 (18.6)	<.001	280 (32.9)	529 (21.0)	<.001
Seizure disorder/neurologic	162 (23.0)	238 (34.9)	<.001	262 (30.8)	793 (31.5)	.68
Visual or hearing impairment	50 (7.1)	128 (18.8)	<.001	84 (9.9)	427 (17.0)	<.001
Health conditions						
High blood pressure	50 (7.1)	128 (18.8)	.02	120 (31.6)	456 (30.9)	.79
High cholesterol	34 (14.5)	31 (9.6)	.076	113 (29.7)	410 (27.8)	.44
Oral health or dental problems	31 (13.2)	31 (9.6)	.18	55 (14.5)	187 (12.7)	.35
Diabetes	29 (12.4)	16 (5.0)	.002	65 (17.1)	289 (19.6)	.28
Cardiovascular disease	25 (10.7)	56 (17.4)	.027	38 (10.0)	164 (11.1)	.54
Communication			.074			<.001
Spoken	487 (71.5)	492 (74.7)		612 (73.3)	1951 (79.8)	
Gestures/body language	140 (20.6)	105 (15.9)		165 (19.8)	355 (14.5)	
Other	54 (7.9)	62 (9.4)		58 (6.9)	140 (5.7)	
Supports needs: behavior			<.001			<.001
None	220 (32.4)	397 (59.8)		312 (37.3)	1588 (64.9)	
Some	276 (40.6)	177 (26.7)		324 (38.7)	612 (25.0)	
Extensive	184 (27.1)	90 (13.6)		201 (24.0)	246 (10.1)	
Support needs: personal care			.025			.097
None	145 (21.1)	132 (19.5)		199 (23.6)	678 (27.3)	
Some	276 (40.2)	234 (34.6)		322 (38.2)	911 (36.7)	
Extensive	266 (38.7)	310 (45.9)		323 (38.3)	891 (35.9)	
Support needs: daily activities			.78			.007
None	25 (3.6)	29 (4.3)		34 (4.0)	126 (5.1)	
Some	110 (16.0)	103 (15.3)		159 (18.8)	572 (23.2)	
Extensive	551 (80.3)	543 (80.4)		653 (77.2)	1763 (71.6)	
Guardianship			.24			<.001
None	195 (28.9)	176 (27.1)		231 (28.9)	760 (32.5)	
Limited guardianship	82 (12.1)	61 (9.4)		58 (7.3)	255 (10.9)	
Full guardianship	374 (55.4)	392 (60.3)		477 (59.8)	1256 (53.7)	
Guardian but level unknown	24 (3.6)	21 (3.2)		32 (4.0)	66 (2.8)	
Self-directed services	303 (50.3)	272 (46.7)	.22	315 (44.6)	869 (42.5)	.33

Data source: NCI Adult Family Survey 2018–2019 States: AZ, GA, LA, MD, MN, MO, NC, OH, OK, PA, UT, VA.

[a] MBDD group included adults with intellectual disability, mood illness or psychiatric disorder, cerebral palsy, limited or no vision, severe or profound hearing loss, brain injury, seizure disorder or neurologic problem, chemical dependency, Down Syndrome, Prader-Willi Syndrome, fetal alcohol spectrum disorder, and other. The MBDD group excluded persons with co-occurring autism.

Pearson's χ^2 test. Most variables were missing <5% of observations; however, the use of self-directed services was missing 17% of observations and was excluded from multivariable analysis. We used generalized estimating equation logistic regression models to account for the correlation structure created by sampling within states with varying procedures and differing eligibility criteria. Two final multivariable logistic models examined factors associated with health care access in autistic individuals. IVs were included in the model on the basis of

TABLE 2 Sociodemographics, Support Needs and Perceptions of Family Members of DD Service Users Who Live at Home by Age of Service Users and Disability Type

	YAs 18–25 y			Adults ≥ 26 y		
	Autism, *n* (%)	MBDD,[a] *n* (%)	*P*	Autism, *n* (%)	MBDD,[a] *n* (%)	*P*
Level of education			.696			<.001
No high school diploma/GED	31 (4.5)	34 (5.1)		35 (4.2)	168 (6.8)	
High school diploma/GED	124 (17.9)	133 (20.0)		168 (20.3)	740 (30.1)	
Vocational school or certificate	51 (7.4)	49 (7.4)		51 (6.2)	177 (7.2)	
Other postsecondary education	487 (70.3)	449 (67.5)		575 (69.4)	1372 (55.8)	
Geography			.019			.002
Urban or suburban	489 (71.1)	433 (65.1)		582 (70.7)	1581 (64.8)	
Rural	199 (28.9)	232 (34.9)		241 (29.3)	860 (35.2)	
Household taxable income in past year, $			.077			<.001
25 000 or less	120 (17.5)	139 (20.9)		193 (23.5)	784 (32.7)	
25 001–50 000	117 (17.1)	113 (17.0)		156 (19.0)	458 (19.1)	
50 001–75 000	95 (13.9)	110 (16.5)		116 (14.1)	292 (12.2)	
> 75 000	238 (34.7)	187 (28.1)		181 (22.1)	330 (13.8)	
Prefer not to say	115 (16.8)	117 (17.6)		174 (21.2)	536 (22.3)	
Family reports getting needed supports and services	425 (69.2)	446 (74.0)	.067	542 (74.3)	1752 (81.1)	<.001
Family is satisfied with the services/supports the family member receives			.003			.002
Always	176 (26.0)	215 (32.7)		272 (33.0)	930 (38.4)	
Usually	335 (49.4)	323 (49.2)		406 (49.2)	1162 (48.0)	
Sometimes/never	167 (24.6)	119 (18.1)		147 (17.8)	330 (13.6)	
Family needs help planning for family member's medical issues	178 (33.7)	116 (24.7)	.002	196 (33.1)	407 (30.1)	.19
Family feels doctor understands needs related to the disability			.034			<.001
Always	368 (55.4)	415 (62.4)		871 (57.9)	2055 (65.9)	
Usually	224 (33.7)	200 (30.1)		488 (32.4)	900 (28.9)	
Sometimes/never	60 (9.0)	44 (6.6)		126 (8.4)	137 (4.4)	
Family believes loved one can see health professionals when needed			.024			<.001
Always	476 (69.5)	514 (75.9)		1085 (70.5)	2513 (79.5)	
Usually	176 (25.7)	141 (20.8)		378 (24.6)	560 (17.7)	
Sometimes/never	33 (4.8)	22 (3.2)		75 (4.9)	88 (2.8)	

Data source: NCI Adult Family Survey 2018–2019 States: AZ, GA, LA, MD, MN, MO, NC, OH, OK, PA, UT, VA.

[a] MBDD group included adults with intellectual disability, mood illness or psychiatric disorder, cerebral palsy, limited or no vision, severe or profound hearing loss, brain injury, seizure disorder or neurologic problem, chemical dependency, Down Syndrome, Prader-Willi Syndrome, fetal alcohol spectrum disorder, and other. The MBDD group excluded persons with co-occurring autism.

theoretical importance and previous research.

RESULTS

Psychiatric disorders were more common in autistic YAs and adults, as was the reported need for extensive supports of all types, compared with peers with MBDDs (Table 1). Approximately 30% of families of autistic YAs reported they did not receive all services included in the individual's service plan (Table 2). Nearly one-quarter of families of autistic YAs said they were sometimes or never satisfied with overall services and support, and one-third reported needing help planning for medical care, both significantly higher rates than families of YA with MBDDs.

Approximately 70% of families of autistic YAs reported their family member was always able to see health professionals when needed, similar to families of autistic adults but significantly lower than families of peers with MBDDs. Only 55% of families of autistic YAs felt the primary care doctor understood needs related to their family member's disability, similar to families of autistic adults, both significantly lower rates than families of MBDD peers.

Black autistic YAs had >3 times higher odds of consistent health care compared with White peers (Table 3). YAs had 65% higher odds of consistent health care if they lived in a rural area and ~33% lower odds if they had a co-occurring health condition or if they needed extensive supports with personal care. Autistic adults had nearly 40% lower odds of consistent care if they needed extensive supports for challenging behavior and 33% lower odds if they had a psychiatric disorder.

DISCUSSION

We found that nearly one-third of autistic YAs who lived with family members and received state DD services had difficulty consistently accessing needed health care, which is a higher rate than MBDD peers. This finding echoed previous research that found lower rates of preventive care among DD service users who live with family.[10] State DD services are typically funded

TABLE 3 Relationship Between Sociodemographic Factors of Autistic DD Service Users and Their Families, Complexity of Health Care Needs of the Service User, and Family-Reported Access to Health Care

	YAs 18–25 y		Adults ≥ 26 y	
	OR	95% CI	OR	95% CI
Sociodemographics of service user				
Race	—	—	—	—
White	1	—	1	—
Black/African American	3.27***	1.71–6.25	0.8	0.51–1.25
Other	0.92	0.49–1.74	1.14	0.61–2.11
Hispanic	0.80	0.27–2.37	0.83	0.32–2.13
Sociodemographics of family/household				
Family member has high school education or less	1.05	0.66–1.66	1.23	0.81–1.87
Family lives in a rural area	1.65*	1.10–2.45	1.11	0.77–1.60
Household income				
≤ 25 000	1	—	1	—
25 001–50 000	1.04	0.55–1.95	0.84	0.51–1.39
50 001–75 000	0.91	0.48–1.75	0.87	0.50–1.51
> 75 000	1.53	0.87–2.69	1.22	0.73–2.04
Prefer not to say	1.66	0.88–3.16	1.00	0.60–1.65
Complexity of health care needs of service user				
Has intellectual disability	1.40	0.96–2.04	0.98	0.68–1.41
Has mood or psychiatric disorder	1.17	0.79–1.73	0.67*	0.47–0.96
Has at least 1 co-occurring chronic physical health condition[a]	0.67*	0.45–0.99	1.12	0.84–1.48
Extensive need for support with challenging behavior	0.80	0.51–1.24	0.62*	0.42–0.93
Extensive need for support with personal care	0.66*	0.44–1.00	0.95	0.65–1.37

Logistic regression using generalized estimating equations to control for clustering within states. CI, confidence interval; OR, odds ratio; —, not applicable.

[a] Co-occurring health conditions include cardiovascular disease, cancer, high blood pressure, high cholesterol, dysphagia (difficulty swallowing), pressure ulcers, Alzheimer's disease or other dementia, oral health problems, sleep apnea, or other health conditions not listed.

*$P < .05$; **$P < .01$; ***$P < .001$.

through Medicaid Home and Community Based Service (HCBS) waivers. These waivers expand eligibility for needed services and reduce unmet health care needs in autistic children.[11] However, it is unclear how HCBS waivers may differentially prioritize, require, or support medical care for adults unless the individual is enrolled in a managed care program that includes physical and behavioral health service packages.

