



# Children's Specialized Hospital Research Center Newsletter

July 2024 | Volume 4 Issue 2

## Welcome!

The Children's Specialized Hospital (CSH) Research Center Newsletter provides an overview of research conducted at CSH. We regularly share information about CSH studies, lectures, and resources. Each issue also features CSH research news and upcoming events and activities. Please reach out with any suggestions or questions.

## About the Research Center at CSH

The Research Center at Children's Specialized Hospital strives to advance pediatric rehabilitation by initiating and supporting evidence-based studies that explore innovative interventions, technologies and approaches to specialized care for children and adolescents.

### In This Issue:

- |   |  |   |                                  |   |   |
|---|--|---|----------------------------------|---|---|
|   |  | 1 | Welcome                          |  |  |
|  |  | 2 | Featured Researcher              |  |  |
|  |  | 3 | Deeper Dive                      |  |  |
|  |  | 3 | Upcoming Conferences             |  |  |
|  |  | 4 | Recent CSH Publication           |  |  |
|   |  | 4 | Meet Our Interns                 |  |   |
|   |  | 5 | Featured Study (Recruiting Now!) |  |   |
|   |  | 6 | Distinguished Lecture Series     |  |   |
|   |  | 6 | Contact Us                       |  |   |
|   |  | 7 | Meet the Research Center Team    |  |   |

## JOIN OUR STUDIES

Several research studies are actively recruiting participants. To see which studies you may be eligible to join, and to learn more about how to participate, see our [autism](#), [brain injury](#), [chronic health conditions](#), [cognition](#), and [mobility](#) studies.

# Featured Researcher: Madelyn Cannone

## MSN, CPNP-AC, Pediatric Nurse Practitioner in CSH Physiatry Department

Madelyn Cannone, MSN, CPNP-AC is a Pediatric Nurse Practitioner currently working at Children's Specialized Hospital in the Pediatric Physiatry Department. Madelyn provides pediatric physiatry services in her outpatient clinic at CSH Union and CSH East Brunswick, and also covers the physiatry needs of CSH long term care patients in Mountainside and Toms River. Madelyn received her undergraduate degree in Neuroscience with a minor in Special Education from Boston College in 2017, and then decided to continue her education to pursue nursing following graduation.



She completed an accelerated Bachelors of Science in Nursing program at the University of Pennsylvania School of Nursing in 2018, and began working as an inpatient pediatric rehabilitation RN at the Seashore House at the Children's Hospital of Philadelphia. Madelyn received her MSN from the Pediatric Acute-Chronic Nurse Practitioner program at the University of Pennsylvania in 2022, and began her training as a pediatric physiatry APN fellow at CSH in 2023. She completed her physiatry APN fellowship as well as the NJLEND fellowship through Rutgers University Boggs Center on Developmental Disabilities in the Spring 2024. Madelyn's clinical and academic work is primarily centered around the intricate, complex care needs of children with physical and neurodevelopmental disabilities.

Madelyn recently completed her NJLEND fellowship through Rutgers University Boggs Center on Developmental Disabilities, where she presented her research on the discrepancies and barriers to inclusion of children with Cerebral Palsy (CP) within the general education classroom. She used her literature review findings and clinical experiences to create an interdisciplinary, educational pamphlet for families of children with CP to give to their child's teachers, in order to better educate general educators on CP and to promote inclusion of these students within the least restrictive environment.

**You can find the pamphlet, Tips-for-Teachers, by scanning this QR code:**



**And please see her poster on the following page!**

### Other Publications:

- Cannone, M. R. (2023). Pediatric Anti-N-Methyl-D-Aspartate Receptor Encephalitis. *Pediatric Nursing*, 49(6).

**Additionally, Madelyn also recorded a video about what inspired her research and other details about the process. Please [click here](#) to view it!**

Thank you so much for this excellent write-up Madelyn, and for all of your hard work on behalf of children with CP and other children with special healthcare needs!



