

ROSE F. KENNEDY University Center for Excellence in Developmental Disabilities

**Montefiore Einstein** 



Montefiore Einstein

### 2023 ANNUAL REPORT

Advocacy and Information Dissemination 16 



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A MESSAGE FROM THE DIRECTORS

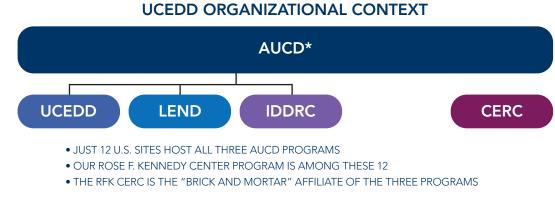




### Independence, productivity, and community inclusion

...embody the vision of the national network of University Centers of Excellence in Developmental Disabilities (UCEDD).\* Our Rose F. Kennedy (RFK) UCEDD is among the nation's 68 UCEDDs, which pursue this vision through a fourfold mission of training (multidisciplinary, preservice), services (technical assistance [TA], community education, direct services), research (clinical/translational, policy), and information dissemination (FY 2023 Annual Report). Authorized under Public Law 106-40, UCEDDs have been key to every major disability initiative over the past four decades, from early intervention to healthcare, employment, assistive technology, and transportation.

For 67 years our UCEDD and affiliated RFK Center programs have served the developmental disabilities (DD) community in the Bronx and beyond, with the RFK Children's Evaluation and Rehabilitation Center (CERC) as our clinical home base. We commemorated this history with the inaugural RFK Center Day in April 2023, bringing together RFK's UCEDD, CERC, LEND (Leadership Education in Neuro-developmental and Related Disabilities), and IDDRC (Intellectual and Developmental Disabilities Research Center) programs. Self-Advocates shared how the UCEDD honed their advocacy skills. We introduced our "Disability as Diversity: Reducing Researcher Roadblocks" study of including people with DD in research, under the auspices of Einstein-Montefiore's Clinical and Translational Service Award. Our Children and Youth with Special Health Care Needs (CYSHCN) program provided TA and education to families and local health departments, while our VaxFacts DDNY initiative transformed into a Long COVID resource.



\*Association of University Centers on Disability (AUCD) website

#### Our FY 2023's 28 conference talks and posters, 30 peer-reviewed manuscripts, and \$8,914,007 in leveraged funds attest to our UCEDD's productivity.

# RFK DAY

**Marking 67 years** of engaging the DD community, 225 people attended our inaugural Rose F. Kennedy Center Day in April. In addition to the UCEDD, the RFK Center includes the Children's Evaluation and Rehabilitation Center, Leadership Education in Neurodevelopmental and Related Disabilities, and Intellectual and Developmental Disabilities Research Center programs. Einstein-Montefiore is among twelve or so sites in the country with the latter three programs.

Speakers included Paul Rivera, who highlighted how he and other self-advocates organized a campaign to remove transportation barriers. Joanne Siegel, LCSW, co-director of UCEDD, emphasized advocacy's transformative impact, stating, "Advocacy changes lives; it breaks down barriers to care and empowers individuals." Another self-advocate, Danielle Lanzetta, reflected that "the Kennedy Center shaped who I am today." Additional speakers included parent advocates, Lisa Shulman, MD (LEND director), Sophie Molholm, PhD, and Steven Walkley, DVM (IDDRC directors) and Robert Marion, MD (keynote).



Exemplary Services Clinical Training Research Community Education

- From left to right: Joanne Siegel, LCSW; Robert Marion, MD; Lisa Shulman, MD; Sophie Molholm, PhD; Steve Walkley, DVM; and Karen Bonuck, PhD.
- 2. From left to right: Joanne Siegel, LCSW, with self-advocates: Zefa Dedic, Maria Cruz, and Paul Rivera .
- **3.** Philip O. Ozuah, MD, PhD, giving the opening address.
- **4-5.** Presenting "From Research Bench to Clinic: The Einstein Story of KDM5C": Julie Secombe, PhD, and Lisa Shulman, MD, with Amy Robl, parent advocate.
- **6.** Joanne Siegel, LCSW, between self-advocates Paul Rivera and Danielle Lanzetta.











# TRAINING

UCEDD faculty members lead medical student and resident education, service activities, and interdisciplinary preservice training. We're especially proud of our multiyear intellectual and developmental disabilities (I/DD) curriculum and of the creation of Einstein's chapter of the American Academy of Developmental Medicine and Dentistry (AADMD). With approximately 100 members, this student organization is among Einstein's most active.

#### AADMD

Vincent Siasoco, MD, MBA, UCEDD's director of model services, is the faculty advisor for this student chapter. The group organizes events for our RFK UCEDD self-advocates, Special Olympics NY, and the nonprofit Positive Exposure gallery.

#### Infusing I/DD into the Curriculum

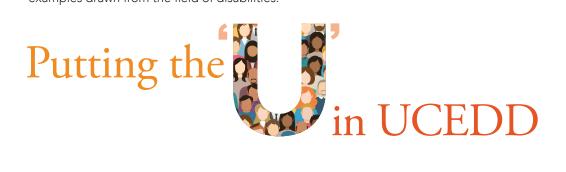
UCEDD co-director, Joanne Siegel has put Einstein at the forefront of I/DD in medical education. Along with physician colleagues (V Siasoco, E Muniz, L Shulman, R Seijo, and M Lavaliere), parents/caregivers, self-advocates, and medical students, they provide didactic education, panels, clinical rotations, and community exposure to I/DD across the Einstein curriculum.

#### **Textbook Beauty**

The Textbook Beauty Project flips the script on dehumanizing medical visuals. Created by then medical students James Barnett and Samantha DiSalvo with Positive Exposure's Rick Guidotti in December 2022, this project is building humanizing, inclusive online photo galleries of individuals with genetic and developmental conditions that recognize beauty within difference and challenge the way we define beauty. Medical and allied health institutions can access these images, including them in medical education to decrease stigma towards persons with disabilities or genetic conditions.

#### Impact Course

UCEDD co-director Karen Bonuck teaches in this new multiyear Einstein course on community -based research, mixed methods, and research opportunities, offering these interactions with examples drawn from the field of disabilities.









### **AADMD Student Chapter Activities**

Vincent Siasoco, MD, MBA, held two Healthy Athletes events called Health Promotion, in which medical students volunteered and provided free health screenings for the Special Olympics in September and December 2022.

An inclusive wheelchair basketball event - organized by Einstein AADMD student chapter board member Luisa Alvarez in April 2023 was held at the Henry Viscardi School in Nassau County.

**3.** The AADMD Student Leadership Award was presented to the Einstein AADMD student chapter co-presidents, Bailey Frohlich and Samantha DiSalvo.

**4–5.** Textbook Beauty Project: Medical students James Barnett and Samantha DiSalvo presented at the annual AADMD conference in Denver.

## TRAINING

#### LEND

#### Leadership Education in Neurodevelopmental and Related Disabilities program

The RFK LEND program has had a remarkable year in FY 2024, successfully recruiting and training a diverse cohort of 60 long-term, 45 medium-term, and 1,000 short-term trainees across 15 disciplines, including medicine, psychology, social work. speech/occupational/physical therapy, and audiology. This year's cohort included nine self-advocates and family members of individuals with developmental disabilities, many of whom are long-standing patients (or the parents of patients) at the Rose F. Kennedy Children's Evaluation and Rehabilitation Center. The program's diverse trainee population, with 53% from groups underrepresented in medicine and 27% identifying as Hispanic, underscores its commitment to inclusivity. Additionally, the program strengthened its faculty by recruiting new experts in Audiology, Applied Behavioral Analysis, and Self-Advocacy, further enhancing the quality of training and mentorship provided.