Increased access to health care seen in young, Black autistic individuals may reflect newer Medicaid-managed care models which have sought to increase the use of community-based health services in an effort to decrease high levels of emergency department use and hospitalizations in adults with DD.[12] States have also initiated campaigns to facilitate transition into HCBS services for students with DDs who are leaving high school at age 21, such as Pennsylvania's High School Graduate Initiative, avoiding lengthy waitlists for services and supports. Expansion and innovation of HCBS services is critical for reducing gaps in access to care for autistic individuals across their adult years, as is increased training for practitioners.

Lowered odds of consistent care for autistic adults with complex health and behavioral challenges are concerning. Rates of health conditions were higher in adults in our study, signaling the importance of upstream preventive care. Most co-occurring conditions examined in this study are ambulatory care sensitive conditions, which should not result in hospitalization if there is adequate primary care. Yet, emergency department use and hospitalization for ambulatory care sensitive conditions are elevated in autistic adults and adults with MBDDs.[12] We note that surveillance activities and focus on unequal care could improve if the federal government recognizes people with DDs as a federally designated medically underserved population, as advocated by the American Medical Association.

Unmet service needs and low satisfaction among families of autistic YAs may signal lower-quality care. People with disabilities who live in congregate care settings benefit from regulatory requirements for routine health care, but families may need additional supports to achieve routine health care schedules at home. It is imperative that health providers refer families to state DD services that could help provide care coordination.

This study has several limitations. Findings only generalize to autistic adults who use DD services and do not represent those who do not receive DD services or do not live with family members. The prevalence of co-occurring health conditions was likely underestimated because the AFS did not explore obesity or gastrointestinal issues common in this population. Additionally, there was no measure of overall health or information on the use of specialty care. It is possible that families who use more specialty care may rely less on primary care visits. We were unable to control for insurance type or the potential that individuals under age 26 were insured via their parents' plans; however, most adult DD service users are funded through HCBS waivers.

ABBREVIATIONS

AFS: adult family survey
DD: developmental disabilities
HCBS: home and community based services
IV: independent variable
MBDD: mental, behavioral or developmental disabilities
NCI: National Core Indicators
YA: young adult

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Reproductive Health and Substance Use Education for Autistic Youth

Laura Graham Holmes, PhD,[a] Jessica E. Rast, MPH,[b] Anne M. Roux, MPH, MA,[b] Emily F. Rothman, ScD[c]

abstract

BACKGROUND: We provide an update on reproductive health education (RHE) and substance use prevention education (SUPE) participation for autistic youth compared with other youth with and without individualized education plans (IEPs) and 504 plans. The 800 000 autistic youth served by the US special education system need education to make informed decisions about reproductive health and substance use.

METHODS: Data were from the National Longitudinal Transition Study-2012, a survey designed to yield nationally representative estimates of the experiences of US youth. Autistic youth ($n = 390$) who received RHE and SUPE were compared with youth with all other IEP classifications ($n = 4420$), with a 504 plan ($n = 350$), and with no IEP or 504 plan ($n = 980$). All youth were ≥14 years old and able to self-report on a survey. Bivariate and multivariate regression analyses were performed for each group to identify characteristics associated with RHE and SUPE receipt.

RESULTS: Autistic youth reported a significantly lower rate of RHE (47.4%) and SUPE (49.6%) inclusion versus students with no IEP or 504 plan (59.2% and 57.4%, respectively). Autistic girls were more than twice as likely to report RHE receipt than autistic boys (55.1% vs 45.9%). For autistic youth, no markers for receipt of SUPE were identified.

CONCLUSIONS: Autistic youth are underserved when it comes to school-based RHE and SUPE, potentially undermining self-determination and leading to poorer lifespan health trajectories. Research and policy advocacy are needed to ensure that these youth have access to RHE and SUPE.

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[a] *Silberman School of Social Work, Hunter College, City University of New York, New York, New York;* [b] *AJ Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania; and* [c] *Department of Occupational Therapy, Boston University, Boston, Massachusetts*

Dr Graham Holmes conceptualized and designed the study, drafted the original manuscript, and revised the manuscript; Ms Rast conceptualized and designed the study, curated the data, carried out the analyses, and reviewed the manuscript; Ms Roux assisted in data interpretation, drafted the original manuscript, and provided supervision; Dr Rothman assisted in data interpretation, reviewed and edited the manuscript, and provided supervision; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Laura Graham Holmes, PhD, Silberman School of Social Work, 2180 Third Avenue, New York, NY 10035. E-mail: lghpublishing@gmail.com

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WHAT'S KNOWN ON THIS SUBJECT Autistic adolescents need reproductive health and substance use prevention education but may not get it. Only 5 states mandate accessible health education for youth with disabilities. However, districts increasingly provide teachers professional development to support disability-inclusive health education.

WHAT THIS STUDY ADDS This study used a national dataset to determine rates of autistic youth who reported reproductive health and substance use prevention education. Less than half of these youth received either, significantly lower than students not receiving special education services.

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Approximately 800 000 youth classified as autistic are served by the US special education system, with 92% enrolled in public schools and most spending at least half of their time in general education classrooms.[1] An individualized education plan (IEP) is developed by a multidisciplinary team for every youth receiving special education services under Part B of the Individuals With Disabilities Education Act. Students with disabilities who do not need or qualify for special education may instead receive 504 plan accommodations (eg, extra time on tests), developed in accordance with Section 504 of the Rehabilitation Act of 1973, to help them to access the general education curriculum. It is critical to understand if health education strategies are being implemented for youth with disabilities as intended.

Autistic adolescents need reproductive health education (RHE) and substance use prevention education (SUPE) just like their neurotypical peers. School-based RHE is designed to prepare youth for healthy relationships, teach socially appropriate and consensual dating behavior, increase accuracy and comfort when reporting sexual health issues, and encourage positive self-image and communication skills.[2] RHE topics typically include anatomy, reproduction, age of consent, abstinence, and personal values. School-based SUPE is designed to counteract substance use patterns that could become established in adolescence and contribute to morbidity and mortality over the lifespan. SUPE can include evidence-based approaches such as social resistance skills training (eg, increasing social influence awareness), normative education (eg, correct inaccurate perceptions of high substance use prevalence), and competence enhancement (ie, life skills such as problem-solving, resisting influence, increasing self-control, and coping and social skills).[3]

The Centers for Disease Control and Prevention[4] and American Academy of Pediatrics (AAP)[5] emphasize the role of schools in promoting health for adolescents and adults with disabilities. The AAP recommends that developmentally appropriate RHE be provided to every student with intellectual and developmental disabilities, including autistic youth.[6] Additionally, the Substance Abuse and Mental Health Services Administration[7] has highlighted the importance of SUPE in schools. In response, schools have adopted policies that support appropriate health education for youth with disabilities. Most high schools (86%) include SUPE in their health education policies.[8] Currently, 5 states mandate accessible health education. Districts have increasingly provided professional development on effective health instruction and mandate strategies to support disability-inclusive health education.[8] These policy metrics are promising, but the extent to which autistic youth are included in health education and factors that affect inclusion remain understudied.

In the next decade, 707 000 to 1 116 000 US autistic youth will reach 18 years of age[9,10]; therefore, it is critical to understand the health education strategies being implemented for these youth. The only previous nationally representative data on inclusion of youth with disabilities in RHE and SUPE was the 2000 National Longitudinal Transition Study-2 (NLTS-2). The authors of the NLTS-2 reports found that across IEP disability classification groups, autistic youth were the least likely to receive RHE (28%) or SUPE (25%).[11] In the current study, we provide an update and investigate the inclusion of autistic youth in RHE and SUPE using the National Longitudinal Transition Study-2012 (NLTS-2012).[12] Specifically, we (1) estimate the rate of RHE and SUPE receipt among autistic youth compared with other youth with and without IEPs and 504 plans and (2) identify factors associated with the receipt of RHE and SUPE.

METHODS

The NLTS-2012[12] was designed to yield nationally representative estimates of the characteristics and experiences of US youth, focusing on those who received special education services. The NLTS-2012 investigators sampled youth who (1) received special education services in 1 of 12 federally designated categories as part of an IEP, (2) received accommodations under a 504 plan, or (3) did not receive IEP services or 504 accommodations. Surveys were administered to parents and then to youth if the parent believed that the youth could participate. NLTS-2012 design details are available elsewhere.[12]

Participants

This study examined 4 groups: (1) youth in the autism IEP category ($n = 390$), (2) youth in any other IEP category ($n = 4030$), (3) youth with 504 plan accommodations ($n = 350$), and (4) youth with no IEP or 504 plan ($n = 980$). Because some autistic youth may not have IEPs or 504 plans, references to youth in specific IEP categories (eg, autistic youth) should be interpreted as autistic youth with an IEP. Analyses were limited to students age ≥14 years in grades 9 to 13 or an ungraded class in a public school setting (not in a residential or private school setting or homeschooled) and who answered the youth questionnaire on their own behalf. Proxy respondents were not asked whether youth received RHE or SUPE.

Dependent Variables

The dependent variable for RHE analysis was the response to the item "In school year (2011–2012 or 2012–2013), did school staff provide you with reproductive health or pregnancy prevention education or services?" The dependent variable for SUPE analysis was the response to the item, "In school year (2011–2012 or 2012–2013), did school staff provide you with substance abuse counseling or education? This includes both drugs and alcohol." Responses to these items included yes and no. Regression analyses were conducted separately for RHE and SUPE.

Independent Variables

For all 4 study groups, independent variables included demographic information (ie, age, sex, race, household income as a percentage of the federal poverty level). In addition, for youth with an IEP, the following variables were included: parent and youth attendance at an IEP meeting in the past 2 years and how well youth could carry on a conversation, understand what is said to them, get to places outside the home, count change, and use a telephone and look up telephone numbers. Responses to these items included no trouble, a little trouble, a lot of trouble, or cannot.

Analysis

Receipt of RHE and SUPE

Bivariate RHE and SUPE receipt estimates are presented for the following groups: youth in each IEP category, youth with 504 plan accommodations, and youth with no IEP or 504 plan. Univariate logistic regressions with RHE and SUPE receipt as the outcomes and a dummy indicator for no IEP or 504 plan versus each IEP category or with 504 plan accommodations were used to test for differences between the no IEP or 504 plan group and each other group.