# Deeper Dive: Madelyn Cannone's poster



Robert Wood Johnson  
Medical School

## THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service  
New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program

### Provider-Family-Teacher Collaboration & Education: Promoting Inclusion of Children with Disabilities within the General Education Classroom

Madelyn Cannone, MSN, CPNP-AC, NJLEND Nursing Fellow  
Manuel Jimenez, MD, MS

#### Background

**Individuals with Disabilities Education Act – IDEA:** Federal mandate that requires states to provide **free, appropriate, public education (FAPE)** to all students with disabilities within the **least restrictive environment (LRE)**.

**LRE** – All children with disabilities are to be educated with children who do not have disabilities, to the maximum extent appropriate.

**Inclusion** – Children with special needs have the right to participate in the same community activities and programs they would attend if they did not have a disability.

Benefits of Inclusion		
<b>Academic</b>	<ul style="list-style-type: none"> <li>Higher grades</li> <li>Higher achievement scores on standardized tests</li> <li>Improved literacy skills</li> <li>Better post-secondary school outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Fewer school absences</li> <li>Better instruction and comprehension</li> <li>Higher academic expectations</li> </ul>
<b>Social</b>	<ul style="list-style-type: none"> <li>Improved peer relationships</li> <li>Improved social competence</li> <li>Improved school satisfaction and sense of belonging</li> <li>Better models for social behavior and communication</li> </ul>	<ul style="list-style-type: none"> <li>Improved functional living &amp; adaptive skills</li> <li>Improved self-esteem</li> <li>Reduction in inappropriate behaviors</li> <li>Greater acceptance in the community</li> <li>Increased community participation &amp; employment as adults</li> </ul>
<b>Benefits for All Students</b>	<ul style="list-style-type: none"> <li>Improved acceptance &amp; understanding of people with disabilities</li> <li>Desensitization towards people who are "different"</li> <li>Increased appreciation of individual differences</li> <li>Better preparedness for becoming parents &amp; community leaders</li> <li>Increased opportunities to teach peers and collaborate</li> <li>Decreased overall stigma toward individuals with disabilities</li> </ul>	

#### Problem Analysis:

##### Inclusion in Real-World Practice

Despite federal mandates and the known benefits of inclusion, adoption of inclusion within the general classroom has fallen short in practice.

- In the 2021-2022 school year, 15% of all public-school students received special education and/or related services, under IDEA.
- 95% of those students were enrolled in regular public schools.
  - 67% of those students spend at least 80% of their school day within the general education classroom.
    - SLP (88%), learning disability (75%), other health impairment (70%), DD (70%), visual impairment (70%).
  - Less than 1/3<sup>rd</sup> of students with more specific or involved disabilities spend the majority their school day within general education classes.
    - Deaf-blindness (30%), ID (20%), multiple disabilities (15%).

#### Objective

To better understand the **barriers to inclusive practice** within the **general education classroom**.

To utilize **family-provider-teacher collaboration** to **promote the general educator's knowledge about the implications of their student's disability, their student's right to inclusion, and ways to foster inclusive practice** for all children with disabilities.

#### Process and Methods

- Literature review** to identify factors that contribute to general educators' reluctance or resistance to inclusion.
  - Reviewed 32 peer-reviewed articles, published within the last 20 yrs.
  - Search engines: PubMed, Google Scholar
- Interviews** with disability rights attorneys, families of children with disabilities, CSH faculty and general education teachers regarding disability rights and inclusion.

Identified **three main factors** that **influenced inclusive practice within the general education classroom**:

- The general education teacher's **knowledge about common pediatric disabilities**.
- Teacher **self-efficacy and confidence** in their ability to teach children with disabilities.
- The general education teacher's **understanding of disability-education laws** and the rights of the child.

*"Inclusion is a practice, not a place."*

#### References:



#### Pamphlet:



#### Resources on Inclusion:



#### Final Product and Implications

Using these three factors, we identified **interventions & strategies to improve general educator knowledge and confidence** toward teaching students with disabilities.

- Collaboration** between teachers, families, medical providers, and other disciplines within the child's life.
  - Interdisciplinary collaboration amongst the child's care team allows for greater info sharing and knowledge acquisition.
- Education and professional development** opportunities for general educators to learn more about common pediatric disabilities and disability rights.
  - With enhanced education and knowledge about disability, teachers have shown greater self efficacy and more positive attitudes toward inclusion.