The RFK LEND program provides comprehensive training that includes core lectures, leadership seminars, and clinical experiences and emphasizes health equity and overcoming disparities. Trainees engage in community-based learning, advocacy, and policy events, and receive continuing education through various initiatives such as the RFK Early Intervention Training Institute and the Group Attachment-Based Intervention program. The program also collaborates with the Montefiore Hospital System to improve autism and developmental disability services.

### EINSTEIN CURRICULAR CONTRIBUTIONS

LEND

**CORE LECTURES** By self- and family-advocate trainees to the LEND cohort

#### **EINSTEIN**

2ND YEAR Neurology and Human Behavior and Intro to Clinical Medicine

**INTRO TO CLERKSHIP** Multidisciplinary panel moderated by RFK CERC social workers and advocates

BIOETHICS Medical decision-making in the master's degree program

IMPACT COURSE **UCEDD** faculty







**1.** From left to right: Maria Valicenti-McDermott, Dr.; Mollie Lobl, Dr.; Carol Terilli, PT, DPT, C/NDT; Rosa Seijo, Dr.; Lisa Shulman, Dr.; Diana Rodriguez, LMSW; Amy Morales-Lara, MSW; Vanessa Gozalez, LMSW; Ida Barresi, MA, CCC-SLP; Joanne Siegel, LCSW; Mayra Alvarez, PhD.

2. Mayra Alvarez, PhD, and Diana Rodriguez, LMSW, presenting on housing disparity at AUCD's 2022 conference.

3. Carol Terilli, PT, DPT, C/NDT, with Liz Weintraub, Self-Advocacy Specialist, at AUCD 2022.

4. Two Developmental-Behavioral Pediatrics fellows: Lisa Marie Caraballo and Bassit Malam, presenting their research poster at AUCD's 2022 conference. 5. Ida Barresi, MA, CCC-SLP, and Daniella Soba, OTR/L, presenting a research poster at AUCD 2023.

## COMMUNITY SERVICES

#### Our UCEDD

In the UCEDD lexicon, community services include community training, technical assistance, and model/demonstration services. We participate with our statewide partners (shown below/ at right) as part of the New York Developmental Disabilities network, which includes our sister UCEDDs (the Westchester Institute for Human Development and the University of Rochester) Together we were partners in the Community of Practice for Cultural Competency.

Through community training and education, we educate our federal, state, and local legislators and support services for our children and adults with I/DD. On November 16, 2022, we visited the Washington, DC, offices of Senator Chuck Schumer and Representatives Ritchie Torres and Adriano Espaillat to discuss federal efforts to achieve greater community inclusion through home and community-based services and the Autism Cares Act.

UCEDD staff and RFK CERC families and self-advocates participated with Rick Guidotti in filming FRAME [Faces Redefining the Art of Medical Education] Representation + Aging" by Positive Exposure.

# Bilingual <sub>Educational</sub> support group Annual CERC parent workshop

Finally, Our UCEDD provides model/demonstration services via RFK CERC, our affiliated clinical program. RFK CERC is a multidisciplinary diagnostic and treatment center that serves approximately 7,000 children and adults with I/DD annually. It is home to the department of pediatrics' division of developmental medicine at Einstein-Montefiore, its largest division.

#### BRONX COMMUNITY SELF-ADVOCATES

#### **RFK UCEDD**

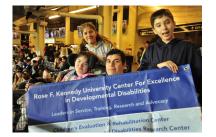
Weekly social, educational, and advocacy activity; advice on UCEDD products and projects

#### SANYS

Community integration strategies, needs and concerns; annual conference (SANYS — Self-Advocates of NY State)

#### **FEDERAL**

Legislative advocacy via in-person and virtual meetings and letter-writing efforts









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### The RFK UCEDD, Part of the New York State DD Network





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#### **2023 HONOREE**

### JOANNE FLORIO SIEGEL Montefiore/Einstein





BRONXPOWERWOMEN.COM



 UCEDD co-director Joanne Siegel, LCSW, was honored as one of the Bronx Power Women of 2023. She was recognized for her work serving the Bronx DD community within the Montefiore Einstein community and through the Bronx DD Council.

2. On March 3, 2023, the UCEDD staff organized Bronx County participation in a NYC Developmental Disabilities legislative remote breakfast and developed a policy position paper for Health Care Services for Persons with Developmental Disabilities with self-advocate Danielle Lanzetta.

3. UCEDD staff participated in the planning of the Bronx DD Council's 35th Family Support Conference on May 18, 2023, in which 350 family members and agency staff networked and shared information and resources for this event, "Supporting Families and Moving Forward."

**4.** In May 2023, CERC and UCEDD joined forces to provide education to 75 families on topics such as education and transition services, guardianship, supported decision making, employment, college, and career planning for Bronx families.

#### RFK UCEDD COMMUNITY ADVISORY COMMITTEE

- Advocates and families from diverse backgrounds
- People who offer input on UCEDD plans and activities

## ADVOCACY & INFORMATION DISSEMINATION

**As noted in our Directors' Message,** UCEDDs are pivotal to advancing the nation's disability initiatives. At RFK, this occurs during self-advocate weekly meetings, on trips to the state capital in Albany, and via Zoom for phone and local legislator meetings. In addition, we disseminate "news you can use" to families and professionals throughout New York State.

#### **CYSHCN** Clips

This monthly online newsletter was produced by our Children and Youth with Special Health Care Needs project (see page 15). Packed with news, webinars, activities, resources, and opportunities for CYSHCN statewide, content for the newsletter is also provided by the Westchester Institute for Human Development and University of Rochester Strong Center UCEDDs. Its 200+ contacts include the state's 58 CYSHCN programs and families. CYSHCN Clips is featured on the state department of health website. https://us7.campaign-archive.com/ home/?u=9a25ceb298f8af5821317e34f&id=fd69eb785e.

#### VaxFacts DDNY

Our information dissemination activities in FY 2023 featured our VaxFacts DDNY newsletter. With support from the New York State Council on Developmental Disabilities, this online newsletter for the state's Mandarin-, Spanish-, and English-speaking DD communities featured content on COVID-19 vaccine boosters and long COVID.











- **1.** Self-advocates at a legislative rally at the state capitol.
- **2.** Joanne Siegel, LCSW, with parent advocates at the annual legislative education meeting.
- **3.** Families meet with legislators in Albany in support of direct-care workers.
- **4.** CYSHCN bimonthly newsletter and VaxFacts DDNY newsletter (in English, Spanish, and Chinese).



# CYSHCN

#### Five Years Strong: CYSHCN Project Keeps Families at the Forefront

Our Children and Youth Special Health Care Needs project provides technical assistance to New York's 58 local health departments, CYSHCN programs, and community education. Our CYSHCN team conducts family engagement sessions, surveys, and interviews to understand community needs. Over 160 multilingual family sessions engaged hundreds of participants across New York. Nearly 200 surveys and 120 interviews provided vital insights to help us tailor outreach in underrepresented areas.



Monthly meetings with local health departments focused on strategic outreach, information dissemination, and awareness-building. Customized assessments using the Family Engagement Plan enabled data-driven goal-setting and measurable support. Collaborative regional meetings fostered best-practice-sharing and problem-solving among partners.

#### **CYSHCN Community Education for Families**

Learn the Signs; Act Early — Empowering Parents' Developmental Knowledge (9/28/2022). Elizabeth Isakson, Dr., director of Docs for Tots, discussed developmental milestones, monitoring, and screening. She highlighted recent guideline changes that might affect families of young children. YouTube recording: https://youtu.be/VPpVSfloemg.



"Transition healthcare information is **DESPERATELY** needed for those who have aged out of school and in the the OPWDD world."

