

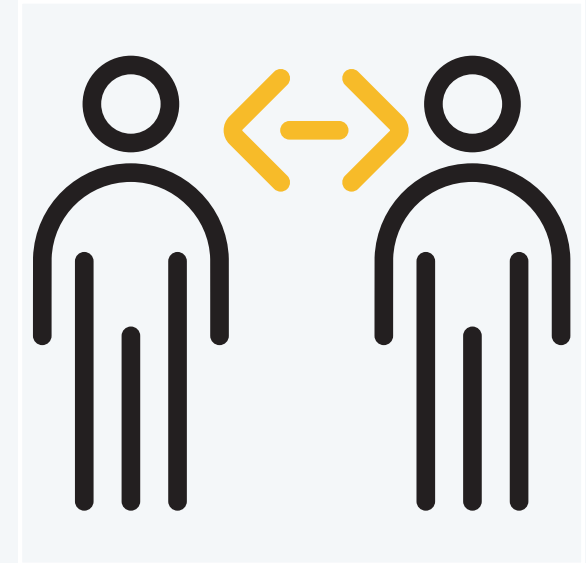
Understanding Autism through Participant Involvement: SPARK Research Match

Dr. Wendy K. Chung
April 6, 2022



About Research Match

- SPARK Research Match **launched in July 2017**.
- SPARK Research Match invites SPARK participants to participate in **new** research that is **not** part of the main SPARK study.
- Researchers around the world can apply for access to Research Match.
- To date, over 98,000 families have been invited to a Research Match study, and almost 44,000 have participated at least once (many multiple times, some over 10 times!)



How does Research Match work?

- As part of SPARK, participants can hear about and choose to participate in Research Match studies.
- Participants can choose to:
 - Share their information with the new study team to schedule a visit in-clinic or interview.
 - Complete surveys online.
- After the research team analyzes their data, they help SPARK communicate the results back to participants and the SPARK community.



Participant Access Committee - Scientific Members



Robin Kochel

Baylor College of Medicine
Texas Children's Hospital



Christine Nordahl

University of California -
Davis



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George Washington
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Tychele Turner

Washington University –
St. Louis

Participant Access Committee - Community Members



I am the single parent advocate of a amazing 12 year old Lil Super Hero self-advocate. Together, we are a dynamic Super Hero Advocacy Duo.

Rico Winston



My connection to autism is my 18 year old son who was diagnosed at the age of one.

Denise Lombardi



I am a parent of a college student on the autism spectrum

Noreen O'Connor-Abel



I am the single parent of a 17-year-old son with ASD. As a "vet" mom, I try to help other parents new to the Autism journey, and I am currently the Parent Leader for the Smart Start Circle of Parents Group and the Chapter Leader for Autism Society of North Carolina New Hanover County Chapter.

Grelynn Bradley



I am an autistic adult who has hosted presentations on autism since the age of 11, and believes that genetic research can help enhance autism in a positive light. The more we understand autism, the more society will be willing to accept its members with autism.

James Williams

Research Match Testimonials

“We were able to get together with SPARK Research Match, which then in turn allowed researchers to find out that George was a good fit for their study...I learned a lot from the social group study about how to interact with George more as a person than as a parent...It far exceeded any expectation we could possibly have had about what we would do, who we would meet, and how helpful it would be to George.”

– Colin, autism dad and SPARK participant



Research Match Testimonials

“Research Match has helped us reach a much larger group of families and let them know about [our] study and has brought in families to our clinic for the studies. We’re trying to help them feel more comfortable and feel more confident and feel like they have tools to approach other kids their age.”