We then used these strategies to create something tangible

**"Tips for Teachers"** – a personalized, educational pamphlet for families & providers of children with cerebral palsy to **jointly fill out and provide to the child's teacher**, with a focus on:

- Educating teachers about the **implications of the student's disability**.
- Services the child is **entitled to under IDEA**.
- Student specific techniques** that the teacher can use to **better promote inclusion** of that child within the classroom.

What is Cerebral Palsy?  
Overview of IDEA, LRE, & Inclusion  
Benefits of Inclusion  
Inclusion Strategies for Cerebral Palsy  
Fill-in-the-blank portion for personalized recommendations from the child's family and healthcare team.  
Resources for further information about inclusion.

- Given to families of patients with Cerebral Palsy during outpatient doctors appointments.
- Made available online for Children's Specialized Hospital providers to print for patients, as needed.

DID YOU KNOW?

## Upcoming Events/Conferences/Grants

- National Autism Conference  
August 5-8, 2024. Harrisburg, PA
- Association of Pediatric Hematology/Oncology Nurses Conference  
September 11-13, 2024. Salt Lake City, Utah
- Society for Developmental and Behavioral Pediatrics Conference  
September 12-16, 2024. Washington, D.C.
- Pediatric Complex Care Association Conference  
September 25-27, 2024. Arlington, VA
- International Society for Pediatric Diabetes (ISPAD) Conference  
October 16-19, 2024. Lisbon, Portugal
- Autism New Jersey Annual Conference  
October 24-25, 2024. Atlantic City, NJ





## CSH Recent Publications

Dr. Jaime Crowley-Zalak, Dr. Kathryn Peterson, Dr. Cathleen C. Piazza, and colleagues recently published, "Long-Term Outcomes after Behavior-Analytic Intervention for Pediatric Feeding Disorders" in *Journal of Developmental and Physical Disabilities*.

### From the abstract:

"Many children with autism spectrum disorder experience feeding difficulties that can lead to increased health risks (e.g., severe nutrition deficiencies, obesity-related illnesses) if left untreated. Intensive feeding programs that use behavior-analytic interventions have reported positive outcomes for treating challenging behavior associated with pediatric feeding disorders at discharge and up to 1 year post discharge. Whether these children achieve and maintain long-term goals is unknown. The purpose of the current study was to evaluate outcomes of behavior-analytic intervention for pediatric feeding disorders among children with and without autism spectrum disorder in an intensive feeding program post discharge. Caregivers of former patients reported on the positive and negative impact of the program and their child's growth and diet variety at follow-up. 85% of caregivers reported the program had a positive impact. Increases in height-for-age z scores were significant from admission to discharge from the intensive program, and progress in growth and diet variety remained the same or improved for most children at follow-up. Results suggest that behavior-analytic intervention in an intensive feeding program produced positive short- and long-term outcomes for children and their families."

Read the study [here](#). See the full list of CSH research publications [here](#).



## Meet our summer Research Center interns!



### Brithany Andrade



Brithany will be a senior at Rutgers-Newark and is majoring in Neuroscience. She is working with the Chronic Illness Management Program research team. Her other research interests include pediatric oncology and neurology. In her free time, she enjoys running and is currently training for a marathon.

### Erin Kylish



Erin will be a senior at the University of South Carolina and is majoring in Biochemistry. She is working with the Brain Injury team. Her other research interests include medicine and gene therapy. In her free time, she enjoys running, reading, and spending time with her family and dogs.

### Maeve McGowan



Maeve will be a senior at Lehigh and is majoring in Psychology. She is working with the Neurodevelopmental research team. Her other research interests include health behavior change, developmental disorders, and health communication. In her free time, she enjoys playing sports, practicing her instrument, and going to the beach.

### Pranita Sannidhi



Pranita will be a senior at Rutgers-New Brunswick and is majoring in Cell Biology & Neuroscience. She is working with the Psychiatry research team. Her other research interests include neurodegenerative disorders and menstrual equity. In her free time, she enjoys baking, crocheting, and watching TV.





# RECRUITING NOW

## FEATURED STUDY

**SPARK** 

## You Can Transform Autism Research.

Join **SPARK** and play an important role  
in the largest study of autism ever.