Parent comment from Transitions: Healthcare talk

### **CYSHCN Community Education** for Professionals

#### Obesity in Children and Adolescents with I/DD (2/28/2023)

In a timely webinar, RFK nutritionist Keth Ayoob, Dr., discussed newly released guidelines from the American Academy of Pediatrics and barriers to healthy weight. He explained the new guidelines to state and local health department staff members and reviewed strategies for helping children maintain or approach a healthy weight.

#### Accessible Recreation for Children with Disabilities (4/19/2023)

This panel on accessible/adaptive sports explored the state's recreation opportunities and drew nearly 50 attendees. Panelists included Chris Noel, NYC Parks ADA accessibility coordinator; Leah Akins, New York State ADA accessibility coordinator; and Leanne Fusco, Special Olympics New York's director of health programming.



AAP's first clinical practice guideline on obesity advises early, intensive care that focuses on 'whole child January 9, 2023

#### Transitions: Healthcare (1/24/2023)

The transition from pediatric to adult healthcare for CYSHCN is often fraught and difficult. Colleagues from our partners at the University of Rochester UCEDD, Dennis Kuo, MD, MHS (chair of developmental-behavioral pediatrics), Lisa Latten, MSEd (clinic administrator and parent), and Jeiri Flores (disability advocate) shared tips from their perspectives. YouTube: https://youtu.be/bX\_SGHg\_AS4.

#### **Transitions: From Early Intervention to Preschool** to School Age (5/8/2023)

Just as fraught as the healthcare transition is for older children, transition to preschool and primary school settings is stressful as families navigate timelines, identify appropriate settings, and complete the application process. This seminar provided insight on parental experiences, advocacy, the roles of providers and schools, and recommendations for local health departments.

"As a parent of a special needs child this brings light to my own personal life for both of my children and the changes my family should implement".

Parent comment from Obesity Talk Feedback Survey



# **RESEARCH AND EVALUATION**

#### Research

Our UCEDD faculty and staff completed research on infusing I/DD into the curriculum, attitudes towards COVID-19 vaccines in New York's I/DD community, and sleep. Our affiliated RFK CERC, LEND, and IDDRC programs' research spans sensory and neural processing in children with autism, screening for hearing problems, and the incorporation of teleheatlh.

#### Evaluation

Our UCEDD collects standard process and satisfaction evaluation metrics in the web-based National Information and Reporting System (NIRS) for the Association of University Centers on Disabilities. NIRS data for our UCEDD can be found at https://www.aucd.org/nirs.

We also conduct evaluative research. In FY 2023, the three state UCEDDs surveyed and interviewed nearly 200 CYSHCN and their families about accessing services and support, COVID-19's continued impact, and interactions with local health departments and CYSHCN programs.

#### **RESEARCH PAPERS BY UCEDD (selected)**

Impact of the COVID-19 Pandemic on Behavioral Health of People with Intellectual and/or Developmental Disabilities. Psychiatric Services, 2022.

Infusing Intellectual and Developmental Disability Training into Medical School Curriculum: A Pilot Intervention. Medical Education Online, 2023.

COVID-19 Vaccines for Children with Developmental Disabilities: Survey of New York State Parents' Willingness and Concerns. Journal Developmental and Behavioral Pediatrics, 2021.

Effects of a Sleep Health Education Program for Children and Parents on Child Sleep Duration and Difficulties: A Stepped-Wedge Cluster Randomized Clinical Trial. JAMA New Open, 2022.

The TeleKidSeq Plot Study: Incorporating Telehealth into Clinical Care of Children from Diverse Backgrounds Undergoing Whole-Genome Sequencing. Medical Education Online, 2023.

The Feasibility of Screening for Sleep Problems in Early Childhood Education Programs. Behavioral Sleep Medicine, 2022.

#### **TRANSPORTATION ACCESS:**

"We haven't had busing... still don't have a busing nurse for this year.... I've been taking him to school with the baby. I strapped two strollers together with some ribbon and Velcro. I take him in the morning, I pick him up. I mean, it's been a hot mess." (Manhattan)

**CAREGIVER STRESS DURING COVID-19:** "And with people working remotely, certain agencies were already backlogged. And that just added extra delays.... It was crisis mode in our home, and I needed support.... I almost [had] a nervous breakdown myself." (Bronx)

> **ON COVID-19'S IMPACT:** "ABA stopped...he was obviously regressing.... It feels like the good behaviors that the teacher had worked hard to cultivate in him before have disappeared." (Nassau Co.)

#### ACCESS TO SERVICES:

"The State needs to commit more money to close staffing shortages and increase rates for DSPs direct services providers and make it more appealing for service providers to work with special populations." (Brooklyn)

PARENT STRESS: "Mentally. Oh, my God. Some days I cry. I sit and cry. I'm like, oh, Lord, help me to see the positive." (Staten Island)

> **COMMUNITY SPACES:** "You'd be surprised by the information you find at a local

bodega, at the laundromat."

(Bronx)

## DISABILITY AS DIVERSITY



#### Disability as Diversity: Reducing Researcher Roadblocks (D2/R3)

Einstein-Montefiore's Institute for Clinical and Translational Research (ICTR) was awarded a \$30 million grant from the National Center for Advancing Translational Science in March 2023. Core to this ICTR grant is its Disability as Diversity: Reducing Researcher Roadblocks research project. Translational science aims to identify and reduce barriers to advancing research across the translational spectrum, and is generalizable across diseases (ICTR website). D2/R3 tackles the translational science problem of people with disabilities being underrepresented in research.

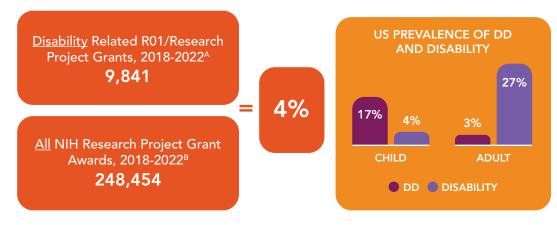
Led by Karen Bonuck, PhD, D2/R3 is a mixed-methods study of researcher-level perceived



barriers and capacity to conduct disability-inclusive research. Its overarching goal is to promote equity among people who benefit from National Institutes of Health research. With its focus on adult people with developmental disabilities (PWDD), D2/R3 seeks to:

- Close the gap in health outcomes research on adult PWDD, especially as growing numbers of children with autism and other DDs transition to adulthood.
- Produce findings that can be generalized to all PWDD, given that DDs are a constellation of heterogenous lifespan conditions.
- Ultimately, reduce the health disparities experienced by the DD population.

#### TRANSLATIONAL SCIENCE PROBLEM Adults with disabilities and DD "missing" from NIH research despite high prevalence



<sup>A</sup>National Advisory Council on Minority Health and Health Disparities Working Group on Persons Living with Disability <sup>B</sup> NIH Data Book

Child - DD: NIHIS & Disability; Amer Comm Survey, 2019 Adult - DD Adult: McDermott 2018 AJIDD; Disability: CDC Infographic



#### Miriam Franco, BA

She is featured with her son Kevin in our UCEDD-produced film "Common Threads," about the universality of the disability experience. Miriam juggled obtaining her BA in disability studies this year with being the lead person on our Children and Youth with Special Health Care Needs grant.



#### Patrick George III, MSSR

Our study coordinator for the Disability as Diversity: Reducing Researcher Roadblocks study. He joined Einstein-Montefiore's Institute for Clinical and Translational Science in April 2023. Professionally, his focus has been in public health, working particularly with HIV-vulnerable communities, sexual and gender minorities, people experiencing homelessness, people with substance use disorder, and the disabilities community.

### STAFF SPOTLIGHT

#### **Amy Morales-Lara, MSW**

She is our dissemination programs lead and recently earned a master of social work from CUNY's Hunter College while juggling studies and a role at the Rose F. Kennedy Center. Amy delivered a TEDx talk celebrating her unique journey, bridging creativity and mental health.



