



# Autism Research Program



Improving the Lives of Individuals with Autism Spectrum Disorder

For more information, please visit  
[cdmrp.health.mil/arp](http://cdmrp.health.mil/arp)

**VISION:** Improve the lives of individuals with autism spectrum disorder now and in their future

**MISSION:** Promote innovative research that advances the understanding of autism spectrum disorder and leads to improved outcomes for Service Members, their Families, and the American public

The prevalence of ASD may be as high as **1 in 36<sup>1</sup>** for eight-year-old children across the United States.<sup>1</sup>

Data from the 2020 Autism and Developmental Disabilities Monitoring Network data suggest that autism is almost **4X** more prevalent in boys than girls.<sup>1</sup>

Currently, over **5 million** adults in the United States have autism spectrum disorder.<sup>2</sup>

# CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS

## AUTISM RESEARCH PROGRAM

### CDMRP BACKGROUND & HISTORY

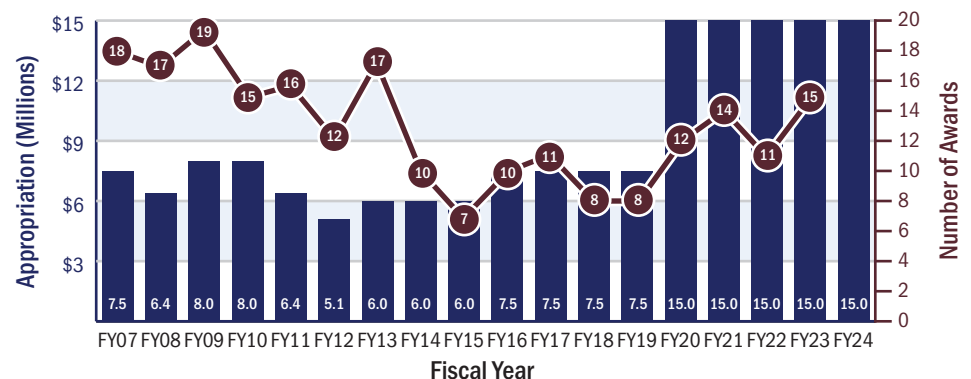
Congress established the Congressionally Directed Medical Research Programs in 1992 from a grassroots effort led by the breast cancer advocacy community. That effort resulted in a congressional appropriation of funds for breast cancer research, and initiated a unique partnership among the public, Congress, and the military. Since then, the CDMRP grew to encompass multiple targeted programs and managed over \$22.3 billion in congressional special interest funds from its inception through FY24. Congress provides overarching intent for each individual CDMRP program and specifies funding as part of the annual DOD appropriations bill.

Since its inception in fiscal year 2007 and through FY24, Congress directed \$164.4 million in appropriations to the ARP.

### ARP BACKGROUND & HISTORY

The ARP focuses on improving the lives of those living with ASD by funding innovative and highly impactful research. The ARP emphasizes research that helps autistic individuals in their transition to adulthood, as well as research aimed at improving health care delivery to autistic adults. The ARP also focuses on ways to improve diagnosis, treatment, and co-occurring conditions to enhance the quality of life for those with autism and their families. Autism spectrum disorder encompasses a wide range of complex developmental disorders characterized by mild to severe challenges in social, emotional, and communication abilities. Additionally, many autistic individuals experience co-occurring conditions such as anxiety, gastrointestinal issues, sleep disorders, and aggression that are not well understood. Researchers are unsure what causes autism; however the research field is advancing on several fronts, and researchers expect the answers related to autism to be multifaceted.

ARP Appropriations and Number of Awards



<sup>1</sup> Maenner, Matthew J. 2023. "Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020." *MMWR. Surveillance Summaries* 72 (2): 1–14. <https://doi.org/10.15585/mmwr.ss7202a1>.

<sup>2</sup> Dietz, Patricia M., Charles E. Rose, Dedria McArthur, and Matthew Maenner. 2020. "National and State Estimates of Adults with Autism Spectrum Disorder." *Journal of Autism and Developmental Disorders* 50 (12). <https://doi.org/10.1007/s10803-020-04494-4>.

# FUNDING DIRECTION

## AREAS OF INTEREST

The ARP strives to balance the research portfolio by focusing on the gaps focused on the gaps defined by the scientific and consumer communities. The ARP addresses these gaps through strategic goals and areas of interest. The areas of interest encompass topics of increased emphasis and need in the scientific setting or autistic individuals' daily lives. The ARP programmatic panel reviews the areas of interest every fiscal year and updates them according to the current needs of the community.

## STRATEGIC GOALS

The ARP identified four near- to medium-term goals to achieve its strategic direction. Here, we highlight a few studies within each strategic goal poised to impact the ASD community as they continue to make progress.