SPARK is an online autism research study that aims to make new discoveries and advance the understanding of autism. With over 275,000 participants, SPARK is now the largest study of autism ever. But in order to advance discoveries in autism for all individuals and families, we need everyone to join. And to find answers for you, we need to understand what makes you unique.

### Join Our Growing **SPARK** Community of **350,000+**

It's simple and it's free. Your contributions will make a difference. Register online today.

**Together, we will advance autism research for years to come.**

**RWJBarnabas**  
HEALTH

Children's  
Specialized  
Hospital 

[SPARKforAutism.org/CSH](https://SPARKforAutism.org/CSH)

[SPARKcsh@childrens-specialized.org](mailto:SPARKcsh@childrens-specialized.org) | 908-301-5958



# Distinguished Lecture Series

On August 14th, Dr. Alisa Khan (Boston Children's Hospital/Harvard Medical School) will present "Integrating the Family Voice into Pediatric Care to Improve Patient Safety, Quality, and Equity," from 12-1:30pm. The talk will be offered at CSH-New Brunswick and virtually. To register, [click here](#).



**Next 2024 speaker:**





Be on the lookout for more information about upcoming speakers, and please contact [thackett@childrens-specialized.org](mailto:thackett@childrens-specialized.org) with any suggestions for speakers/topics. It is appreciated!



## CONTACT US



To learn more about our research, if you are interested in discussing potential collaborations, or if you have questions or comments, please contact us:

-  **Claire Marchetta, MPH** Interim Director of Research  
[cmarchetta@childrens-specialized.org](mailto:cmarchetta@childrens-specialized.org), 732-258-7288
-  **Joman Y. Natsheh, MD, PhD** Research Lead, Developmental and Behavioral Pediatrics  
[jnatsheh@childrens-specialized.org](mailto:jnatsheh@childrens-specialized.org), 908-588-9608
-  **Mayank Seth, PhD** Research Lead, Psychiatry  
[mseth@childrens-specialized.org](mailto:mseth@childrens-specialized.org), 908-588-9609
-  **Tomiko Hackett, MPH** Research Engagement Coordinator  
[thackett@childrens-specialized.org](mailto:thackett@childrens-specialized.org), 732-258-7296

# Meet the CSH Research Center Team

**Michael Dribbon, Ph.D.**



Vice President of Business Development and Chief Innovation & Research Officer

Research Focus: Intervention outcomes, Social Determinants of Health

Michael likes music, travel, and time with family.

**Claire Marchetta, MPH**



Interim Director of Research

Research Focus: Epidemiological factors for developmental disabilities and birth defects

Claire enjoys outdoor recreation and spending time with family and friends.

**Joman Y. Natsheh, M.D., Ph.D.**  
Research Lead, Developmental and Behavioral Pediatrics



Research Focus: Neural and behavioral correlates of action-control in children with neuro-developmental disorders

Joman enjoys reading, especially Arabic literature. She loves to travel and explore, and she can spend hours immersed in graphic design.

**Mayank Seth, Ph.D.**  
Research Lead, Psychiatry



Research focus: identification of factors underlying poor clinical outcomes, with an eye towards developing more efficacious rehab interventions

Mayank enjoys spending time with family & friends, reading, and listening to music. He also enjoys going on hikes and biking.

**Amira Herstic, MS**

Research Coordinator, Developmental and Behavioral Pediatrics

Research Focus: Neuroscience of language and motor development in children with ASD and ADHD

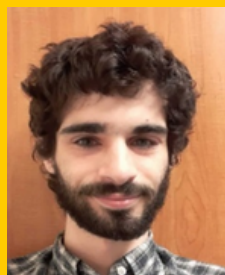


Amira enjoys reading, crocheting, traveling, and spending time with family.

**Uriel Richman, MA**

Research Assistant, Developmental and Behavioral Pediatrics

Research Focus: Cognition and child development



Uriel enjoys hiking, camping, visual arts and playing tabletop games.

**Tomiko Hackett, MPH**

Research Engagement Coordinator

Research Focus: Mental health/substance use disorders as well as other chronic illnesses



Tomiko enjoys traveling, being in nature, reading, and spending time with friends.