– *Latha Soorya, Ph.D., Director, AARTS Center at Rush*



Recent SPARK Research Match Studies

Early impact of COVID-19 on families

Background:

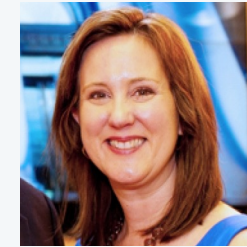
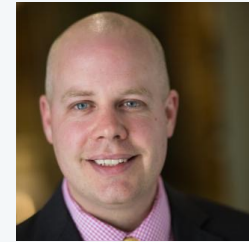
- The COVID-19 pandemic was very disruptive globally, but individuals with autism and their families may have unique impacts, challenges, and needs during such a crisis.
- Research Match and the SPARK cohort were uniquely poised to allow families and individuals to share their collective experiences almost immediately, and ongoing throughout the pandemic, through repeated online surveys.

Study Goal:

- Identify areas of need and targets for funding, research, and intervention.



PIs – Wendy Chung, Casey White, Kiely Law
Institution – Simons Foundation



PIs – Luther Kalb, Daniele Fallin
Institution – Kennedy Krieger Institute, Johns Hopkins



PI – Anjana Bhat
Institution – University of Delaware

Early impact of COVID-19 on families

Study Method:

- Over 3,500 parents completed the survey

Study Results:

- Over 75% reported major disruptions in most ASD services.
- Access to remote services was limited.
- Most parents reported little to no benefit from remote services.
- 64% reported moderate/severe negative impact on child's ASD symptoms, behaviors, and challenges.