Factors Associated With RHE and SUPE Receipt

The percentage of youth who received RHE and SUPE are presented for each level of each independent variable by group, and significant differences in receipt of RHE and SUPE were assessed using logistic regression. Multivariate logistic regression was used to examine associations of all independent variables with receipt of RHE and SUPE. Separate regression analyses were performed for each group. Analysis was performed using Stata version 15 and accounted for the need to incorporate both the sampling weights and sampling design variables.[12]

RESULTS

Receipt of RHE

Figure 1 shows the percentage of youth in each IEP category who reported receiving RHE. Less than half of autistic youth reported receiving RHE (47.4%), significantly fewer than youth with no IEP or 504 plan (59.2%). Compared with autistic youth, only youth in the intellectual disability IEP category

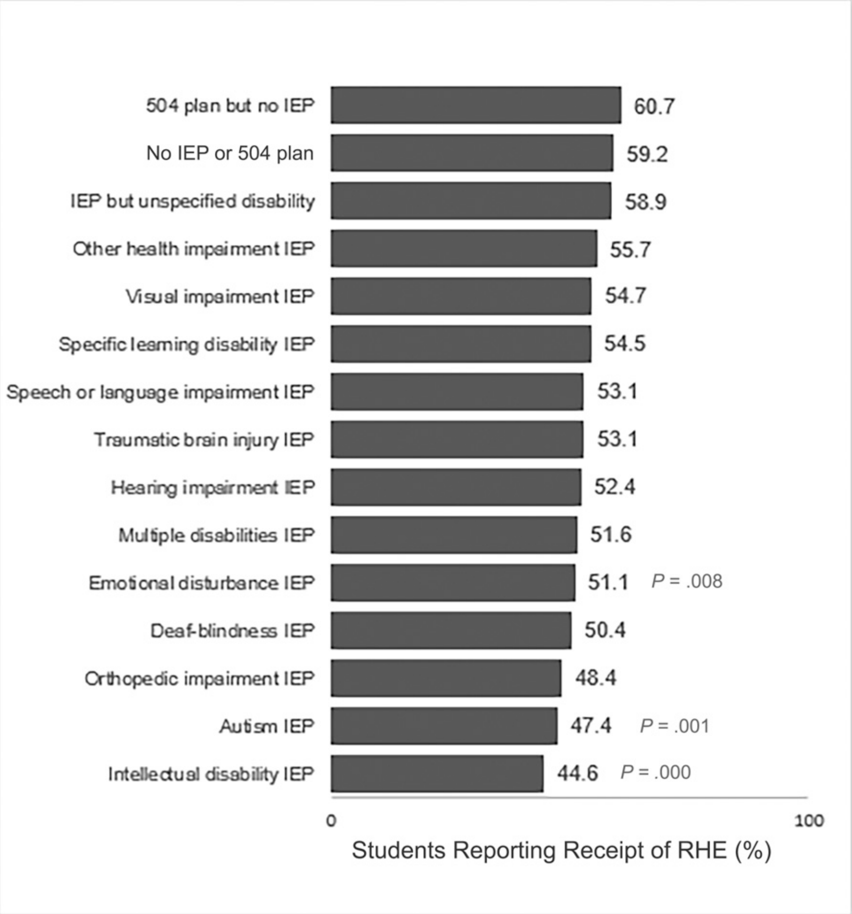

FIGURE 1
Estimates of the percentage of students receiving RHE by disability classification. Statistical comparisons made to the no IEP or 504 plan group.

reported lower receipt of RHE (44.6%).

Receipt of SUPE

Figure 2 shows the percentage of youth in each IEP category who reported receiving SUPE. Half of autistic youth (49.6%) reported receiving SUPE, significantly fewer than youth with no IEP or 504 plan (57.0%). Youth in the intellectual disability, emotional disturbance, multiple disabilities, and orthopedic impairment IEP categories also reported lower receipt of SUPE than those with no IEP or 504 plan.

Factors Associated With RHE Receipt

The only factor associated with RHE receipt in bivariate analyses for autistic youth was how well the youth could use the telephone and look up telephone numbers. Youth who could do this very well were more likely to receive RHE than those who could not (50% vs 31%; Table 1). For youth in any other IEP category, all disability characteristics and attendance at an IEP meeting were associated with receipt of RHE, with poorer functional ability associated with a lower probability of receiving RHE in all cases. For youth with no IEP or 504 plan,

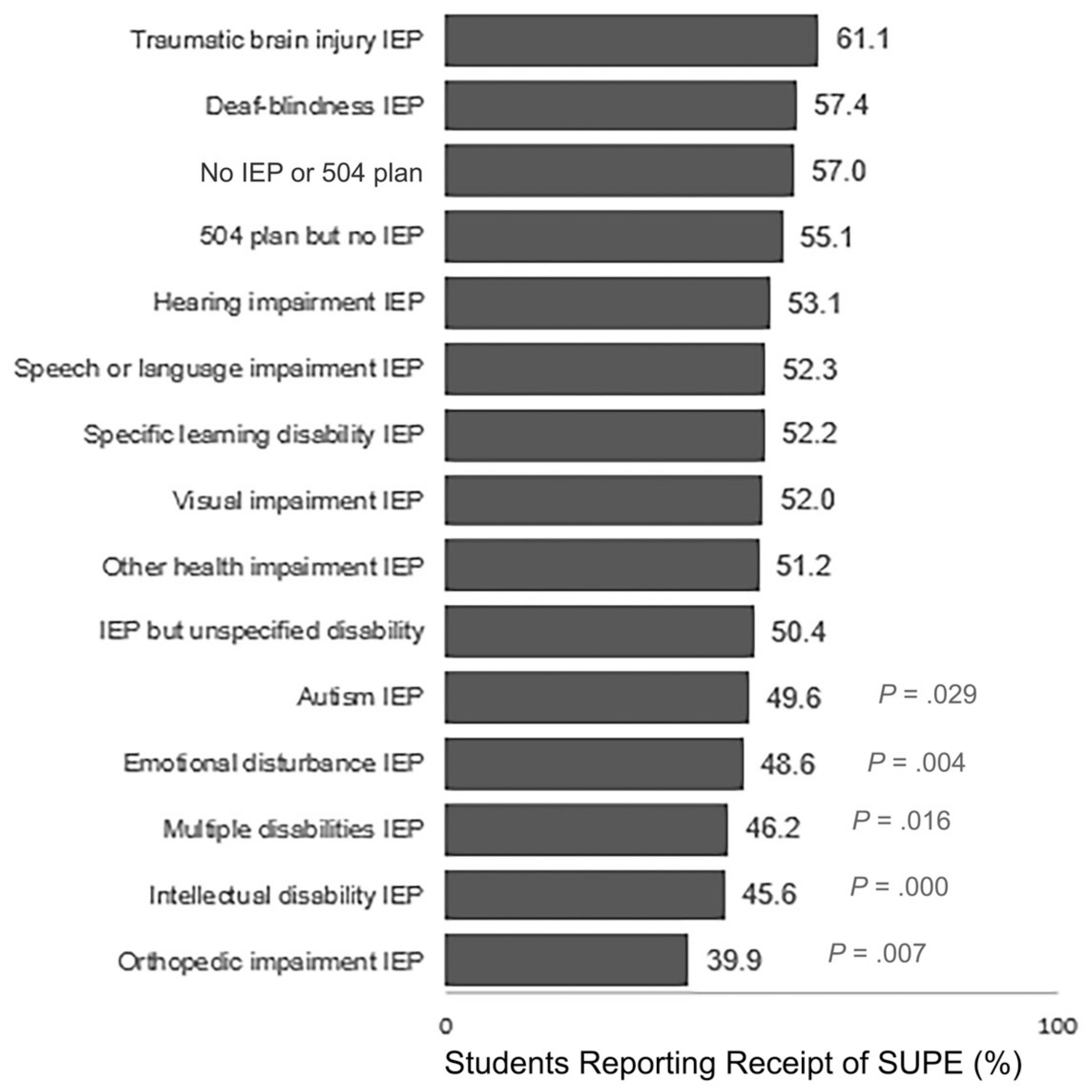

FIGURE 2

Estimates of the percentage of students receiving SUPE. Statistical comparisons made to the no IEP or 504 plan group.

TABLE 1 Percentage Estimates and CIs for Receipt of RHE by Demographic and Disability Characteristics

	Autism IEP(n = 390)		Other IEP(n = 4420)		504 Plan(n = 350)		No IEP or 504 Plan(n = 980)	
Characteristic	%	95% CI	%	95% CI	%	95% CI	%	95% CI
All patients	47.4**	41.7–53.1	—	—	60.7	54.8–66.2	59.2	55.5–62.7
Age, y								
14–16	48.2	40.4–56.1	52.5	48.9–56.1	61.2	53.3–68.5	59.8	55.4–64.0
17–21	46.3	38.1–54.5	54.7	51.1–58.2	59.6	49.5–69.0	57.8	51.2–64.1
Sex								
Female	55.1	40.9–68.6	54.7	50.4–59.0	61.2	52.3–69.5	57.2	52.2–62.0
Male	45.9	40.0–51.9	52.7	49.5–56.0	60.2	51.2–68.5	61.4	56.4–66.2
Race								
White	46.0	39.6–52.6	53.7	50.3–57.1	60.5	53.5–67.1	59.9	55.5–64.2
Black	54.9	38.4–70.3	53.4	47.7–59.1	58.9	45.8–70.9	59.5	50.3–68.1
Other/multiracial	53.0	34.4–70.8	54.2	47.0–61.3	62.4	42.4–78.9	54.1	43.1–64.6
Household income <185% FPL	39.7	30.6–49.5	51.4	48.1–54.7	60.1	49.9–69.5	54.3*	48.9–59.6
Household >185% FPL	51.0	43.9–58.0	56.2	52.0–60.5	60.9	53.9–67.6	62.6*	58.0–66.9
Parent did not attend an IEP meeting	29.3	13.4–52.6	55.4	48.2–62.3	—	—	—	—
Parent attended an IEP meeting	48.5	42.6–54.5	52.8	49.8–55.8	—	—	—	—
Youth did not attend an IEP meeting	40.1	28.7–52.6	47.3**	42.2–52.4	—	—	—	—
Youth attended an IEP meeting	48.8	42.6–55.2	55.6**	52.4–58.7	—	—	—	—
How well does youth carry on a conversation?								
Not at all well or with a lot of trouble	51.4	39.4–63.3	39.5**	30.6–49.2	—	—	—	—
With no trouble or a little trouble	46.6	40.0–53.4	54.2**	51.3–57.0	—	—	—	—
How well does youth understand what is said to him or her?								
Not at all well, with a lot of trouble, or with a little trouble	43.7	37.1–50.5	50.3*	46.4–54.1	—	—	—	—
With no trouble	54.5	45.1–63.6	55.2*	51.6–58.7	—	—	—	—
How well does youth get to places outside the home?								
Very well or pretty well	50.3	43.6–57.0	54.8***	51.9–57.7	—	—	—	—
Not very well or not at all well, not allowed	38.6	28.8–49.3	39.3***	32.7–46.4	—	—	—	—
How well does youth count change?								
Very well or pretty well	48.3	40.5–56.3	—	—	—	—	—	—
Not very well or not at all well	41.8	32.3–52.0	—	—	—	—	—	—
How well does youth use the telephone and look up telephone numbers?								
Very well or pretty well	49.9**	43.2–56.6	—	—	—	—	—	—
Not very well or not at all well	31.0**	20.6–43.8	—	—	—	—	—	—

—, not applicable; FPL, federal poverty level.