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### Katie McGrath, MSSW

A doctoral candidate, she is our senior research coordinator. In addition to researching and writing peer-reviewed papers, she designed our English-, Chinese-, and Spanish-language (COVID-19) VaxFacts newsletters in 2023.



# **GRANTS AND CONTRACTS**

#### **FEDERAL FUNDING**

#### University Center for Excellence in Developmental Disabilities Education

Contact: Karen Bonuck, PhD, Joanne F. Siegel, LCSW Funder: Administration for Community Living \$606,307

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

Contact: Lisa Shulman, MD Funder: Health Resources and Services Administration \$20,000

#### Leadership Education in Neurodevelopment and Related Disabilities

Contact: Lisa Shulman, MD Funder: Health Resources and Services Administration \$813,000

#### MCHB Developmental Behavioral Pediatrics Training Program

Contact: Elisa Muñiz, MD, MS Funder: Health Resources and Services Administration \$264,696

#### **Disability as Diversity: Reducing Researcher Roadblocks**

Contact: Karen Bonuck, PhD Funder: National Center for Advancing Translational Science (subaward of CTSA 1UM1TR004400; PIs: Keller and Kim 1UM1TR004400) \$361,972

#### CERC—Administration for Community Living Expanding the Public Health Workforce

Contact: Karen Bonuck, PhD, Joanne F. Siegel, LCSW Funder: Administration for Community Living \$113,670

#### Intellectual and Developmental Disabilities Research Center

Contact: Sophie Molholm, PhD, Steven Walkley, DVM Funder: National Institute of Child Health and Human Development \$1,000,000

#### STATE FUNDING

### **Children and Youth with Special Health Care Needs** Contact: Karen Bonuck, PhD, Joanne F. Siegel, LCSW

Funder: New York State Department of Health (DOH) \$362,500

**Comprehensive Systems** Contact: Oscar Purugganan, Dr. Funder: New York State Office of Children and Family Services \$50,000

#### LOCAL FUNDING

### Contact: Anne Murphy, PhD Funder: New York City Administration for Children's Services \$3,960,600

**Children Under Five** Contact: Anne Murphy, PhD Funder: New York City Department of Health and Mental Hygiene \$475,077

#### **Developmental Disability Clinic Deficit-Based Reimbursement**

Contact: Elisa Muniz, MD, MS Funder: New York City Department of Health and Mental Hygiene \$70,429

#### Autism Recreational and Socialization

Contact: Tammy Fried, LCSW Funder: New York City Department of Health and Mental Hygiene \$132,005

#### **Developmental Disability Clinic**

Contact: Gail Bergin, NP Funder: New York City Department of Health and Mental Hygiene \$203,751

#### Foundation Funding

Robin Hood Main Grant Contact: Anne Murphy, PhD Funder: Robin Hood Foundation \$475,000

#### Simons Powering Autism Research (SPARK)

Contact: Lisa Shulman, MD Funder: Simon's Foundation \$5,000

#### New York State Office of Children and Family Services Early Childhood

#### Group Attachment-Based Intervention Expansion (Five Boroughs)

## PRODUCTS

#### **Conference and Poster Presentations (27)**

Barresi, Ida; Ingrasci, Katherine; Park, Minna & Valicenti-McDermott, Maria (November 2022). Words Matter: The Impact of Parental Language on Mealtime Experiences. Presentation given at AUCD 2022

Dumont, R.; Sivori, T.; Schiano, N.; Weaver, M.; Knell, E.; Stanicki, Toole, N.; Shehadeh, A.; Carpender, K.; Zagorac, S.; Haley, M.; Njoroge, J.; Lawlor, K.; Barrett, A.; Martin, R.; Simms, K.; Molholm, Sophie, Ridgway, Elizabeth & Schaaf, R.; (April 2023). Improving Occupational Engagement: Parent-Identified Goals for Occupational Therapy for Autistic Children. Presentation at American Occupational Therapy Association

Kornhaber, Sherly; Ridgway, Elizabeth; Soba, Daniella & Terilli, Carol (April 2023). I ME Self-Discovery Workshop: Leading the Way to Developing Confidence and Participation through Art, Movement, and Creative Expression. Presentation given at RFK CERC Day

Lobl, Mollie; Benenson, Blanche; Valicenti-Mc-Dermott, Maria & Silver, Ellen (March 2023). Is More Screen Time Associated with Poorer Health in Children with Autism? Presentation given at Eastern Society for Pediatric Research Meeting

Lobl, Mollie; Borcherding, Breck; Muniz, Elisa; Valicenti-McDermott, Maria & Stein, Ruth (March 2023). Is More Screen Time Associated with Poorer Health in Children with Autism? Presentation given at MCHB Fellows Research Meeting

Lobl, Mollie (April 2023). Is More Screen Time Associated with Poorer Health in Children with Autism? Presentation given at RFK CERC Day

Lobl, Mollie; Muniz, Elisa; Benenson, Blanche; Valicenti-McDermott, Maria & Silver, Ellen (March 2023). Is More Screen Time Associated with Poorer Health in Children with Autism? Presentation given at Pediatrics Academic Society Lobl, Mollie; Seijo, Rosa (November 2022). Getting It Done: Using Behavioral Intervention to Successfully Vaccinate with DD against COVID-19. Poster presentation at AUCD

Molholm, Sophie & Ridgway, Elizabeth (April 2023). Adapting a Manualized Occupational Therapy Intervention Using Ayres Sensory Integration for Autistic Children for Remote Delivery. Presented at American Occupational Therapy Association (virtual)

Ridgway, Elizabeth; Terilli, Carol; Conly, Tim; Hunt, J., Kelly, D. and Schaaf, R. (November 2023). Exploring the Journey of Clinicianto-Clinician. Poster presentation in Bronx, NY

Seijo, Rosa (November 2022). Vaccination Clinic for Children and Adolescents with DD. Presentation given at AUCD 2022

Seijo, Rosa (April 2023). Vaccination Clinic for Children and Adolescents with DD. Presentation given at Pediatric Academic Society

Shulman, Lisa (November 2022). ASD: Understanding and Advocating for Intervention. Conference presentation at AAP Developmental Behavioral Pediatric Course: An Intensive Clinical Update for Primary and Specialty Care in Orlando, FL

Shulman, Lisa (November 2023). Effective Recruitment and Retention of a Diverse Pediatric Population in a Genome-Sequencing Study. Conference presentation at ASHG Annual Meeting

Shulman, Lisa (November 2022). Etiology, Diagnosis, and Intervention Updates in ASD. Conference presentation at AAP Developmental Behavioral Pediatric Course: An Intensive Clinical Update for Primary and Specialty Care in Orlando, FL

Shulman, Lisa (November 2022). Introduction to the Childhood Autism Rating Scale-2, ASD for the Primary Care Clinician: Early Diagnosis and Management Learning Community 2022–23. Pediatric Physicians' Organization at Boston Children's Hospital (virtual)

Shulman, Lisa (April 2023). Profound Autism: What Is It? Why Is This Coming up Now? And More Questions to Consider. Presentation given at Sinergia's Autism Initiative

Shulman, Lisa (August 2022). Toe Walking in Young Children with Autism: Prevalence and Clinical Associations. Presentation given at AIR-P Research Day at Autism CARES 2022 Conference (virtual)

Shulman, Lisa; Seijo, Rosa & Valicenti-McDermott, Maria (November 2022). Vaccinating Children and Adolescents with Autism for COVID-19: The Role of Behavioral Interventions. Presentation given at AUCD 2022

Siasoco, Vincent (November 2022). An Interprofessional Approach to Improving Oral Healthcare. Conference presentation at Cerebral Palsy State Medical Director's Council on Clinical Care Conference.