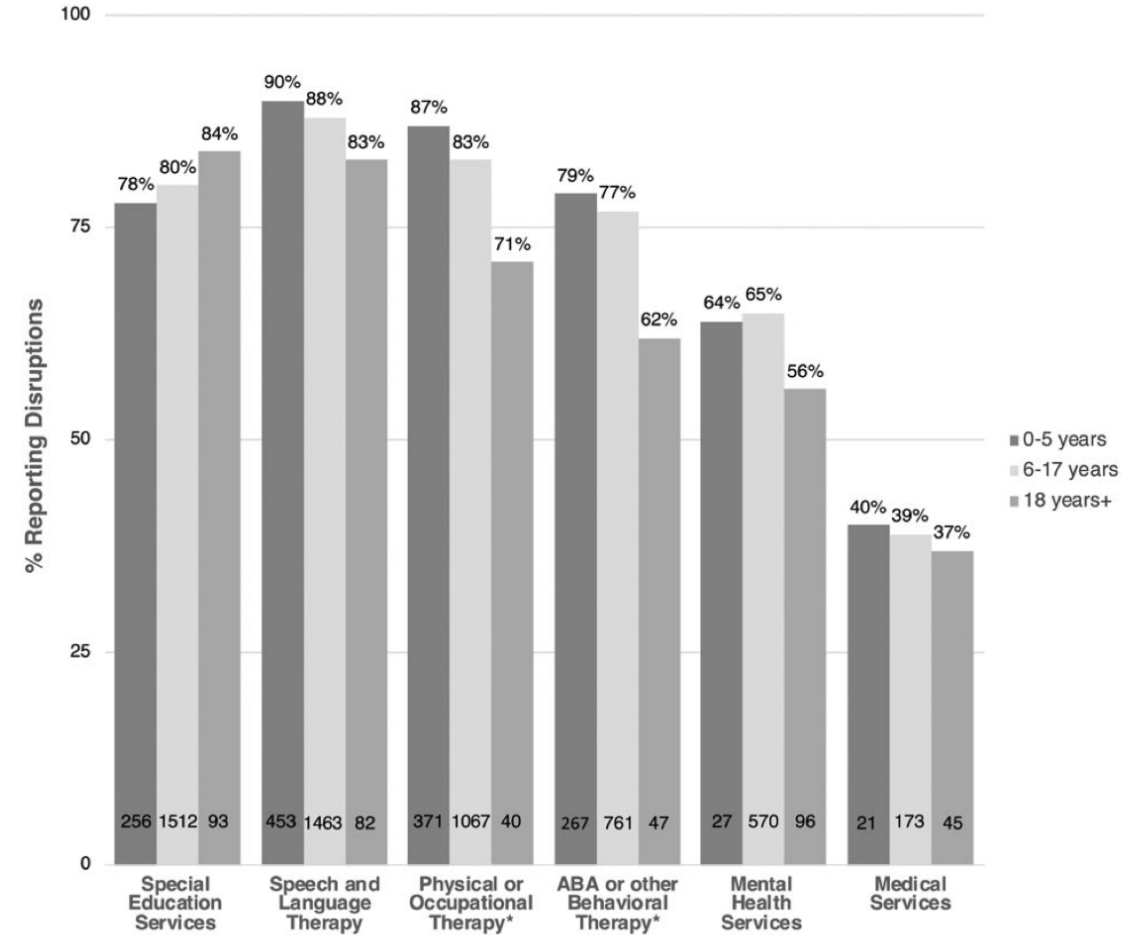
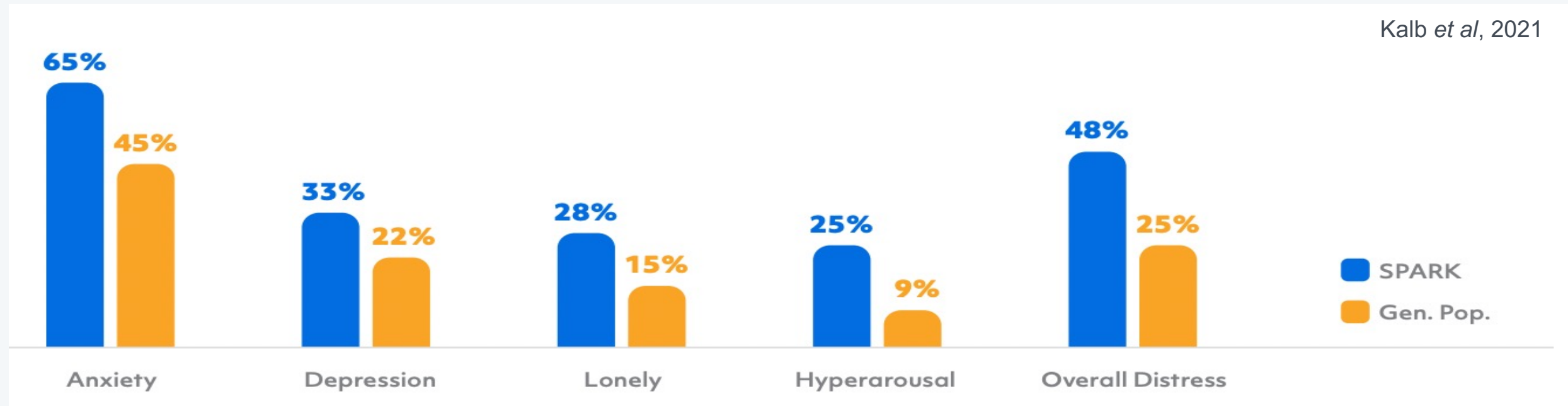


Fig. 1 Children/Dependents with disrupted ASD services/therapies

Early impact of COVID-19 on families

- Kalb's study compared SPARK families to responses from a similar survey of parents in the general U.S. population
- Bhat's study examined factors that may have worsened disruptions and mental health outcomes from the pandemic



Early impact of COVID-19 on adults with autism

Study Method:

- Similar surveys on COVID-19 experiences were offered to adults with autism.
- Surveys were completed in March/April 2020.
- **Over 400 autistic adults** completed the surveys included in the two featured studies.
 - Ages 18 to 74 (average age 37)



PIs – Ryan Adams
Institution – Cincinnati Children's



PIs – Vanessa Bal
Institution – Rutgers University



PIs – Somer Bishop
Institution – UCSF



PIs – Julie Lounds Taylor
Institution – Vanderbilt University Medical Center

Early impact of COVID-19 on adults with autism

Study Results:

- **Prior to the pandemic**, around 2/3 of the participants had a job, and 20% were students
 - 70% were receiving at least one service or therapy
 - Most had attended some college and had a college or graduate degree
- **93% of participants reported negative impacts from the pandemic**
- **45% reported a moderate to severe amount of psychological distress**