* $P < .05$; ** $P < .01$; *** $P < .001$.

fewer from low-income households received RHE compared with not from low-income households.

In multivariate analyses, autistic girls had 2.26 times the odds of RHE receipt compared with boys (odds ratio [OR], 2.26; 95% confidence interval [CI], 1.17–4.39); all other variables were not significant. Youth in any other IEP category were more likely to receive RHE if they attended an IEP meeting (OR, 1.40; 95% CI, 1.07–1.82) and were able to get to places outside the home with no trouble (OR, 1.54; 95% CI, 1.11–2.14).

Factors Associated With SUPE Receipt

There were no statistically significant bivariate associations with receipt of SUPE for autistic youth (Table 1). In contrast, for youth in all other IEP categories, those who had attended an IEP meeting and those who had less difficulty with carrying on a conversation or getting to places outside the home were more likely to report that they received SUPE than youth with more difficulties or who had not attended an IEP meeting. For youth with no IEP or 504 plan, 60% of younger youth (ages 14–16 years) reported receipt of SUPE compared with 51% of older youth (ages 17–21 years).

No statistically significant associations were found with receipt of SUPE and any independent variable in multivariate logistic regression for autistic youth, youth with 504 plan accommodations, or youth with no IEP or 504 plan (Table 2). For youth in all other IEP categories, attendance at an IEP meeting (OR, 1.49; 95% CI, 1.18–1.87), having no trouble with carrying on a conversation (OR, 1.99; 95% CI, 1.32–3.01), and having no trouble getting to places outside the home (OR, 1.59; 95% CI, 1.21–2.09) were associated with a higher odds of SUPE receipt.

DISCUSSION

Inclusion of autistic youth in school health programs, including RHE and SUPE, has the potential to alter health trajectories across the life course by supporting sexual and reproductive health and healthy relationships and by preventing substance use initiation. However, we found that autistic youth were significantly less likely than youth with no IEP or 504 plan to receive RHE or SUPE. Indeed, autistic youth with IEPs are one of the most underserved subgroups among students with disabilities.

Comparing our NLTS-2012 results to those of a previous analysis of NLTS-2 data, rates of RHE and SUPE for the autism group seem to have improved from 28% to 47% for RHE and 25% to 49% for SUPE. However, these two datasets are not directly comparable because the NLTS-2 investigators used teacher report for receipt of RHE and SUPE, meaning that youth with greater support needs were included, while

TABLE 2 Percentage Estimates and CIs for Receipt of SUPE by Demographic and Disability Characteristics

	Autism IEP(n = 390)		Other IEP(n = 4420)		504 Plan(n = 350)		No IEP or 504 Plan(n = 980)	
Characteristic	%	95% CI	%	95% CI	%	95% CI	%	95% CI
All patients	49.6*	43.7–55.5	—	—	55.1	48.3–61.7	57.0	53.4–60.6
Age, y								
14–16	51.6	44.2–58.9	49.4	46.1–52.8	55.8	47.5–63.8	60.0*	55.4–64.4
17–21	47.0	38.3–56.0	52.8	49.6–56.1	53.7	44.3–62.9	50.5*	44.7–56.2
Sex								
Female	40.5	28.1–54.2	51.9	47.9–56.0	52.5	43.3–61.5	54.6	49.7–59.5
Male	51.3	44.8–57.7	50.3	47.3–53.3	57.4	48.2–66.1	59.7	54.3–64.9
Race								
White	48.5	41.7–55.4	51.7	48.5–54.9	53.6	45.4–61.6	57.5	52.9–61.9
Black	50.8	34.6–66.8	49.5	44.4–54.7	55.7	42.6–68.0	60.3	51.0–68.8
Other/multiracial	54.8	37.1–71.5	49.0	42.2–55.9	68.7	49.7–83.0	50.8	41.1–60.4
Household income <185% FPL	51.3	42.2–60.4	49.1	46.1–52.1	52.3	41.7–62.7	56.7	51.1–62.1
Household >185% FPL	48.6	41.0–56.2	53.6	49.7–57.4	56.9	48.0–65.3	57.3	52.5–62.0
Parent did not attend an IEP meeting	46.3	24.2–69.9	47.8	41.3–54.4	—	—	—	—
Parent attended an IEP meeting	50.4	44.2–56.7	51.2	48.3–54.1	—	—	—	—
Youth did not attend an IEP meeting	44.7	33.5–56.5	43.9***	39.9–47.9	—	—	—	—
Youth attended an IEP meeting	50.4	43.6–57.3	53.6***	50.8–56.5	—	—	—	—
How well does youth carry on a conversation?								
Not at all well or with a lot of trouble	45.3	33.1–58.1	33.2***	25.7–41.6	—	—	—	—
With no trouble or a little trouble	50.3	44.0–56.6	51.8***	49.4–54.3	—	—	—	—
How well does youth understand what is said to him or her?								
Not at all well, with a lot of trouble, or with a little trouble	46.7	39.5–54.0	50.5	46.8–54.1	—	—	—	—
With no trouble	54.1	44.4–63.6	51.0	47.9–54.1	—	—	—	—
How well does youth get to places outside the home?								
Very well or pretty well	52.6	46.0–59.1	52.0***	49.5–54.6	—	—	—	—
Not very well or not at all well, not allowed	41.2	30.6–52.7	39.2***	33.0–45.8	—	—	—	—
How well does youth count change?								
Very well or pretty well	48.6	41.2–56.1	—	—	—	—	—	—
Not very well or not at all well	48.0	38.2–58.0	—	—	—	—	—	—
How well does youth use the telephone and look up telephone numbers?								
Very well or pretty well	51.0	44.0–57.8	—	—	—	—	—	—
Not very well or not at all well	36.9	24.7–51.0	—	—	—	—	—	—

—, not applicable; FPL, federal poverty level.

* $P < .05$; *** $P < .001$.

the NLTS-2012 only included youth who could self-report, meaning that students whose parents did not perceive them as able to complete a self-report survey or interview were not included.

We do not know why more than half of autistic youth are excluded from RHE and SUPE, but we suspect that noninclusion may be related to perceived need. Teachers who responded to the NLTS-2 were least likely to rate autistic students who did not receive RHE or SUPE as being likely to benefit compared with other students with disabilities.[11] Additionally, autistic girls included in the NLTS-2012 were more likely to receive RHE than boys, possibly because girls are considered to be more affected by RHE. This is at odds with recent research wherein investigators indicated that autistic people desire relationships and engage in sexual behavior, including during adolescence.[13] Furthermore, studies have revealed that autistic adults are just as likely to have drug abuse or dependence diagnoses compared with control adults,[14] and 23% to 44% of autistic college students report using alcohol.[15] Of note, youth with 504 plan accommodations were about as likely as youth with no IEP or 504 plan to receive RHE.

Although we found significant differences between groups on receipt of RHE and SUPE, the absolute differences between groups were not large (eg, for RHE, reported receipt by group ranged from 44.6% to 60.7%). This could indicate problems with how the survey items were worded or interpreted by participants. Of note, these items were created by a national panel of experts and have been used previously.[11] Because of the design of the NLTS-2012, only youth with an IEP who could self-report were included in the autism category in this study, and results may not be generalizable to autistic youth who require either more or fewer supports (eg, those with 504 plan accommodations). A strength of self-report is that youth may know better than parents or teachers what education they received, although it is also possible that they do not recall. Additionally, from these data, we cannot demonstrate whether the learning needs of autistic students who received RHE or SUPE were appropriately supported.

The results of this study reveal that autistic students in the US are underserved when it comes to RHE and SUPE, despite Centers for Disease Control and Prevention, AAP, and Substance Abuse and Mental Health Services Administration recommendations underscoring the importance of school-based health programming for youth. Research that supports accessible and inclusive RHE and SUPE for students with intellectual and developmental disabilities is urgently needed to inform policy changes and address this education gap.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
CI: confidence interval
IEP: individualized education plan
NLTS-2: National Longitudinal Transition Study-2
NLTS-2012: National Longitudinal Transition Study-2012
OR: odds ratio
RHE: reproductive health education
SUPE: substance abuse prevention education

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Emergency Visits for Autistic Children and Children With ADHD

Whitney Schott, PhD, Sha Tao, MPH, Lindsay Shea, PhD

abstract

BACKGROUND AND OBJECTIVES: Autistic children and children with attention-deficit/hyperactivity disorder (ADHD) may have more frequent visits to the emergency department (ED). We aim to identify the primary reasons for ED visits among autistic children and children with ADHD, compared to a random sample of visits.

METHODS: Using 2008 to 2017 Nationwide Emergency Department Sample data, we assessed the most frequent primary diagnoses for ED visits among children (ages 3–12 and 13–18 years, separately) (1) with an autism diagnosis, (2) with ADHD, and (3) a random sample (1 000 000 visits). We regressed primary reasons for visits on autism or ADHD diagnosis, controlling for individual characteristics, to assess the odds of presenting for these reasons.

RESULTS: Although the 10 most frequent diagnoses among the random sample were physical health conditions, autistic children and children with ADHD often presented for psychiatric conditions. Older children with autism and with ADHD more frequently presented for mood disorders (10%–15% of visits; odds ratios [ORs] = 5.2–8.5) and intentional self-harm (ORs = 3.2–5.0). Younger children with ADHD more commonly presented with mood disorders (6.6% of visits; OR = 18.3) and younger autistic children more often presented with attention-deficit, conduct, and disruptive behavior disorders (9.7% of visits; OR = 9.7).

CONCLUSIONS: Autistic children and children with ADHD have higher odds of presenting to the ED for psychiatric conditions than a random sample, including for self-harm. Clinicians should treat these populations sensitively, recognize and assess the risk for self-harm, and facilitate continuing psychiatric care.