Siasoco, Vincent (May 2023). Organizing Health Providers to Advise a State IDD System. Presentation given at American Academy of Developmental Medicine and Dentistry Annual Conference

Siasoco, Vincent (November 2022). The Art and Science of Oral Health for Those with Special Health Care Needs: Equitable Health for All. Presentation given at Greater NY Dental Meeting

Soba, Daniella; Terilli, Carol; Kornhaber, Sherly & Ridgway, Elizabeth (November 2023). From COVID-19 to Co-Video Sessions in the Bronx: Pandemic Lessons in Telehealth. Poster presentation in Bronx, NY

Stein, Ruth (April 2023). Comparison of Developmental Profiles of Young Children Referred for Concern for Autism Spectrum Disorder with and without ASD Diagnosis: DBPNet Study. Conference presentation at PAS, Washington, DC

Stein, Ruth (April 2023). Which Young Children Need an Autism Diagnostic Observation Schedule (ADOS) for Diagnosis? A DBPNet Study. Presentation given at PAS, Washington, DC Stein, Ruth; Muniz, Elisa; Castillo, Fiorella & Barresi, Ida (2023). Descriptive Analysis of Challenges to Complete Feeding Evaluations in Children with Developmental Disabilities. Presentation given at Academic Pediatric Association QI Research Conference

Stein, Ruth; Muniz, Elisa; Silver, Ellen; Benenson, Blanche & Castillo, Fiorella (2023). School Engagement and Associations with Children's Mental Health Conditions. Presentation given at Maternal and Child Health Bureau Annual Developmental-Behavioral Pediatrics Fellows' Meeting

#### **Electronic Products (1)**

Bonuck, Karen (March 2023). Big 10 March Kickoff. First meeting with institutional collaborators for the D2/R3 project, Alternative formats: visual format or large print

#### Newsletters (19)

Bonuck, K; Passmore, R; Mckenzie; S & Franco, M. (2023). Newsletter: CYSHCN Clips. CYSHCN Clips is the biweekly newsletter of our New York State Department of Health-funded Children and Youth with Special Health Care Needs project. It is distributed to the state's 58 local health departments and two other state UCEDDs. Seven issues were published within the fiscal year. https://us7.campaign-archive.com/ home/?u=9a25ceb298f8af5821317e34f&id=fd69eb785e

Cardin, Marie-J. (2023). Kid and Teen Scene. Kid Teen Scene magazine is created by patients who attend the Fisher Landau Center for Treatment of Learning Disabilities. To obtain a copy, email erriveli@montefiore.org

McGrath, Kathleen (2023). Newsletter: Fall VaxFacts DDNY Disability News (English, Spanish, and Mandarin). Ten issues were published within the fiscal year.

Ridgway, Elizabeth & Terilli, Carol (November 2022). What Is "Fidelity"? Is It the Next Step in Creating Evidence for Neuro-Developmental Treatment (NDT) Contemporary Practice? NDTA Network News; Quarter 3,19–21. https://www.ndta.org/Portals/77/docs/Network-Archives/NDTA\_Network\_Q3\_FN.pdf?ver=VADsAAfse0ET9DbywJZGtw%3d%3d

#### **Reports and Monographs (4)**

Bonuck, Karen; Siegel, Joanne; McGrath, Kathleen & Franco, Miriam (2023). UCEDD Annual Report 2021. The annual report from 2021 highlights activities, grant sources, and other UCEDD-related events. To obtain a copy, email karen.bonuck@einsteinmed.edu

Bonuck, Karen & George III, Patrick (2023). Report: D2/R3 Big 10 Infographic. To obtain a copy, email patrick.georgeiii@einsteinmed. edu

NYC Division of Mental Hygiene, IDD Subcommittee & Siegel, Joanne (2023). Report: 2023 NYC Division of Mental Hygiene Local Service Plan. Article 41 of the NYS Mental Hygiene Law requires development and submission of an annual Local Services Plan to the Office of Addiction Services and Supports, the Office of Mental Health, and the Office for People with Developmental Disabilities. It establishes the local priorities, needs, and outcomes for the coming year and the metrics used to measure the outcomes. The local plans are approved by the Community Services Board, composed of local service providers, consumers, and other community members. To obtain a copy, email osiegel@ montefiore.org

NYS DDPC members & Siegel, Joanne (2023). Report: 2022–2026 NYS Developmental Disabilities Planning Council State Plan. The Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 requires each state and U.S. territory to operate a Developmental Disabilities Council. The New York State Developmental Disabilities Planning Council is the DD council representing New York State. Project ideas are developed in response to the five-year state plan; projects focus on advocacy, systems change, integration, and inclusion in all aspects of a person's life. To obtain a copy, email josiegel@montefiore.org

#### Other (3)

Barnett, James (April 2023). How Textbook Beauty Is Changing How We See Patients. This paper describes the work of Positive Exposure in bringing inclusive imagery into medical school textbooks. https://helenjournal.org/may-2023/how-textbook-beauty-ischanging-how-we-see-patients

Morales-Lara, Amy (July 2022). Social Media Templates for Newsletter Dissemination. Shared each month on Facebook and Twitter as part of newsletter dissemination. To obtain a copy, email amy.morales-lara@einsteinmed. edu

Siegel, Joanne (2023). Thirty-Fifth Bronx DD Council Family Support Conference Flyer. Flyer for annual conference. To obtain a copy, email josiegel@montefiore.org

#### Pamphlets, Brochures, and Fact Sheets (12)

Gonzalez, Vanessa (March 2023). DIAL infographic (infographic). This infographic was developed to share valuable information on the Disability Information & Access Line (DIAL); also available in Mandarin Chinese, Spanish

McGrath, Kathleen (April 2023). Ten Things to Know about the Unwinding of the Medicaid Continuous Enrollment Provision (infographic)

McGrath, Kathleen (November 2022). Accessible Fitness for PWD (infographic); also available in Mandarin Chinese, Spanish

McGrath, Kathleen (September 2022). Art Activities for People with Disabilities (infographic); also available in Mandarin Chinese, Spanish

McGrath, Kathleen (December 2022). COVID Safety Guidelines infographic; also available in Mandarin Chinese, Spanish

McGrath, Kathleen (November 2022). COVID Treatment Options (Infographic)

McGrath, Kathleen (February 2023). Disability Justice Framework (infographic); also available in Mandarin Chinese, Spanish

McGrath, Kathleen (October 2022). Long COVID (infographic); also available in Mandarin Chinese, Spanish

McGrath, Kathleen (February 2023). Medicaid Changes (infographic). We developed this Medicaid infographic in response to the ending of the public health emergency; also available in Mandarin Chinese, Spanish

McGrath, Kathleen (March 2023). Public Health Emergency Ending: Six Things You Need to Know (infographic); also available in Mandarin Chinese, Spanish

McGrath, Kathleen (September 2022). Resource Guide (infographic). This resource quide infographic was created to address the needs of persons with disabilities and disseminated in three languages; also available in Mandarin Chinese, Spanish

McGrath, Kathleen (April 2023). Spring 2023 Disability Events (infographic); also available in Mandarin Chinese, Spanish

#### **Publications in Scholarly Journals** Published/In Press/Preprint (33) \*Peer-reviewed

\*Barbaresi, W., Cacia, J., Friedman, S., Fussell, J., Hansen, R., Hofer, J., Roizen, N., Stein, R. E. K., Vanderbilt, D. & Sideridis, G. (2022). Clinician Diagnostic Certainty and the Role of the Autism Diagnostic Observation Schedule in Autism Spectrum Disorder Diagnosis in Young Children. JAMA Pediatrics, 176(12), 1233-1241. https://doi.org/10.1001/jamapediatrics.2022.3605