LEVELS OF PSYCHOLOGICAL DISTRESS



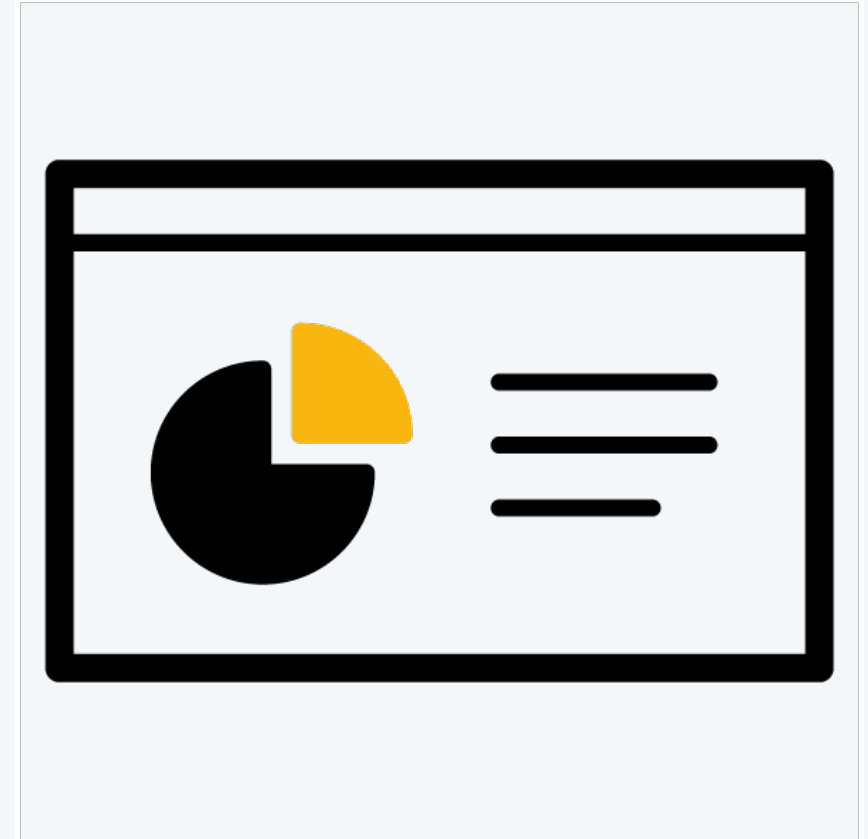
Early impact of COVID-19 on autistic adults

Study Results (cont.):

- Of participants who received online services (around 100), **around 75% reported a moderate to significant benefit.**
- **More than 1/3 of participants said they felt hopeful about the future 3 or more days a week.**

Future Research Directions:

- What types of online service work and for whom?
How can we improve remote services and therapies?
- How can we increase hopefulness to help with coping?



COVID-19 Studies: Press Coverage



Director's Messages

Joshua A. Gordon, M.D., Ph.D.
Director of NIMH

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Messages by Year

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Messages by Topic

Addressing the Needs of the Autism Community During COVID-19

autistic

By [Joshua Gordon](#)



April 27, 2021

[Follow the NIMH Director on Twitter](#)

April is Autism Awareness Month, and this April's observance comes after a particularly challenging year with the coronavirus (COVID-19) pandemic. As I noted in my last [Director's Message](#), the effects of the pandemic are especially challenging for the most vulnerable, including those on the autism spectrum and