AJ Drexel Autism Institute, Drexel University, Philadelphia, Pennsylvania

Dr Schott conceptualized the study, conducted literature review, drafted the initial manuscript, and reviewed and revised the manuscript; Dr Shea conceptualized the study and reviewed and revised the manuscript; Mr Tao conducted all data analysis and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Whitney Schott, AJ Drexel Autism Institute, 3020 Market St, Suite 560, Philadelphia, PA 19104. E-mail: whitney.b.schott@drexel.edu

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WHAT'S KNOWN ON THIS SUBJECT Autistic hildren and children with developmental disabilities have more emergency department visits than neurotypical children, and mental health reasons drive many visits for adolescents. Emergency department visits for mental health conditions have been increasing over the last decade.

WHAT THIS STUDY ADDS Mood disorders and behavioral concerns drive many visits to the emergency department among autistic children and children with ADHD; suicidal ideation or intentional self-harm is a main presenting diagnosis among adolescents. Risk assessment and follow-up psychiatric care may be necessary.

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Autism spectrum disorder (ASD) is the fastest-growing developmental disability in the United States, reaching a prevalence of 1 in 54 in 2020,[1] and attention-deficit hyperactivity disorder (ADHD) is the most prevalent developmental disability, diagnosed for 9.5% of children in 2017.[2] Research suggests that visits to the emergency department (ED) among children with developmental disabilities like these may be more frequent than for their neurotypical peers.[3–5]

In some cases, children with developmental disabilities may present to the ED when psychiatric care needs are not otherwise met.[6] In fact, psychiatric diagnoses drive many ED visits among autistic youth ages 12 to 15.[7] Such visits have risen substantially over the last decade for children with mental health diagnoses, and visits for intentional self-harm have also increased.[8] Although we know psychiatric diagnoses are more common among children with developmental disabilities, it is not clear how often they are the leading causes of presentation to the ED. We examined primary reasons for ED visits among children ages 3 to 18 with diagnoses of ASD or ADHD to assess whether psychiatric conditions were among the top 10 reasons for ED visits and whether the top 10 reasons differed from a random sample of visits over the period 2008 to 2017.

METHODS

We used 2008 to 2017 data from the Nationwide Emergency Department Sample (NEDS), which contains data for > 30 million annual ED visits. All analyses were based on weighted data adjusted for complex survey design to produce nationwide visits-level statistics with ED visits as the unit of analysis

Patient Characteristics

We used Clinical Classification Software (CCS), which classifies *International Classification of Diseases, 9th Revision* (ICD-9) and *10th Revision* (ICD-10) diagnoses into clinically relevant categories. We defined 2 diagnostic groups of children ages 3 to 18 years by developmental disorder: (1) autism (ICD-9 = 299.xx, ICD-10 = F84.x) and (2) ADHD (attention-deficit, conduct, and disruptive behavior disorders, CCS = 652). Visits were assigned to the corresponding group if any diagnosis of that condition was coded, regardless of the order in which it was coded (up to 35 diagnoses were allowed). The primary reason for presentation at the ED was identified with the primary diagnosis coded. When the primary diagnosis was the same as the developmental disability group into which the child was classified, we recoded the primary reason as the secondary diagnosis. We also examined primary reasons for ED visits for a random sample of visits of children 3 to 18 years old (with or without developmental disabilities, $n = 1\,000\,000$). Controls included age (in integers), sex, region, health plan type, residence type, income quartile, and ED "disposition" (eg, transfer or inpatient admission).

Analysis

We calculated descriptive statistics and then sorted primary diagnoses in order of frequency to rank the 20 most frequent reasons for ED presentation within each group. We conducted logistic regressions of primary diagnosis on diagnostic group and controls, estimating odds ratios (ORs) for each diagnostic group compared with the random sample, separately for each group.

RESULTS

Nationwide, there were an estimated 20 338 690 annual pediatric (ages 3–18) ED visits on average for the period 2008 to 2017. Of these, 107 337 (0.5%) were for autistic patients and 448 094 (2.2%) were for patients with ADHD. In 2017, these values were 0.8% and 2.5% of total visits, respectively.

Patients with 1 of these 2 developmental disabilities had higher rates of transfer and inpatient admission than the general population; 13.9% (autism) and 13.1% (ADHD) were admitted to inpatient, and 5.9% and 7.9%, respectively, transferred to other facilities (compared with 3.3% admitted to inpatient, 2.1% transferred in the random sample) (Table 1). The proportion of visits for psychiatric conditions increased for the autism and ADHD groups yet remained relatively stable in the random sample.

Physical Conditions

Among the random sample of pediatric visits of both younger and older children, the 10 most frequent primary diagnoses were physical conditions (Tables 2 and 3). Among visits of younger autistic children, the top 10 physical conditions differed from the random sample for the following conditions: epilepsy and convulsions (6.4% of visits), other gastrointestinal disorders (3.4% of visits), and nausea and vomiting (3.1% of visits). For older autistic children, the top 10 reasons for presentation included epilepsy and convulsions (8.8% of visits), which was not a top 10 condition in the random sample. Among visits of younger children with ADHD, a top 10 condition for presentation not as common in the random sample was "open wounds of extremities;" among older children with ADHD, there were no physical conditions that did not appear in the top 10 conditions of the random sample.

TABLE 1 Individual Characteristics, Autistic Patients, Patients with ADHD, and Random Sample

	Autism (n = 237 154)			ADHD (n = 985 432)			Random Sample (n = 1 000 000)	
	Est. Pop. n	%	P	Est. Pop. n	%	P	Est. Pop. n	%
Age group, y								
3–12	70 677	65.8	<.0001	218 971	48.9	<.0001	266 792	59.7
13–18	36 660	34.2	<.0001	229 123	51.1	<.0001	180 294	40.3
Sex								
Male	85 705	79.8	<.0001	300 359	67.0	<.0001	224 420	50.2
Female	21 619	20.1	<.0001	147 668	33.0	<.0001	222 561	49.8
Missing	13	0.0	—	66	0.0	—	105	0.0
Hospital region								
Northeast	25 689	23.9	<.0001	98 077	21.9	.0009	84 087	18.8
Midwest	23 461	21.9	.0391	116 197	25.9	.0205	105 582	23.6
South	34 929	32.5	<.0001	186 891	41.7	.0051	171 780	38.4
West	23 259	21.7	.0020	46 929	10.5	<.0001	85 638	19.2
Primary payer								
Public	62 807	58.5	<.0001	274 191	61.2	<.0001	234 932	52.5
Private including HMO	37 039	34.5	.0044	139 909	31.2	<.0001	159 156	35.6
Self-pay	2954	2.8	<.0001	17 312	3.9	<.0001	34 789	7.8
No charge	4400	4.1	.1070	15 896	3.5	.0054	17 220	3.9
Missing	137	0.1	—	786	0.2	—	990	0.2
Residence								
Large central metropolitan	32 212	30.0	.0128	105 848	23.6	<.0001	124 244	27.8
Large fringe metropolitan	25 805	24.0	.0018	100 924	22.5	.3835	97 907	21.9
Medium metropolitan	25 136	23.4	.0451	113 776	25.4	<.0001	97 310	21.8
Small metropolitan	9518	8.9	.1274	47 199	10.5	.0198	41 943	9.4
Micropolitan	9506	8.9	<0001	53 421	11.9	.1058	50 278	11.2
Rural	4839	4.5	<.0001	25 597	5.7	<.0001	33 868	7.6
Missing	321	0.3	—	1329	0.3	—	1536	0.3
Disposition type								
Routine	84 584	78.8	<.0001	346 942	77.4	<.0001	414 087	92.6
Transfer	6329	5.9	<.0001	35 366	7.9	<.0001	9253	2.1
Inpatient admission	14 955	13.9	<.0001	58 507	13.1	<.0001	14 881	3.3
Other	1469	1.4	<.0001	7278	1.6	.0536	8866	2.0
Income level								
Q1 (low)	29 054	27.1	<.0001	144 999	32.4	.1267	148 323	33.2
Q2	27 709	25.8	.0003	122 565	27.4	.4189	120 924	27.0
Q3	25 416	23.7	<.0001	96 679	21.6	.9221	96 591	21.6
Q4 (high)	23 483	21.9	<.0001	76 281	17.0	.3787	74 435	16.6
Missing	1675	1.6	—	7570	1.7	—	6813	1.5
Year								
2008	6181	5.8	<.0001	34 475	7.7	<.0001	42 792	9.6
2009	6825	6.4	<.0001	39 497	8.8	<.0001	46 718	10.4
2010	7226	6.7	<.0001	38 120	8.5	.0024	42 584	9.5
2011	9085	8.5	<.0001	46 294	10.3	.4205	44 578	10.0
2012	9979	9.3	.0075	46 813	10.4	.6732	45 994	10.3
2013	10 792	10.1	.7722	47 599	10.6	.1625	44 369	9.9
2014	12 852	12.0	<.0001	49 076	11.0	.0267	43 846	9.8
2015	13 161	12.3	.0001	48 582	10.8	.2145	45 734	10.2
2016	14 855	13.8	<.0001	46 858	10.5	.9096	46 527	10.4
2017	16 381	15.3	<.0001	50 782	11.3	.0035	43 944	9.83

Source: Authors' calculations from NEDS data, 2008–2017. Est. Pop. N = weighted estimate of the population of this group among ED visits in the United States; Est. Pop. % = weighted estimate of the percentage of this group among ED visits in the United States figures for the random sample do not represent the entire United States; it is random sample of 1 000 000 visits. P values represent χ^2s for row differences between the diagnostic group and the random sample..

Psychiatric Conditions

Psychiatric diagnoses were not among the 20 most frequently diagnosed conditions in the random sample of children, except for mood disorders for older children (ranking 12th). In contrast, psychiatric conditions were among the top 10 conditions for both younger and older children with an autism or ADHD diagnosis. These included mood disorders and suicide or intentional self-harm.