\*Berruti, A. S., Schaaf, R. C., Jones, E. A., Dumont, R., Ridgway, E., Knell, E., Stanicki, A., Toole, N., Shehadeh, A., Carpenter, K., Zagorec, S., Haley, M., Njoroge, J., Lawlor, K., Barrett, A., Martin, R., Simms, K., Sivori, T., Schiano, N., & Weaver, M. (2022). Notes from an epicenter: Navigating Behavioral Clinical Trials on Autism Spectrum Disorder Amid the COVID-19 Pandemic in the Bronx. Trials, 23, 691. https://doi.org/10.1186/s13063-022-06635-9

\*Bonuck, K., Collins-Anderson, A., Schechter, C.B., Felt, B.T. & Chervin RD (2002). Effects of a Sleep Health Education Program for Children and Parents on Child Sleep Duration and Difficulties: A Stepped-Wedge Cluster Randomized Clinical Trial. JAMA Netw Open. 2022;5(7): e2223692. doi:10.1001/jamanetworkopen.2022.2369

\*Bonuck, K., Iadarola, S., Gao, Q., Siegel, J.F. COVID-19 Vaccines for Children with Developmental Disabilities: Survey of New York State Parents' Willingness and Concerns. J Dev Behav Pediatr. 2022 Dec 1;43(9):521-528. doi: 10.1097/DBP.000000000001113. Epub 2022 Sep 2. PMID: 36067424; PMCID: PMC9698114.

\*Cotter, M., Reisli, S., Francisco, A. A., Wakim, K. M., Oakes, L., Crosse, M. J., Foxe, J. J. & Molholm, S. (2023). Neurophysiological Measures of Auditory Sensory Processing Are Associated with Adaptive Behavior in Children with Autism Spectrum Disorder. Journal of Neurodevelopmental Disorders, 15(1), 11. https://doi.org/10.1186/s11689-023-09480-2

\*Crosse, M. J., Foxe, J.J., Tarrit, K., Freedman, E.G. & Molholm, S. (2022). Resolution of Impaired Multisensory Processing in Autism and the Cost of Switching Sensory Modality. Communications Biology, 5(1), 601. https:// doi.org/10.1038/s42003-022-03519-1

\*De Sanctis, P., Wagner, J., Molholm, S., Foxe, J.J., Blumen, H.M. & Horsthuis, D.J. (2023). Neural Signature of Mobility-Related Everyday Function in Older Adults at Risk of Cognitive Impairment. Neurobiology of Aging, 122, 1-11. https://doi.org/10.1016/j.neurobiolaging.2022.11.005

\*Foxe, J.J., Knight, E. J., Myers, E.J., Cao, C.Z., Molholm, S. & Freedman, E. G. (2022). The Strength of Feedback Processing is Associated with Resistance to Visual Backward Masking During Illusory Contour Processing in Adult Humans. NeuroImage, 259, 119416. https://doi.org/10.1016/j.neuroimage.2022.119416

Francisco, A.A., Foxe, J.J., Berruti, A., Horsthuis, D.J. & Molholm, S. (2023). Response Inhibition and Error-Monitoring in Cystinosis (CTNS Gene Mutations): Behavioral and Electrophysiological Evidence of a Diverse Set of Difficulties. bioRxiv. https://doi. org/10.1101/2023.03.31.535145

\*Francisco, A.A., Foxe, J.J. & Molholm, S. (2023). Event-Related Potential (ERP) Markers of 22q11.2 Deletion Syndrome and Associated Psychosis. Journal of Neurodevelopmental Disorders, 15, 19. https://doi.org/10.1186/ s11689-023-09487-9

Horsthuis, D.J., Molholm, S., Foxe, J.J. & Francisco, A. A. (2023). Event-Related Potential (ERP) Evidence of Early Visual Processing Differences in Cystinosis. bioRxiv. https://doi. org/10.1101/2023.03.31.535154

\*ladarola, S., Siegel, J.F., Gao, Q., McGrath. K. & Bonuck K.A. COVID-19 Vaccine Perceptions in New York State's Intellectual and Developmental Disabilities Community. Disabil Health J. 2022 Jan; 15(1):101178. doi: 10.1016/j. dhjo.2021.101178. Epub 2021 Jul 31. PMID: 34362712; PMCID: PMC8325377.

\*Knight, E.J., Freedman, E.G., Myers, E.J., Berruti, A.S., Oakes, L.A., Cao, C.Z., Molholm, S. & Foxe, J.J. (2023). Severely Attenuated Visual Feedback Processing in Children on the Autism Spectrum. Journal of Neuroscience, 43(13), 2424–2438. https://doi.org/10.1523/ JNEUROSCI.1192-22.2023

\*Knight, E.J., Krakowski, A.I., Freedman, E.G., Butler, J.S., Molholm, S. & Foxe, J.J. (2022). Attentional Influences on Neural Processing of Biological Motion in Typically Developing Children and Those on the Autism Spectrum. Molecular Autism, 13(1), 33. https://doi. org/10.1186/s13229-022-00512-7

\*Lee, C.M., Green Snyder, L., Carpenter, L.A., Harris, J., Kanne, S., Taylor, C.M., Sarver, D.E., Stephenson, K.G., Shulman, L.H., Wodka, E. L., Esler, A. & on behalf of the SPARK Consortium (2023). Agreement of Parent-Reported Cognitive Level with Standardized Measures among Children with Autism Spectrum disorder. Autism Research, 16(6), 1210–1224. https://doi.org/10.1002/aur.2934

\*McGinn, D.E., Crowley, T.B., Heung, T., Tran, O., Moss, E., Zackai, E.H., Emanuel, B.S., Chow, E.W.C., Morrow, B.E., Swillen, A., Bassett, A.S. & McDonald-McGinn, D.M. (2022). Influence of Parent-of-Origin on Intellectual Outcomes in the Chromosome 22q11.2 Deletion Syndrome. Genes, 13(10), 1800. https:// doi.org/10.3390/genes13101800

\*Nemerofsky, S.L., Silver, E.J., Liechty, E.A., Pearlman, S.A. & Campbell, D. (2022). Factors Associated with Neonatal Coding Knowledge: Results of a National Survey. Journal of Perinatology, 42(10), 1415–1416. https://doi. org/10.1038/s41372-022-01414-5

Reisli, S. & Molholm, S. (2023). Pre-Attentive Representation of Prediction Certainty in Autism: A mismatch negativity (MMN) study. bioRxiv. https://doi. org/10.1101/2023.06.06.543878

\*Ross, L.A., Molholm, S., Butler, J.S., Bene, V. A.D. & Foxe, J.J. (2022). Neural Correlates of Multisensory Enhancement in Audiovisual Narrative Speech Perception: A fMRI Investigation. NeuroImage, 263, 119598. https://doi. org/10.1016/j.neuroimage.2022.119598

\*Rubinstein, T.B., Dionizovik-Dimanovski, M., Davis, A.M., Smith, C., Faust, L., Rutstein, B., Mitchell, M., Jones, J.T., Harris, J.G., Rodriguez, M., Tesher, M., Onel, K., Gabbay, V., Stein, R.E.K., von Scheven, E. & \*Knight, A.M. (2023). CARRA Mental Health Workgroup. Multicenter Study of Utility and Acceptability of Depression and Anxiety Screening in Adolescents and Young Adults with Childhood-Onset Systemic Lupus. Arthritis Care Res (Hoboken). 2023 Apr; 75(4):724–733. doi: 10.1002/acr.24825. Epub 2022 Dec 23. PMID: 34806329; PMCID: PMC10544846.