### Address Needs of Persons with Autism into Adulthood

Lindsay Shea, Dr.P.H., and her team at Drexel University are tracking community participatory experiences and preferences of autistic adults over time to generate new evidence that will help improve services and policies related to community-based participation.

Emma Sartin, Ph.D., and her team at University of Alabama Birmingham are developing a tool to that will guide autistic teens and adults while they make decisions about transportation and independent mobility.

### Advance Effective Treatments and Interventions for Autism

Laura Klinger, Ph.D., and Brianne Tomaszewski, Ph.D., from University of North Carolina at Chapel Hill are examining the efficacy of a novel intervention to improve transition outcomes such as self-determination, executive function, work readiness, and coping skills for autistic youth.

Christopher Lopata, Psy.D., and his colleagues at Canisius College are testing the feasibility and initial efficacy of a paraprofessional-run after school social intervention for autistic children without intellectual disability.

This study aims to increase ease of access to support services by lowering costs and training paraprofessional school staff to implement the program.

### Understand Causes, Mechanisms, and Signs of ASD

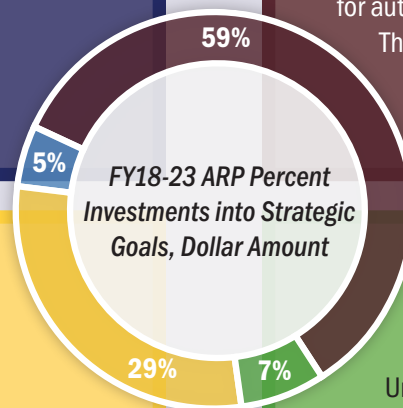
Stephen Walker, Ph.D., and his team at Wake Forest University Health Sciences are investigating the effectiveness and safety of microbiota transfer therapy, a treatment strategy with high promise for the treatment of co-occurring Gastrointestinal symptoms in autistic children.

Bridget Fernandez, M.D., and her team at Childrens Hospital Los Angeles are determining whether whole gene sequencing is a viable option for ASD diagnosis in Hispanic children. This could allow for more Hispanic children to receive earlier diagnoses, which would improve treatment outcomes.

### Support Those Caring for the Autism Community

Jeffery Hine, Ph.D., and his team Vanderbilt University Medical Center are refining a program to train pediatric physicians to provide better medical care for autistic children.

Beth Malow, M.D., from Vanderbilt University Medical Center, and Micha Mazurek, Ph.D., from University of Virginia, tested and implemented a primary care physician training program to improve medical care for autistic transition-age teens and adults.



# RESEARCH SUPPORTING AUTISTIC ADULTS

The ARP is committed to supporting autistic individuals throughout their lifespans by funding research that addresses unique challenges that autistic individuals face, including:



**INADEQUATE  
ASSESSMENT TOOLS**



**POOR HEALTH OUTCOMES  
AS COMPARED TO  
NEUROTYPICAL PEERS**



**DIFFICULTIES WITH  
TRANSITIONS TO  
INDEPENDENT LIVING**

**2022**



## **Codesigning and Evaluating a Novel Tele-Assessment Tool for Autistic Adults**

Zachary Warren, Ph.D., Vanderbilt University Medical Center

Adults seeking autism diagnosis encounter several barriers, including limited local expertise in autism in adults and inadequate assessment tools. Using telemedicine to administer assessments offers an opportunity to address barriers to access. The research team will create a tele-assessment tool and protocol to support diagnostic decision making for adults presenting with concerns about autism. This project will include autistic adults, experts in adult autism assessment, and community service providers to rigorously review the features of the tool for use within the home and real-time virtual interviewing. This tool will allow for more undiagnosed autistic adults to receive diagnoses and improved care.



“As an autistic community member on the CDMRP Autism Research Program, I am delighted with how open other committee members are to the lived experience of autistics and their caregivers. I’m very proud of the respect this program gives to the research desires of autistics and their families.”

**Anne Nagel,**  
ARP Programmatic Panel Member 2023-24

## **DID YOU KNOW ?**

According to the CDC, approximately 2.21% of adults in the United States have autism spectrum disorder.<sup>3</sup> Because ASD is a lifelong condition, many adults with ASD continue to need services and supports. Research that focuses on autistic adults remains a critical research gap.

<sup>3</sup> CDC. 2024. “Key Findings: Estimated Number of Adults Living with Autism Spectrum Disorder in the United States, 2017.” Autism Spectrum Disorder (ASD). February 23, 2024. <https://www.cdc.gov/autism/publications/adults-living-with-autism-spectrum-disorder.html>.