The Premier Source for
Developmental Disability News






Autism Families Report Major Impacts From Pandemic

by Shaun Heasley | January 15, 2021



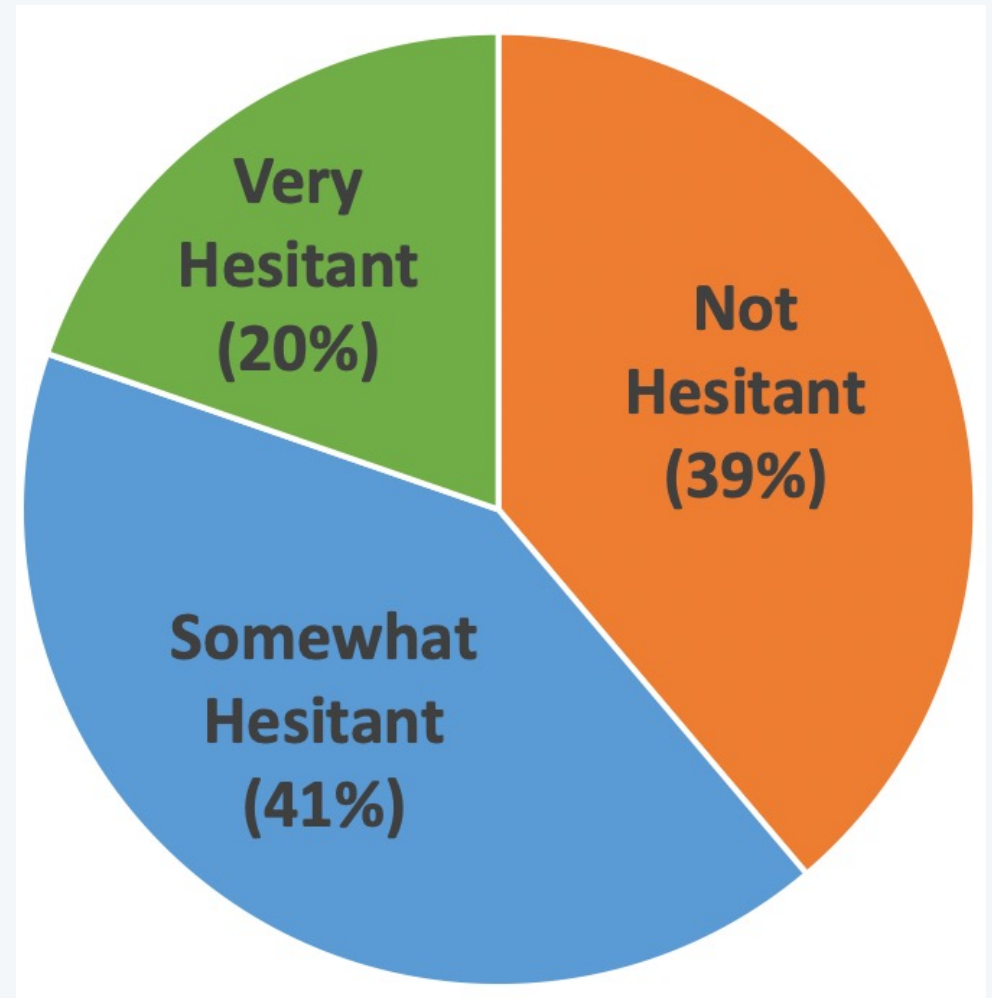
Kenton Jolly and his sons Noah, left, and Isaiah walk up stairs at Riverfront Park in Columbia, S.C. Isaiah, who has autism, has struggled with the lack of interaction and loss of routine associated with virtual learning. (Joshua Boucher/The State/TNS)



A new survey of thousands of families of those with autism across the country finds that the COVID-19 pandemic has prompted symptoms of the developmental disorder to worsen and “significant, ongoing disruptions to therapies.”

Intention to receive the vaccine (Oct 2020)