\*Sanders, J.S., Pillai, R.L.I., Sturley, R., Sillau, S., Asato, M.R., Aravamuthan, B.R., Bonuck, K., Cervenka, M.C., Hammond, N., Siegel, J.F., Siasoco, V. & Margolis, B.A. (2022). Impact of the COVID-19 Pandemic on the Behavioral Health of People with Intellectual and Developmental Disabilities. Psychiatric Services (Washington, DC), 73(12), 1389–1392. https:// doi.org/10.1176/appi.ps.202100524

\*Schaaf, R.C., Mailloux, Z., Ridgway, E., Dumont, R., Haley, M., Failla, M.D., Landesman, L., Mash, L.E. & Harper, J. (2022). Sensory phenotypes in autism: Making a Case for the Inclusion of Sensory Integration Functions. Journal of Autism and Developmental Disorders. https://doi.org/10.1007/s10803-022-05763-0

\*Schulte, E.E., Alderman, E., Feldman, J., Hametz, P., Havranek, T., Kaskel, F.J., Levy, A., Manwani, D. & Stein, R.E.K. (2002). Using the "Coach Approach": A Novel Peer Mentorship Program for Pediatric Faculty. Acad Pediatr. 2022 Sep-Oct; 22(7):1257–1259. doi: 10.1016/j. acap.2022.03.020. Epub 2022 Apr 3. PMID: 35381378.

\*Sebastin, M., Odgis, J.A., Suckiel, S.A., Bonini, K.E., Di Biase, M., Brown, K., Marathe, P., Kelly, N.R., Ramos, M.A., Rodriguez, J.E., Aguiñiga, K.L., Lopez, J., Maria, E., Rodriguez, M.A., Yelton, N.M., Cunningham-Rundles, C., Gallagher, K., McDonald, T.V., McGoldrick, P.E., Robinson, M., Rubinstein, A., Shulman, L.H., Wolf, S.M., Yozawitz, E., Zinberg, R.E., Abul-Husn, N.S., Bauman, L.J., Diaz, G.A., Ferket, B.S., Greally. J.M., Jobanputra, V., Gelb, B.D., Horowitz, C.R., Kenny, E.E. & Wasserstein, M.P. (2023). The TeleKidSeq Pilot Study: Incorporating Telehealth into Clinical Care of Children from Diverse Backgrounds Undergoing Whole-Genome Sequencing. Pilot and Feasibility Study. 2023 Mar 22; 9(1):47. doi: 10.1186/s40814-023-01259-5. PMID: 36949526; PMCID: PMC10031704.

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\*Valicenti-McDermott, M., Barresi, I., Rosenthal, M. & Seijo, R. (2023). Screening for Hearing Impairment in School-Age Children and Adolescents with Developmental Disabilities in an Ethnically Diverse Community. Clinical Pediatrics. Advance online publication. https://doi.org/10.1177/00099228231176344

\*Valicenti-McDermott, M., Rivelis, E., Schechtman, M., Seijo, R., Bernstein, C. & Cardin, M. J. (2022). Letter to the Editor: Transition to In-Person School after Remote Learning: Mental Health Concerns in Youth with Developmental Disabilities. Journal of Child and Adolescent Psychopharmacology, 32(9), 496– 497. https://doi.org/10.1089/cap.2022.0046

\*Valicenti-McDermott, M., Schlussel, D., Hurley, C., Rivelis, E., Bernstein, C. & Cardin, M.J. (2023). Comorbidities in School-Age Children and Adolescents with Autism in an Ethnically Diverse Population: Brief Report. Journal of Child and Adolescent Psychopharmacology, 33(5), 190–194. https://doi.org/10.1089/ cap.2023.0006

\*Wakim, K. M., Foxe, J. J., & Molholm, S. (2023). Cued motor processing in autism and typical development: A high-density electrical mapping study of response-locked neural activity in children and adolescents. European Journal of Neuroscience. Advance online publication. https://doi.org/10.1111/ejn.16063

\*Wakim, K.M., Freedman, E.G., Tivarus, M. E., Christensen, Z., Molholm, S. & Foxe, J.J. (2022). Effects of Human Immunodeficiency Virus Infection and Former Cocaine Dependence on Neuroanatomical Measures and Neurocognitive Performance. Neuroscience, 502, 77–90. https://doi.org/10.1016/j.neuroscience.2022.08.008 \*Whitney, K., Felt, B., Collins-Anderson, A. & Bonuck, K. (2023). The Feasibility of Screening for Sleep Problems in Early Childhood Education Programs. Behavioral Sleep Medicine. Advance online publication. https://doi.org/1 0.1080/15402002.2023.2177294

Williams, Z.J., Schaaf, R., Ausderau, K.K., Baranek, G.T., Barrett, D.J., Cascio, C.J., Dumont, R.L., Eyoh, E.E., Failla, M.D., Feldman, J.I., Foss-Feig, J.H., Green, H.L., Green, S.A., He, J.L., Kaplan-Kahn, E.A., Keçeli-Kaysılı, B., MacLennan, K., Mailloux, Z., Marco, E. J., Mash, L.E., ... Woynaroski, T.G. (2023). Examining the Latent Structure and Correlates of Sensory Reactivity in Autism: A Multisite Integrative Data Analysis by the Autism Sensory Research Consortium. Research Square. https://doi.org/10.21203/rs.3.rs-2447849/v1

\*Zhou, X., Feliciano, P., Shu, C., Wang, T., Astrovskaya, I., Hall, J. B., Obiajulu, J.U., Wright, J.R., Murali, S.C., Xu, S.X., Brueggeman, L., Thomas, T.R., Marchenko, O., Fleisch, C., Barns, S.D., Snyder, L.G., Han, B., Chang, T.S., Turner, T.N., Harvey, W.T., ... Chung, W.K. (2022). Integrating de Novo and Inherited Variants in 42,607 Autism Cases Identifies Mutations in New Moderate-Risk Genes. Nature Genetics, 54(9), 1305–1319. https://doi. org/10.1038/s41588-022-01148-2

#### **Press Communications (18)**

Ayoob, Keith-Thomas (June 2023). Seven Best High-Protein Snacks, According to Registered Dietitians; available in French, Spanish. https://www.forbes.com/health/body/besthigh-protein-snacks/

Ayoob, Keith-Thomas (January 2023). Eight Fast-Food Desserts That Are Totally Worth Ordering, According to Experts. https://www. eatthis.com/experts-favorite-fast-food-desserts/]

Ayoob, Keith-Thomas (January 2023). Bitter Chocolate: Study Points to the Presence of Toxic Metals in Famous Brands, But There is Controversy. https://www.oliberal.com/mundo/chocolate-amargo-estudo-aponta-presenca-de-metais-toxicos-em-marcas-famosas-mas-ha-controversias-1.654034 Ayoob, Keith-Thomas (March 2023). CCC Statement on the Artificial Sweetener Erythritol and Cardiovascular Event Risk; available in Spanish. https://caloriecontrol.org/ccc-statement-on-the-artificial-sweetener-erythritol-and-cardiovascular-event-risk/

Ayoob, Keith-Thomas (May 2023). CNN.com: Don't use sugar substitutes for weight loss, World Health Organization advises https:// www.cnn.com/2023/05/15/health/who-sweeteners-weigh-loss-guideline-wellness/index. html

Ayoob, Keith-Thomas (May 2023) Food Business News: WHO Recommendation Goes against Non-sugar Sweeteners. https://www. foodbusinessnews.net/articles/23823-who-recommendation-goes-against-non-sugar-sweeteners

Ayoob, Keith-Thomas (November 2022). National Geographic: How Nutritious Are Your Favorite Thanksgiving Foods? https:// www.nationalgeographic.com/science/article/ healthier-thanksgiving-feast-turkey-calories-stuffing-pie-pumpkin