2023



### **Development of a Novel, Evidence-Based Tool to Facilitate Independence for Autistic Individuals**

Emma Sartin, Ph.D., MPH, University of Alabama at Birmingham

Many autistic young adults remain reliant on friends and family for transportation. Families often do not know how to tell if, or when, their autistic teen is ready for behind-the-wheel training. Driver rehabilitation specialists, people trained to help teens and families make this decision, are limited in number, which makes it difficult to find a nearby professional and contributes to costly rehabilitation services. Sartin and her team are developing a virtual driver readiness exam to determine if autistic teens are ready for behind-the-wheel driver training. If successful, this assessment will remove barriers to accessing decision-making supports and improve independence and quality of life for autistic teens and adults.



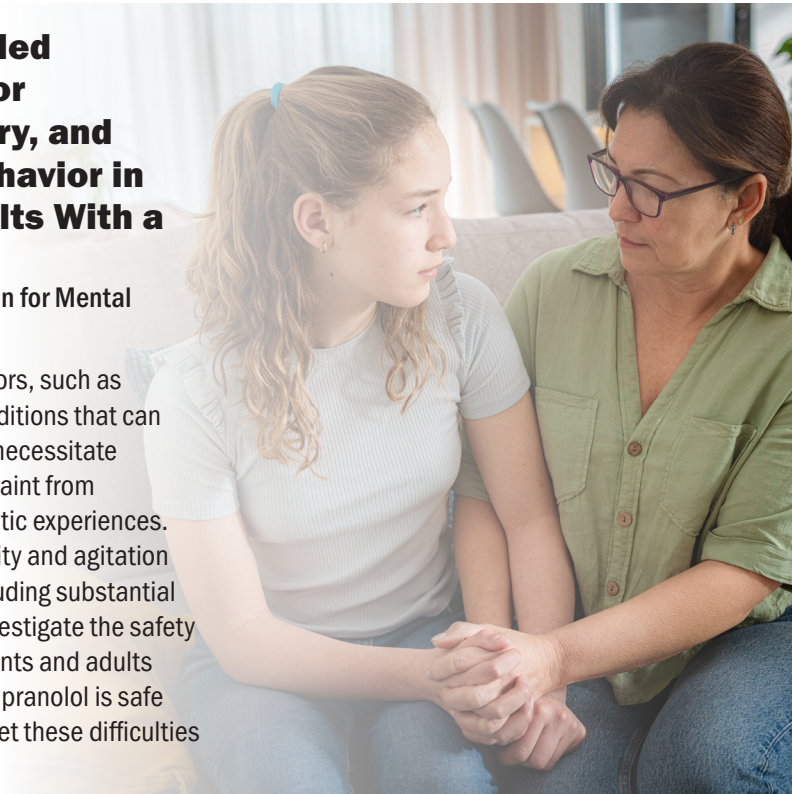
2023



### **Randomized, Controlled Trial of Propranolol for Aggression, Self-injury, and Severe Disruptive Behavior in Adolescents and Adults With a Diagnosis of Autism**

Jeremy Veenstra-VanderWeele, M.D., Research Foundation for Mental Hygiene, Inc.

Aggression, self-injury, and other severe disruptive behaviors, such as property destruction, are among the most debilitating conditions that can co-occur with autism. If not treated, these behaviors may necessitate frequent hospitalizations, which may require physical restraint from medical professionals for safety and result in other traumatic experiences. Risperidone and aripiprazole are FDA approved for irritability and agitation in autism, but cause several problematic side effects, including substantial weight gain and movement issues. This clinical trial will investigate the safety and efficacy of high-dose propranolol for autistic adolescents and adults struggling with severe behaviors. If this trial shows that propranolol is safe and effective, it will provide a new treatment option to target these difficulties with less significant side effects.



“The ARP is an impressive collection of scientists, researchers, clinicians, and self-advocates with one primary goal: to improve the lives of individuals and families touched by autism. The strength of this group is the flexibility to think differently. While we certainly fund large university clinical trials, we also fund the early researcher/clinician whose novel idea has the potential to truly alter a person’s autism journey. This positions us to uniquely support autistic individuals, military and civilian families, and the general public in ways not normally available through other research programs.”

**Dan Schulteis**, ARP Programmatic Panel Member, 2017-24 (Chair 2023-24)

# INVESTING IN HEALTH CARE DELIVERY

The ARP recognizes that the needs of the autistic community span beyond effective treatments. A major barrier that autistic people face is access to quality health care, in part due to insufficient provider training. In 2017, the ARP added the area of interest health care provider-focused training or tools to *improve health care delivery for autistic individuals* to fund projects that create novel tools to support high-quality care. These tools aim to provide health care providers the knowledge and resources they need to support autistic people.