Odds Ratios

In adjusted regressions, both younger and older autistic children

TABLE 2 Most Frequent Reasons for ED Visits, % of Visits, and Odds Ratios by Age (3–12) and Diagnostic Group

	Autism (*n* = 156 381)			ADHD (*n* = 482 358)			Random Sample (*n* = 597 777)	
Rank	Description	Percent of Visits	OR (95% CI)	Description	Percent of Visits	OR (95% CI)	Description	Percent of Visits
1	Other upper respiratory infections	7.7	0.65 (0.62–0.68)	Mood disorders[a]	6.6	18.30 (16.55–20.24)	Other upper respiratory infections	12.1
2	Epilepsy; convulsions	6.3	8.27 (7.71–8.87)	Superficial injury; contusion	6.0	0.76 (0.73–0.80)	Superficial injury; contusion	6.7
3	Superficial injury; contusion	5.0	0.71 (0.68–0.74)	Other upper respiratory infections	5.8	0.52 (0.49–0.55)	Open wounds of head; neck; and trunk	5.3
4	Other injuries and conditions due to external causes	4.7	1.03 (0.98–1.08)	Other injuries and conditions due to external causes	3.5	0.82 (0.77–0.87)	Otitis media and related conditions	5.0
5	Attention-deficit, conduct, and disruptive behavior disorders[a]	4.0	9.71 (8.80–10.72)	Sprains and strains	3.3	0.60 (0.57–0.63)	Other injuries and conditions due to external causes	4.5
6	Open wounds of head; neck; and trunk	3.8	0.67 (0.64–0.70)	Abdominal pain	3.0	0.76 (0.72–0.80)	Asthma	3.6
7	Otitis media and related conditions	3.5	0.79 (0.75–0.83)	Open wounds of head; neck; and trunk	2.8	0.68 (0.65–0.72)	Fracture of upper limb	3.6
8	Other gastrointestinal disorders	3.4	1.81 (1.70–1.91)	Asthma	2.8	0.75 (0.71–0.79)	Sprains and strains	3.6
9	Nausea and vomiting	3.1	1.26 (1.19–1.33)	Open wounds of extremities	2.7	0.73 (0.69–0.77)	Abdominal pain	3.5
10	Asthma	2.8	0.68 (0.64–0.72)	Fracture of upper limb	2.3	0.52 (0.49–0.55)	Fever of unknown origin	3.2

Source: Authors' calculations from NEDS data 2008 to 2017. Diagnoses are from CCS. Only top 10 most frequent diagnoses listed for each group. For percent of visits column, *P* values for χ^2 tests between the diagnostic group and the random sample was <.01 for all variables. Logistic regressions control for age (in integers), sex, hospital region, primary payer, residence, and income category. ASD, autism spectrum disorder; ADHD, attention deficit-hyperactivity disorder; OR, odds ratio; 95% CI, 95% confidence interval.

[a] Indicates mental health diagnosis.

had higher odds of going to the ED for epilepsy and seizures compared with the random sample (OR = 8.27 [7.71–8.87] and OR = 12.13 [11.13–13.23], respectively [Tables 2 and 3 and Fig 1]). Younger autistic children had higher odds of presenting to the ED for gastrointestinal disorders (OR = 1.81 [1.70–1.91]).

Both younger and older children with ADHD had substantially higher odds of mood disorder compared with the random sample (OR = 18.30 [16.55–20.24], OR = 8.47 [7.95–9.02], respectively). Among older children with ADHD, odds of presenting to the ED for anxiety disorder or suicide or intentional self-harm were higher (OR = 3.22 [3.03–3.44]; OR = 5.01 [4.64–5.40], respectively). For younger autistic children, odds of ADHD were higher (OR = 9.71 [8.80–10.72]), and for older autistic children, odds were higher for mood disorders (OR = 5.15 [4.74–5.60]), ADHD (OR = 12.06 [10.80–13.46]), anxiety (OR = 3.45 [3.15–3.79]), and suicide or intentional self-harm (OR = 3.17 [2.86–3.51]).

DISCUSSION

The top 10 physical health conditions prompting visits to the ED among autistic children that were not as common among the random sample were epilepsy and seizures, nausea and vomiting, and other gastrointestinal disorders. Clinicians should be prepared to treat these conditions commonly occurring among children with an autism diagnosis.

In place of physical conditions driving most visits in the random sample, mental health conditions emerged among children with diagnoses of autism or ADHD. Children with these developmental disabilities presented more often for mood disorders (10.2% for older autistic children, 15.4% for older children with ADHD). Even among younger children with ADHD, mood disorders drove a substantial portion of visits (6.6%). These findings persisted in adjusted regressions and aligned with previous evidence that mood disorders are a common reason for ED visits among autistic adolescents.

Importantly, suicide or intentional self-harm was among the top 10 reasons for ED presentation among older children with ADHD or autism diagnoses, prompting 3.0% and 2.2% of visits, respectively. These findings bolster previous evidence of increases in this diagnosis at the

TABLE 3 Most Frequent Reasons for ED Visits, % of Visits, and Odds Ratios by Age (13–18) and Diagnostic Group

	Autism (*N* =80 773)			ADHD (*N* = 503 074)			Random Sample (*N* = 402 223)	
Rank	Description	Percent of Visits	OR (95% CI)	Description	Percent of Visits	OR (95% CI)	Description	Percent of Visits
1	Mood disorders[a]	10.2	5.15 (4.74–5.60)	Mood disorders[a]	15.4	8.47 (7.95–9.02)	Sprains and strains	8.3
2	Epilepsy; convulsions	8.8	12.13 (11.13–13.23)	Superficial injury; contusion	5.4	0.71 (0.68–0.74)	Superficial injury; contusion	7.0
3	Attention-deficit, conduct, and disruptive behavior disorders[a]	6.7	12.06 (10.80–13.46)	Sprains and strains	4.6	0.50 (0.47–0.52)	Other upper respiratory infections	5.9
4	Superficial injury; contusion	3.6	0.45 (0.42–0.48)	Anxiety disorders[a]	3.0	3.22 (3.03–3.44)	Abdominal pain	5.2
5	Anxiety disorders[a]	3.2	3.45 (3.15–3.79)	Suicide and intentional self-inflicted injury	3.0	5.01 (4.64–5.40)	Other injuries and conditions due to external causes	3.7
6	Other injuries and conditions due to external causes	3.0	0.66 (0.61–0.72)	Other upper respiratory infections	2.8	0.45 (0.42–0.48)	Open wounds of extremities	3.4
7	Other upper respiratory infections	2.6	0.47 (0.43–0.51)	Other injuries and conditions due to external causes	2.8	0.69 (0.64–0.74)	Fracture of upper limb	2.8
8	Suicide and intentional self-inflicted injury[a]	2.2	3.17 (2.86–3.51)	Abdominal pain	2.7	0.59 (0.55–0.63)	Urinary tract infections	2.5
9	Sprains and strains	2.2	0.22 (0.20–0.24)	Open wounds of extremities	2.7	0.70 (0.66–0.73)	Headache; including migraine	2.5
10	Abdominal pain	2.1	0.51 (0.46–0.56)	Fracture of upper limb	1.9	0.52 (0.49–0.55)	Skin and subcutaneous tissue infections	2.3

Source: Authors' calculations from NEDS data 2008 to 2017. Diagnoses are from Clinical Classification Software (CCS). Only top 10 most frequent diagnoses listed for each group. For percent of visits column, *P* values for χ^2 tests between the diagnostic group and the random sample was $<.01$ for all variables.

Logistic regressions control for age (in integers), sex, hospital region, primary payer, residence, and income category. ASD, autism spectrum disorder; ADHD, attention deficit-hyperactivity disorder; OR, odds ratio; 95% CI, 95% confidence interval.

[a] Indicates mental health diagnosis.

ED,[8–11] although this trend was not necessarily apparent a decade ago.[7]

The increasing frequency of visits for psychiatric reasons over the last decade for children with ADHD or autism diagnoses also bolsters previous findings.[8,12] Such increases could be due to a higher prevalence of psychiatric conditions, increasing awareness of psychiatric conditions, lack of adequate care outside the ED environment, or other reasons. Children with these developmental conditions had higher rates of admission to inpatient care and transfer to other services. Together, these findings could indicate an increasing prevalence of more severe psychiatric impairments over time, although additional research is warranted.

Overall, findings underline the importance of identifying psychiatric issues, arranging for continuing care, and screening ED visits for potential self-harm. Early identification of suicidal ideation may prevent self-harm; ED screening with evidence-based questionnaires is feasible in a pediatric population and could identify cases that would otherwise be missed.[13] In addition to routine screening for abuse, clinicians should screen for self-harm risk and facilitate the continuation of care with psychiatric services when appropriate. Referral, persistent follow-up, and warm transfers could ensure patients obtain necessary psychiatric care.[14,15]

This study has some limitations. NEDS data are at the encounter level, obviating longitudinal investigation and assessment of repeat visits. Second, diagnostic practices changed over this period, so cases captured may differ over time. However, extreme discontinuity is not likely, as diagnoses at ED visits may not rely on extensive clinical testing. Third, there are co-occurring diagnoses, so some visits reflect children with both autism and ADHD diagnoses.

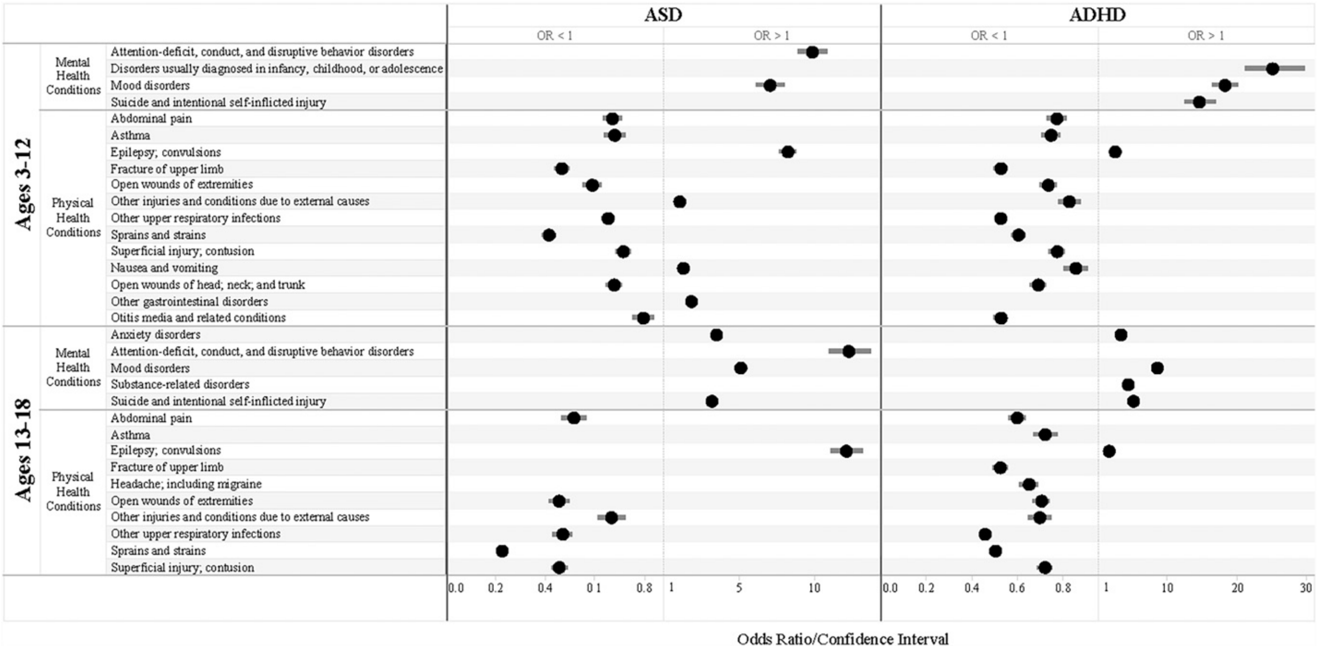

FIGURE 1

Odds ratios and confidence intervals, regressions of reasons for presentation at the ED on neurodevelopmental group and individual characteristics. Odds ratios are represented by circles and 95% confidence intervals appear as bars on either side. Logistic regressions control for age (in integers), sex, hospital region, primary payer, residence, and income category. Conditions are shown in the figure only if they were ranked in the top 10 conditions in terms of frequency for either group.

