

Committee Conducting an Independent Analysis of Department of Defense's Comprehensive Autism Care Demonstration Program

Understanding Methods for Measuring Program Effectiveness and Clinical Effectiveness VIRTUAL PUBLIC SESSION

November 22, 2024
11am-1pm (Eastern times shown)

The Committee conducting an Independent Analysis of Department of Defense's Comprehensive Autism Care Demonstration Program has been tasked with assessing the methods used under the demonstration. This public session is part of the information gathering for the committee's analysis.

The Autism Care Demonstration (ACD), authorized through 2028, provides reimbursement for applied behavior analysis to TRICARE eligible beneficiaries¹ diagnosed with autism spectrum disorder. The Department of Defense has received guidance from Congress in executing various components of the demonstration, such as floor reimbursement rates, reporting requirements for population utilization and trends, and the collecting and reporting of health-related outcomes.

At this session, the committee will engage invited experts in discussion to better understand the distinctions between the type of data and consent usually used for clinical research and clinical care as well as intersections with program evaluation and quality improvement efforts. The session will consider differences in purpose, methods, and goals of these different forms of assessment. The session will examine considerations for determining risks, burdens, and benefits for patients and caregivers and best practices for informed consent for each kind of endeavor.

Questions for the committee to consider should be submitted in advance to akjones@nas.edu.

11:00-11:05am

Public Session and Livestream Welcome

George W. Rutherford, University of California, San Francisco (*Committee Chair*)

11:05-11:15am

Overview of Outcome Measures Used Under the ACD

Presenter will provide brief overview of outcome measures required under the ACD.

Thomas W. Frazier, John Carroll University

Thomas W. Frazier is a licensed clinical psychologist, a professor of psychology at John Carroll University and a research professor in pediatrics and psychiatry at SUNY-Upstate. His clinical research programs focused on the evaluation and treatment of autism and related conditions.

¹ TRICARE is a health benefit program with approximately 9.6 million beneficiaries, including active-duty personnel, Reserve Component personnel, military retirees, and their families, administered by the Defense Health Agency (DHA), Department of Defense.

11:15-12:00pm

Data Collection on Patients: Determining Purpose, Value, Risks, and Burdens

Presenters will provide guidance for collecting data from patients for different purposes, including collection for clinical care and clinical research and monitoring program effectiveness and quality improvement. Presenters may consider similarities and differences between purposes. Presenters will help inform the committee about ethical and other considerations to be made in the selection of methods and tools for data collection and obligations for the use of clinical data in the care of patients, in assessments for clinical effectiveness, and in assessments of program effectiveness. Selection considerations may include determining risks and burdens to patients and caregivers compared to their usual care; considering types of consent and disclosure and best practices for different types of purposes; and considering types of oversight.

Holly A. Taylor, National Institutes of Health

Holly A. Taylor is a research bioethicist and public health scholar whose research has been in the field of research ethics, including informed consent for research participation, subject selection and recruitment and research review and oversight. Taylor has experience with research ethics consultation and has served on Institutional Review Boards in the academic, public and private sector.

Nanette Elster, Loyola University Chicago Stritch School of Medicine

Nanette Elster is a professor at the Neiswanger Institute for Bioethics and Health Policy and teaches a variety of courses in areas related to law, pediatrics, oral health, genetics, and professionalism. Elster is the legal consultant to the Committee on Bioethics for the American Academy of Pediatrics.

12:00-12:30pm

Q&A with the committee

12:30-12:45pm

ABA Treatment Planning and Progress Monitoring: Current Standards of Care

Presenter will provide an overview of the assessment and outcomes measurement standards in the Council of Autism Service Providers Applied Behavior Analysis Practice Guidelines for the Treatment of Autism Spectrum Disorder and a review of research on best practices in assessing people with autism for treatment planning and progress monitoring that informed those standards.

Gina Green, Consultant

Gina Green is a Board Certified Behavior Analyst-Doctoral who co-founded the Association of Professional Behavior Analysts and was its executive director/CEO for more than a decade. She is currently a consultant in private practice. Dr. Green has conducted and overseen research on assessment and interventions for autism and contributed to several sets of professional standards and guidelines.

12:45-1:00pm

Q&A with the committee

1:00pm

PUBLIC SESSION ADJOURNS (Livestream Ends)