## **A Novel Provider-Focused Training Program to Serve Transition-Age Youth and Adults with Autism Spectrum Disorder**

Beth Malow, M.D., Vanderbilt University Medical Center and Micha Mazurek, Ph.D., University of Virginia

This study created and pilot-tested a novel primary care provider training program with the goal of increasing high-quality, community-based health care for adults on the autism spectrum. Specifically, this team used the Project Extension for Community Healthcare Outcomes, Project ECHO, to develop a training curriculum and protocol for autism transition/adult health care training. They will implement and test this curriculum with primary care physicians caring for autistic transition-age youth and adults. Building capacity to meet the healthcare needs of autistic individuals as they transition to and enter adulthood is critical and timely, given estimates of a half-million autistic youth entering adulthood over the next decade.

2018



## **Clinician-less Training in Autism Treatment: An Adaptive Online Parent Education Program**

Ty Vernon, Ph.D., University of California, Santa Barbara

This Clinical Trial Award aimed to create and evaluate an accessible autism intervention training platform. Researchers developed two versions of a smartphone application, called Pivotal, to train parents of young children with autism spectrum disorder using the pivotal response treatment model. Both applications contained eight interactive lessons with video examples, slides and brief quizzes. Only one version of the app offered a self-assessment component for parents to receive feedback on their ability to learn the new intervention techniques. Results indicate parents using the self-scoring version mastered the intervention strategies, but both versions led to improvements in the use of child expressive language and responsiveness. The Pivotal app can improve quality of life for families with limited access to clinicians and offers a method for other therapies to be incorporated into mobile apps.

2019



## **Effectiveness of Evidence-Based Mental Health Practices for Youth with Autism Supported by Online Consultation to Practitioners in Community and Navy Clinics**

Jeffrey Wood, Ph.D., University of California, Los Angeles

Cognitive behavioral therapy can improve emotional regulation issues experienced by children with autism, but this therapy is infrequently used in community mental health centers where many treatments for autistic children occur. Researchers are developing a system to deliver training to clinicians through videoconferences to improve the ability for autistic children to process their emotions. Additionally, researchers will identify implementation factors that affect cognitive behavioral therapy and the ability for this therapy to improve emotional dysregulation. By implementing cognitive behavioral therapy, children can learn how to control their emotions and better handle daily interactions. Another goal of this therapy is to allow autistic children to participate in more inclusive education settings and improve interactions with caregivers, family and friends, offering them a better quality of life.

2020

# BARRIERS TO HEALTHCARE FOR AUTISTIC PEOPLE<sup>3</sup>

Limited physician expertise for autism spectrum disorder diagnosis

Lack of awareness of available screening tools

Communication difficulties between healthcare providers and autistic patients

Scarcity and high cost of quality care for autistic needs

Suboptimal physician awareness of health care considerations pertaining to autistic individuals



## Promoting Residents' Excellence in Patient-Centered CARE for Autistic Adults

Brittany Hand, Ph.D.,  
The Ohio State University

Autistic adults are more likely to experience physical and mental health conditions than the general population. These conditions, combined with a scarcity of providers with sufficient training on how to provide care for autistic adults, leads to many autistic adults receiving insufficient health care. This project aims to create a new training to improve the ability of healthcare providers to care for autistic adults. **PREPARE for Autistic Adults** aims to train residents in internal or family medicine programs. The training consists of pre-recorded presentations, live case studies, and standardized patient encounters where residents practice applying contemporary knowledge with autistic adult actors portraying a clinical case. The research team expects that improving access to high quality health care will improve the wellbeing of autistic people across the lifespan.

2021



## Training the Future Pediatric Workforce to Implement Best Practices for ASD Within Primary Care

Jeffrey Hine, Ph.D., Vanderbilt University  
Medical Center

Many pediatric primary care providers report low confidence in managing autistic children, which leads to many unanswered care questions and delays in meeting patient needs. Hine and his team will refine, implement, and evaluate **ASD in Primary Care Education**, a program intended to train medical residents how to better support autistic children. This training will combine tailored learning modules with hands on practice. Long term clinical practice supports embedded into the electronic health record will provide learning prompts for clinical decision making. Hine's work is poised to create a system where use of best practices for the autism community is the standard.

2022



## Autism Response Protocol: Comparing the Effectiveness of a Hybrid vs Lecture-Based Training on Autism Competence in First Responders

Rose Nevill, Ph.D., University of Virginia

The autism community reports predominantly negative experiences after a 911 call, including use of excessive force, hospital admission, arrest, and in worst cases, death by restraint or gunshot. Autistic people have a higher risk of crisis but often distrust first responders, which leads to avoiding calling 911 unless as a last resort. In this award, the research team will build on previous work in creating a community-informed, evidence-based training program for emergency providers, and test whether a hybrid delivery method with computer-based lessons and in-person practice is more effective than online training alone. Autistic community and emergency responder feedback will inform further refinement of the training program. Implementation of this training has the potential to reduce injuries and death associated with 911 responses.

2023



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<https://cdmrp.health.mil>  
or contact us at:  
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