We allowed for this overlap to capture cases in which children with 1 developmental condition presented to the ED for the other developmental condition. Therefore, findings should be considered for the 2 groups independently, compared only with the random sample. Fourth, groupings were based on coding designed for billing purposes; thus, there may be coding variation among providers. Lastly, we may miss individuals with undiagnosed psychiatric conditions, which could lead to underestimation of differences. We note that NEDS data are nationally representative of ED visits in the United States from 2008 to 2017, representing individuals regardless of insurance coverage.

It is important for clinicians to understand common reasons for presentation to the ED among autistic children and children with ADHD to respond effectively and sensitively. ED visits may be an important point of contact to assess the risk of self-injurious behavior and facilitate psychiatric evaluation and/or continuing care.

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ABBREVIATIONS

ADHD: attention-deficit/hyperactivity disorder
ASD: autism spectrum disorder
CCS: Clinical Classification Software
ED: emergency department
ICD-9: *International Classification of Diseases, 9th Revision*
ICD-10: *International Classification of Diseases, 10th Revision*
NEDS: Nationwide Emergency Department Sample
OR: odds ratio

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A Residency Program Curriculum to Improve Health Care Transitions for Autistic Individuals

Priyanka Fernandes, MBBS, MPH,[a] Jason Timmerman, BA,[a] Emily Hotez, PhD,[a] Madeline Haley, BS,[a] Angela Reyes, MPH,[c] Frederick Ferguson, MD,[b] Alice Kuo, MD, PhD[a,c]

abstract

OBJECTIVES: Physical and mental health outcomes of autistic individuals deteriorate during transition to adulthood. The study aims to identify opportunities to improve physician knowledge in health-care transitions (HCT) for autistic individuals by understanding perceived versus experienced facilitators and barriers in overall HCT curriculum implementation in graduate medical education.

METHODS: Medicine-Pediatrics program directors participated in a Health Care Transition Residency Curriculum Collaborative Improvement Network and used an iterative process to develop and improve HCT curricula. Pre- and postcollaborative semistructured interviews were administered to program directors. The study occurred over 9 months (July 2018–February 2019). Recurring interview themes were analyzed utilizing Dedoose qualitative coding software and presented utilizing percentages and proportions.

RESULTS: Most program directors developed curricula in response to a gap in their current transition curricula. All program directors partially or completely met their goals during the collaborative. The most common types of curricular delivery were didactic (65%) and clinical experience-based (53%). Some tested unique delivery platforms, like the electronic medical record system (29%) and online modules (24%). Program directors often involved residents in the curricular development process and overwhelmingly (65%) felt this was a major facilitator. Competing priorities of faculty (71%) and of residents (53%) were the most common barriers.

CONCLUSIONS: Gaps in HCT curricula delivery were primarily attributed to suboptimal health care systems where training occurs, though existing clinical experiences and diverse learning modalities were successfully leveraged. Using a quality improvement framework and actively engaging resident trainees in curriculum development were successful strategies programs used in the development of HCT curricula.

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[a]Division of Medicine-Pediatrics, Departments of Medicine and [b]Family Medicine, and [c]Fielding School of Public Health, University of California, Los Angeles, Los Angeles, California

Dr Fernandes designed the data collection instruments, coordinated and supervised data collection, and critically reviewed the manuscript for important intellectual content; Dr Hotez conducted the analyses, drafted the initial manuscript, and critically reviewed the manuscript for important intellectual content; Mr Timmerman conducted the initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Haley and Ms Reyes collected data and reviewed and revised the manuscript; Dr Ferguson conducted the initial analyses and reviewed and revised the manuscript; Dr Kuo conceptualized and designed the study, designed the data collection instruments, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Priyanka Fernandes, 911 Broxton Avenue, Los Angeles, CA 90024.
E-mail:pfernandes@mednet.ucla.edu

WHAT'S KNOWN ABOUT THIS SUBJECT Physical and mental health outcomes of autistic individuals deteriorate during the transition to adulthood. Concepts and skills related to pediatric-to-adult health care transitions are not systematically taught in residency training programs, contributing to poor provider knowledge in caring for this population.

WHAT THIS STUDY ADDS The perspectives of residency training program directors regarding the need for a pediatric-to-adult health care transition curriculum in residency training programs, facilitators and barriers for the same and opportunities that exist within current systems.

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SUPPLEMENT ARTICLE

IMPROVING HEALTH CARE TRANSITIONS IN AUTISM: OPPORTUNITIES IN GRADUATE MEDICAL EDUCATION

Growing evidence highlights the unmet physical and mental health needs of autistic individuals as they transition into adolescence and early adulthood.[1,2] Nationally, health systems have not successfully scaled health care transition services, particularly for autistic individuals.[3] Despite the growing evidence of its importance, a recent study showed less than 20% of youth receive transition planning support.[4] Among youth with special health care needs (YSHCN), autistic youth are half as likely to receive transition services compared with non-autistic youth.[5]

Provider knowledge, particularly among adult providers, has been identified as an important barrier in improving health care transitions (HCT) and access among autistic adults.[6,7] Research finds that graduate medical trainees feel unprepared to address transition issues with their patients with chronic diseases.[8] While health care systems might not be set up to facilitate optimal transitions of care, increased exposure to and training in caring for patients in the transitional age group predicts higher self-reported confidence among trainees.[8] Although educational resources have been developed for resident trainees by multiple professional medical organizations, and educational goals and objectives for the topic of HCT have been published,[9,10] there continues to be a discrepancy between recommendations from guidelines and resident practice. Taken together, previous research underscores a gap in physician training in HCT for autistic individuals and YSHCN, likely stemming from a larger gap that exists for HCT training in general.[6,11]

Physicians dually trained in medicine and pediatrics care for patients across the age spectrum and are in a unique position of enhancing the transition experience for their patients. In the current study, we aimed to understand the experiences of medicine-pediatrics program directors participating in a learning collaborative focused on developing HCT curricula for their resident trainees. In particular, we wanted to determine perceived versus experienced facilitators and barriers in curriculum implementation during the collaborative. Findings from this study could help identify opportunities in improving physician training during graduate medical education on the topic of HCT in autistic individuals.

METHODS

Study Design

The study was designed as a prospective cohort study to understand program director experiences before and after participation in a quality improvement learning collaborative described below. The Health Care Transition Residency Curriculum Collaborative Improvement Network (HCT-CoIN) was a national quality improvement learning collaborative over 9 months (June 2018–February 2019), adapted from the Institute for Healthcare Improvement's Breakthrough Series model.[12] The purpose of the HCT-CoIN was to create a toolbox of resources for medicine-pediatrics residency program directors to implement or enhance HCT curricula at their own institutions. Participation in the network was open to all program directors who are members of the Medicine Pediatrics Program Directors Association and participants were provided an incentive of $1000.

Sample

Program directors from 19 medicine-pediatrics residency programs across the country (Table 1) participated in the collaborative and were included in the study. Most worked on developing or enhancing a transition-based curriculum, while some worked on developing or enhancing tools to be used for evaluating residents in HCT. Program directors met monthly to present their improvement projects and discuss lessons learned and next

TABLE 1 Residency Program Characteristics at Baseline

Program Characteristics	$N = 19$
Method of curricular delivery, *n* (%)[a]	
Didactics	12 (63)
Clinic-based (required)	7 (37)
Clinic-based (elective)	2 (11)
Online modules	2 (11)
Subspecialty rotation	11 (58)
Clinical setting, *n* (%)[a]	
Academic	13 (68)
Community-based	7 (37)
Private clinic	3 (16)
Population demographic, *n* (%)[a]	
Urban	16 (84)
Suburban	10 (53)
Rural	3 (16)
Additional program characteristics, median (range)	
Number of residents or cohort	16 (8–24)
Number of core faculty	19 (1–16)

[a] Nonmutually exclusive categories.

steps. One program director withdrew after 4 months of participation; the remaining 18 completed the collaborative.

Data Collection and Measures

We conducted telephone interviews with all program directors at baseline and after completion of the collaborative. Questions at baseline aimed at understanding the intent behind implementing a transition curriculum, individual program goals, and facilitators and barriers in creating a transition curriculum. Questions at follow-up aimed at understanding how successful program directors were in implementing HCT curricula, whether and how they achieved their goals, and experienced facilitators and barriers.

The qualitative coding scheme (Tables 2 and 3) was developed to capture recurring responses within a set of 4 themes: 1) intent behind curricular development, 2) program goals during the collaborative, 3) facilitators, and 4) barriers. All interviews were coded utilizing Dedoose coding software. To obtain interrater reliability a second coder coded 10% of the transcripts at each data collection period and achieved at least 80% interrater agreement on each code.

The host institution and all programs received exemption from their individual institutional review boards before participation in the collaborative.

RESULTS

There were 18 of the 19 program directors who completed the baseline interview and 17 of the 18 programs who completed the follow-up interview. The participating program characteristics are outlined in Table 1.

Intent Behind Curriculum Development

Program directors wanted to implement HCT curricula because they understood the importance of transition planning in the overall care of patients (39%) but recognized their health systems' inadequacies in addressing transitions (50%) (Table 2). A program director stated " … there's not a lot of physicians who have been trained in these areas." About a third of the programs (28%) did not have any transition curriculum at the time of the baseline interview.

Program Goals During Collaborative

Most program directors at baseline (67%) planned on developing a clinical experience-based curriculum, and 53% of program directors at follow-up were successful in doing so. More than half (56%) of program directors planned to adopt a didactic-based curriculum at baseline; 65% reported successful adoption at follow-up (Tables 2 and 3). Seventeen percent of programs planned on developing clinic-based tools and protocols for transition; more than twice the number of programs were successful in doing so by the end of the collaborative (35%), citing " … utilizing a checklist tool will be helpful … ". Similarly, 11% planned on using the electronic health record as a curricular tool and 29% were able to develop these, noting " … biggest change was making dot phrases to put in EPIC (electronic health record system) … " Although not initially reported as goals at baseline, several program directors cited the ability of faculty to work on transition projects outside of the residency curriculum (24%), and collaboration with subspecialties to deliver the curriculum (24%) at follow-up.