Ayoob, Keith-Thomas (May 2023). Put the Sweetener Down. It Doesn't Help with Long-Term Weight Loss, World Health Organization Says; available in French and Spanish. https://www.usatoday.com/story/news/health/2023/05/16/ world-health-organization-sugar-substitutes-weight-loss/70222122007/

Ayoob, Keith-Thomas (February 2023). Samantha Heller's Nutrition & Health Show. https://www.siriusxm.com/search?q=samantha+heller

Ayoob, Keith-Thomas (December 2022). Sirtfood Diet Review. https://www.forbes.com/ health/body/sirtfood-diet-review/

Ayoob, Keith-Thomas (July 2022). The Busy Girl's Guide to Eating Right; available in Spanish. https://www.cortaporlosano.com/la-guiade-la-chica-ocupada-para-comer-bien

Ayoob, Keith-Thomas (April 2023). USDA Wants to Cut the Amount of Milk Provided to Low-Income Families. Many Say They're Concerned. https://www.usatoday.com/story/ money/personalfinance/2023/04/03/usdacuts-wic-milk-options/11511778002/ Ayoob, Keith-Thomas (May 2023). WHO Advise Not to Use Non-sugar Sweeteners for Weight Control. https://www.foodnavigator. com/Article/2023/05/15/WHO-advises-notto-use-non-sugar-sweeteners-for-weightcontrol-in-newly-released-guideline?utm\_ source=newsletter\_daily&utm\_medium=email&utm\_campaign=15-M

Ayoob, Keith-Thomas (May 2023). World Health Organization Warns Non-sugar Sweeteners May Increase Risk of Diabetes and Heart Disease. https://www.marketwatch.com/story/ world-health-organization-warns-against-useof-non-sugar-sweeteners-says-they-may-increase-risk-of-diabetes-heart-issues-and-mortality-in-adults-38d1d4ae?mod=fire-retirement

Ayoob, Keith-Thomas (May 2023). World Health Organization: Artificial Sweeteners Are Bad for Weight Loss and Health. https:// longevitylive.com/food/who-warns-againstusing-artificial-sweeteners-for-weight-loss/

Ayoob, Keith-Thomas (June 2023). You May Be Overlooking This Nutritional Powerhouse. You Shouldn't. Https://www.nationalgeographic.com/premium/article/diet-seeds-nutrition-hierarchy

Bonuck, Karen (March 2023). Bronx Doctor Breaks Down COVID-19 Vaccination Efforts for Those with Developmental Disabilities. https://bronx.news12.com/bronx-doctor-breaks-down-covid-19-vaccination-efforts-for-those-with-developmental-disabilities

Shulman, Lisa (May 2023). BronxNet: Autism Prevalence Rates during Autism Acceptance Month, BronxNet Interview regarding the new autism prevalence rates during Autism Acceptance Month. https://www.youtube.com/ watch?v=3HCnSMva7QQ

#### Web-Based Products (16)

Addressing Sleep Problems in Young Children (March 2023). https://www.einsteinmed.edu/ research-briefs/9975/addressing-sleep-problems-in-young-children/

Ayoob, Keith (July 2022). NY Food Show: Fancy, Tasty, and Pricey. https://thechocolatelife. com/ny-specialty-food-show-fancy-tasty-pricey/ Ayoob, Keith (September 2022). Cadmium 2.0, TheChocolateLife: Live – Cadmium in Cocoa: Is It as Bad as It Is Made Out to Be? https:// www.youtube.com/watch?v=ThPg76KehHc

Ayoob, Keith (December 2022). Dr. Ayoob Answers Your Latest Questions about MSG. https://msgdish.com/dr-ayoob-answers-questions-about-msg/

Ayoob, Keith (May 2023). W.H.O.Guidelines on Non-sugar Sweeteners; available in Spanish. https://caloriecontrol.org/health-benefits-established-safety-of-low-and-no-calorie-sweeteners-supported-by-decades-of-experience/

Ayoob, Keith (September 2022). Worried about Your Cholesterol Levels? Try Incorporating These 38 Foods into Your Diet to Help Lower It. https://www.yahoo.com/lifestyle/ worried-cholesterol-levels-try-incorporating-215159479.html

Bonuck, Karen (September 2022). Children with Developmental Disabilities and COVID-19 Vaccination. https://www. einsteinmed.edu/research-briefs/4864/ children-with-developmental-disabilities-and-covid-19-vaccination/

Bonuck, Karen (June 2023). Long COVID Is a Mass Disabling Condition—Treat It Like One/ The Doctor's Tablet. Dr. Bonuck is a professor of family and social medicine, of obstetrics & gynecology and women's health, and of pediatrics at Einstein and co-director of the Rose F. Kennedy University Center of Excellence in Developmental Disabilities at Einstein-Montefiore. https://blogs.einsteinmed.edu/longcovid-is-a-mass-disabling-condition-treat-itlike-one/

Franco, Miriam; Siegel, Joanne; Bonuck, Karen; Gonzalez, Vanessa & Morales-Lara, Amy (2023). Children and Youth with Special Health Care Needs Resource Guide. Children and Youth with Special Health Care Needs is a DOH-funded project. We were tasked with building an interactive, user-friendly resource guide for families and professionals. Rodriguez, Diana (April 2023). Supporting Parents of Children with Developmental Disabilities on Their Unexpected Journey. The Doctor's Tablet. https://blogs.einsteinmed.edu/supporting-parents-of-children-with-developmental-disabilities-on-their-unexpected-journey/

Schechtman, Merryl (November 2022). ADHD Important Facts. For general educators in Queens, NY, electronic presentations: DOE: Videotape for General Educators on ADHD Important Facts. Taped: November 30, 2022. For a copy email dottoresa@gmail.com

Shulman, Lisa (April 2023). BronxNet: A Discussion on How Autism Is a Disorder That Is Affecting about 1 in 36 Children in America. https://www.youtube.com/watch?v=3HCnSMva7QQ

Shulman, Lisa (April 2023). JOWMA (Jewish Orthodox Women's Medical Association) Podcast—Learn the Signs, Act Early: The Early Identification and Treatment of Autism. https://podcasters.spotify.com/pod/show/ jowma/episodes/Learn-The-Signs--Act-Early-Dr--Lisa-Shulman-on-the-Early-Identificationand-Treatment-of-Autism-e22noo5

Shulman, Lisa (May 2023). NPR: All Things Considered—Interviewed for "Meet the 'glass-half-full girl' a piece on brain plasticity that features a patient cared for by Dr. Shulman at RFK CERC: https://one.npr. org/?sharedMediald=1165131907:1165449742

Siegel, Joanne (2023). Medical Self-Advocacy: Speak Up. https://www.selfadvocacyinfo.org/ wp-content/uploads/2023/03/Medical-Advocacy-by-SANYS.pdf

Siegel, Joanne (October 2022). Webinar #8: Monkeypox and Other Viruses. Video recording of a discussion of common signs and symptoms of monkeypox and other viruses. Speakers: Dr. Vincent Siasoco, director of primary care at the Rose F. Kennedy (RFK) Children's Evaluation and Rehabilitation Center at Montefiore. Dr. Margaret L. Aldrich, director of pediatric infection control and epidemiology at the Children's Hospital at Montefiore. https://youtu.be/XLYm8FPVGH4

#### **Rose F. Kennedy Center Programs:**

University Center of Excellence in Developmental Disabilities (UCEDD)

Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

Intellectual and Developmental Disabilities Research Center (IDDRC)

The Children's Evaluation and Rehabilitation Center **(CERC)** provides services at the Van Etten Building #5 in the Jacobi Medical Center Complex

## Montefiore Einstein

The Van Etten Building 1225 Morris Park Avenue Bronx, New York. 10461 718 430 8500

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