All program directors reported that they met their goals at least partially (6 programs met all short-term goals while 11 programs partly met their short-term goals). The majority (53%) felt they would be able to sustain changes that were adopted during the collaborative.

Facilitators

At baseline, program directors felt that leadership and faculty support and faculty and staff capacity would be the biggest facilitators in curriculum development (50% and 33% respectively) (Tables 2 and 3). At follow-up, program directors stated actively involving residents in the curricular development process served as an important facilitator (65%), in addition to faculty support (53%), reporting " … residents enjoy and are on same page in terms of curriculum … ".

Barriers

Barriers identified at baseline by program directors also held true at follow-up: competing priorities of faculty and staff (67% at baseline, 71% at follow-up) and insufficient number of trained faculty in transitional care (28% at baseline, 18% at follow-up) (Tables 2 and 3). Another important barrier identified at follow-up was competing learning priorities for residents (53%): " … finding time to get things done, everyone is always pulled in different directions in terms of scheduling … " An unanticipated finding on follow-up was the fact that patients ready for transition care were not readily identifiable among the scheduled clinic patients (29%). System-based barriers, such as lack of leadership support and insurance difficulties, were less common among programs at follow-up (12% each).

DISCUSSION

The transition into adulthood is a vulnerable period, as well as an opportunity to promote lifelong physical and mental health for

TABLE 2 Program Director Interview Responses at Baseline ($N = 18$)

Code	*n* (%)	Example Quotations
Why are you implementing a health care transition (HCT) curriculum in your program?		
Recognition of health system inadequacies in transition planning	9 (50)	“ . . . lack of resources not just from the standpoint of lack of clinic, but there's not a lot of physicians who have been trained in these areas.”
Need for improving care for patients	7 (39)	“I think this is what we should be doing–we need this in our curriculum.”
Need for improving clinic protocols around transition	6 (33)	“Hope to identify ways to better serve those who are transitioning to us from peds”
Absence of dedicated transition clinic to deliver or support transition curriculum	6 (33)	“In general, we do not have transitional curriculum nor have a great transitional workflow to any capacity . . . ”
Absence of transition curriculum for residents	5 (28)	“...no standardized curriculum no manpower to develop it . . . ”
What are your goals in implementing this program (short and long term)?		
Creating or refining a clinical experience-based curriculum	12 (67)	“To have an educational program in place in the next year: didactics and meaningful clinical experiences.”
Creating or refining a didactic-based curriculum	10 (56)	“We have med peds meetings and lectures . . . ”
Matching appropriate transition model to the health care system	7 (39)	“Looking towards having a structured inpatient and outpatient transition process on the peds side . . . ”
Creating or refining online modules on health care transition	6 (33)	“The online educational platform will be the greatest benefit for sustainability.”
Developing standardized clinical tools or protocols	3 (17)	“ . . . drafted a policy for the institution . . . ”
Developing clinical tools using the electronic health record	2 (11)	“Biggest barrier is access to EPIC IT group for creating some of the products, particularly the patient registry . . . ”
Hiring staff experienced in health care transitions	2 (11)	“ . . . hire a transitionalist: work at clinic as well as inpatient, and cares for all transitional-aged patients (hopefully for all, not only patients with high needs).”
What facilitators do you have in your program to make this a successful endeavor?		
Leadership or faculty support	9 (50)	“He came to MedPeds because of his interest in transition care . . . he wants to be a champion of care for medically complex patients.”
Appropriate capacity in terms of faculty and staff	6 (33)	“ . . . I don't have such a big clinical burden that I've had in the past, so I have more administrative time.”
What do you foresee as being major barriers for implementing this curriculum?		
Competing priorities of faculty and staff	12 (67)	“ . . . time commitment both from the faculty perspective as well as the trainees' perspectives.”
Inadequate number of trained faculty in health care transitions	5 (28)	“No clinic nor dedicated faculty yet . . . ”
How do you think your trainees will respond to this new curriculum?		
High interest in developing a transition curriculum for program	13 (72)	“They are excited about transitions, they mentioned it during their interviews.”
How have you planned for sustainability?		
Incorporating a longitudinal curriculum into existing rotations or health system's structure	11 (61)	“ . . . plan on making it a longitudinal curriculum where trainees can build upon their prior knowledge over time, . . . we are trying to incorporate it in the pediatric advocacy rotation which is more robust . . . ”
How have you incorporated patients and/or their families into your program planning?		
Developing an advisory board or committee	4 (22)	“We have adolescent leadership advisory board.”

EPIC, electronic health record system; IT, information technology support; MedPeds, Medicine-Pediatrics faculty group; peds, pediatrics.

emerging adults, that requires strategic coordination of services.[13] Disparities during this transition are higher for YSHCN, but particularly for autistic individuals.[4,5] A knowledge gap exists among providers, particularly adult providers caring for autistic individuals,[6,7] and enhancing graduate medical education learning experiences in HCT in a diverse patient population could help fill this gap. Developing a curriculum can improve the confidence among resident trainees in addressing transitions of care among peers and families alike.[8,14] Ours is the first study to investigate program directors' perspectives while adopting transition curricula in medicine-pediatrics residency

TABLE 3 Program Director Interview Responses After Completion of Learning Collaborative ($N = 17$)

Code	*n* (%)	Example Quotations
Do you think your goals were met?		
Yes, met short-term goals*	6 (35)	
No, but made progress in short-term goals*	11 (65)	
What were the major changes you made?		
Creating or refining a didactic-based curriculum	11 (65)	“Primarily didactic – some roleplaying, expert on transitional care faculty come in to speak … ”
Creating or refining a clinical experience-based curriculum	9 (53)	“Residents to be more familiar with the transition process and local resources … ”
Developing standardized clinical tools and protocols	6 (35)	“ … utilizing checklist tool will be helpful … ”
Developing clinical tools using the electronic health record	5 (29)	“ … biggest change was making dot phrases to put in EPIC … ”
Creating or refining online modules on health care transition	4 (24)	“ … added entire section on online learning environment related to transition … ”
Work on noncurricular transition work	4 (24)	“ … (use) excited transition staff to create videos and participate in educational piece … ”
Collaboration with subspecialty to build curriculum	4 (24)	“ … expanding reaching out to subspecialties to see what can offer for caring for patients … ”
How did you use the HCT curriculum (from the collaborative) in your program?		
Learning from and sharing with peers enabled better curricular planning	5 (29)	“Participating in collaboration helpful – can be easy to get discouraged but having deadline and following in QI format helpful to stay accountable”
What was your approach in implementing changes?		
Conducted a needs assessment among residents and faculty	9 (53)	“ … getting sense of what needs are – speaking to stakeholders, needs assessment … ”
Using a quality improvement framework	3 (18)	“ … doing multiple PDSA cycles … through monthly calls helped and was successful … ”
What facilitators helped you implement the curriculum?		
Involving residents in the process	11 (65)	“ … residents enjoy and are on same page in terms of curriculum … ”
Faculty support	11 (65)	“Need champions in several areas other than yourself – need reliable people and more collaborators”
What were your barriers to implementation?		
Competing priorities of faculty and staff	12 (71)	“ … everyone is always pulled in different directions in terms of scheduling … ”
Competing priorities of resident trainees	9 (53)	“ … finding time to get things done, everyone is always pulled in different directions in terms of scheduling … ”
Inadequate number of trained faculty in health care transitions	3 (18)	“I need more faculty development with faculty who are interested in teaching transition.”
Lack of leadership support	2 (12)	“ … having people in higher-up positions be supported … ”
Limitations with health care insurance	2 (12)	“ … huge barrier is insurance … ”
Which changes that you made will be sustainable?		
All changes made during collaborative	9 (53)	“ … sustainable because of strong belief, faculty awareness … ”
What surprising or unanticipated outcomes (positive or negative) occurred during the course of your project?		
Inability to easily identify patient population ready for transition	5 (29)	“ … the patient population is hard to locate … ”

EPIC, electronic health record system; PDSA, plan-do-study-act; QI, quality improvement.

[a] Mutually exclusive answers.

training programs during a national learning collaborative.

Similar to prior studies,[9] program directors in the study highlighted health system inadequacies in addressing transitions into adulthood. Despite this, all programs were successful in meeting and progressing in their goals of developing a transition curriculum during the collaborative. The finding is a testimony to the strength of learning collaboratives and the impact of using a quality improvement framework in curricular development.[12]

Resident trainees appreciate having diverse modalities of HCT curricula.[15] Our study found didactic- and clinical experience-based learning were most popular while delivering HCT curricula. Other modalities which were used included online modules, the electronic health record system, and clinic protocols. Our study was therefore able to attest to the feasibility and acceptability of using diverse educational platforms and strategies for graduate medical trainees, as recommended by the

Transitions Clinical Report Authoring Group.[9]

Program directors leveraged resident participation in HCT curricular development, alongside faculty support, and found these to be major facilitators. These might be particularly important when health systems lack dedicated staff, faculty, and infrastructure to deliver optimal transition care. However, while resident trainees were major facilitators, they posed a barrier because of their busy schedule and competing learning priorities. Therefore, transition curricula should be incorporated in existing clinical experiences.[9]

While our study focused on understanding perspectives around HCT curricula implementation and improvement in general, there are some key takeaways that could benefit physician educators focused on improving health outcomes for autistic individuals. Because the health care transition experience for autistic individuals varies across the country, educators could use an iterative process of a quality improvement framework and include resident trainee perspectives during curriculum development in addressing contemporary health problems relevant to their patient populations. In addition, if lack of patient diversity during residency training impedes learning, results from this study highlight that online modules and simulation cases of autistic individuals can be successfully incorporated into HCT curricula.

There were a few limitations to the study. The baseline surveys were conducted by multiple study team members, which could have introduced some bias in how questions were asked. None of the interviews were recorded and, therefore, notes taken during the interview could not be verified at a later time. Our sample consisted of mainly academic centers and, therefore, does not necessarily reflect the state of transition curricula across different program settings.

CONCLUSION

In reducing the physical and mental health fallout that occurs during the transition to adulthood, it is important to train health care providers to adequately care for transitional-age youth, particularly for autistic youth with special health care needs. A quality improvement framework provides program directors structure in developing HCT curricula even within suboptimal health care settings. Existing clinical experiences and diverse learning modalities should be leveraged to deliver HCT curricula. Resident trainees should be actively engaged in the curriculum development process.

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ABBREVIATIONS

HCT: health care transition/s
HCT-CoIN: Health Care Transition Residency Curriculum Collaborative Improvement Network
YSHCN: youth with special health care needs

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