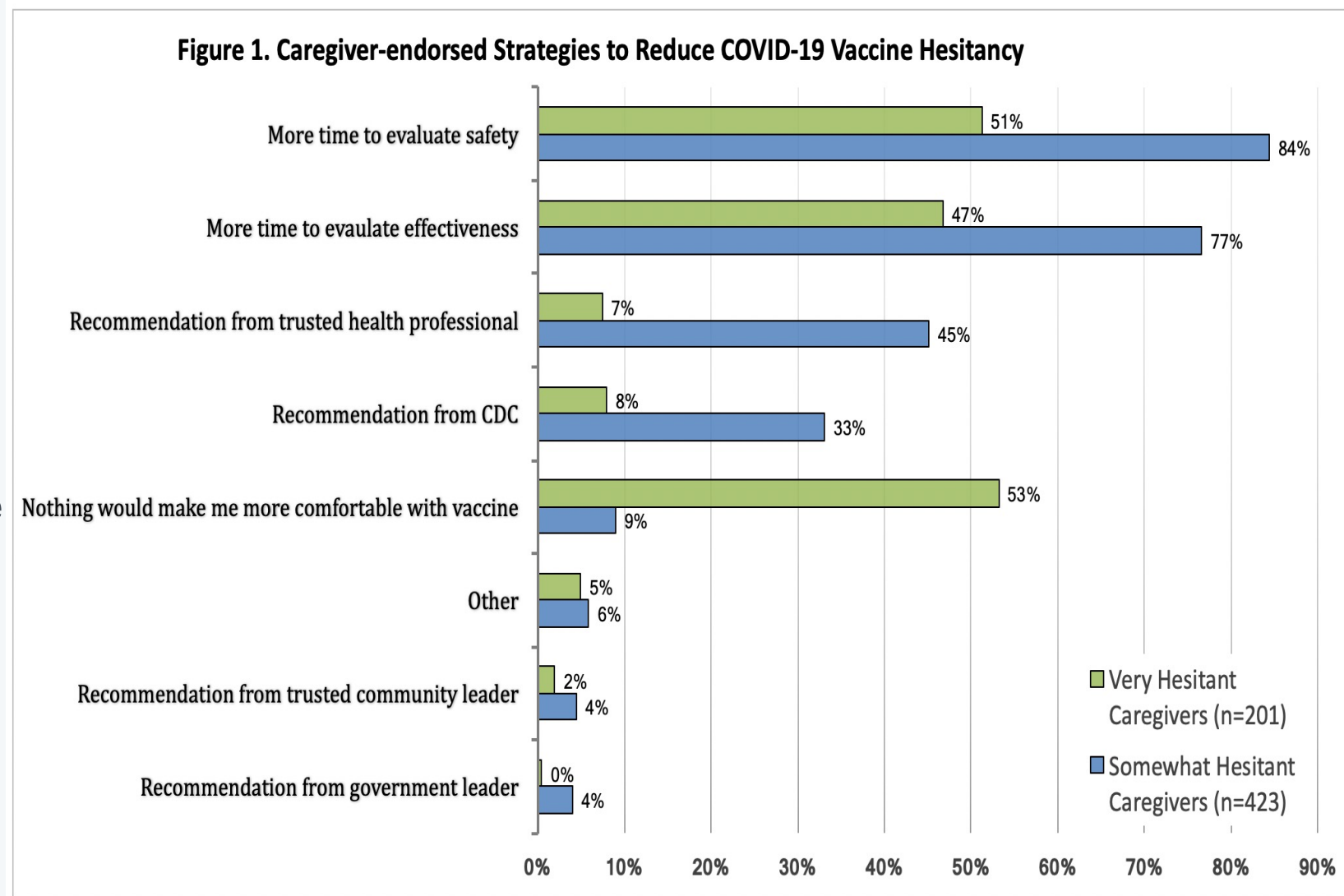
- Classified as **Not Hesitant** (“everyone in household will receive vaccine”), **Somewhat Hesitant** (“unsure”), and **Very Hesitant** (“no one in household will receive vaccine”).
- 61% were somewhat or very hesitant about receiving the COVID-19 vaccine.
- Increased COVID-19 vaccine hesitancy** associated with:
 - ✓ Neighborhood economic disadvantage and increased general vaccine hesitancy ($p < .01$)
 - ✓ Female, younger age, & belief that vaccines caused child’s ASD ($.01 \leq p < .05$)
 - ✓ No association with race, ethnicity, or knowing someone with severe COVID at T1



n=1,020

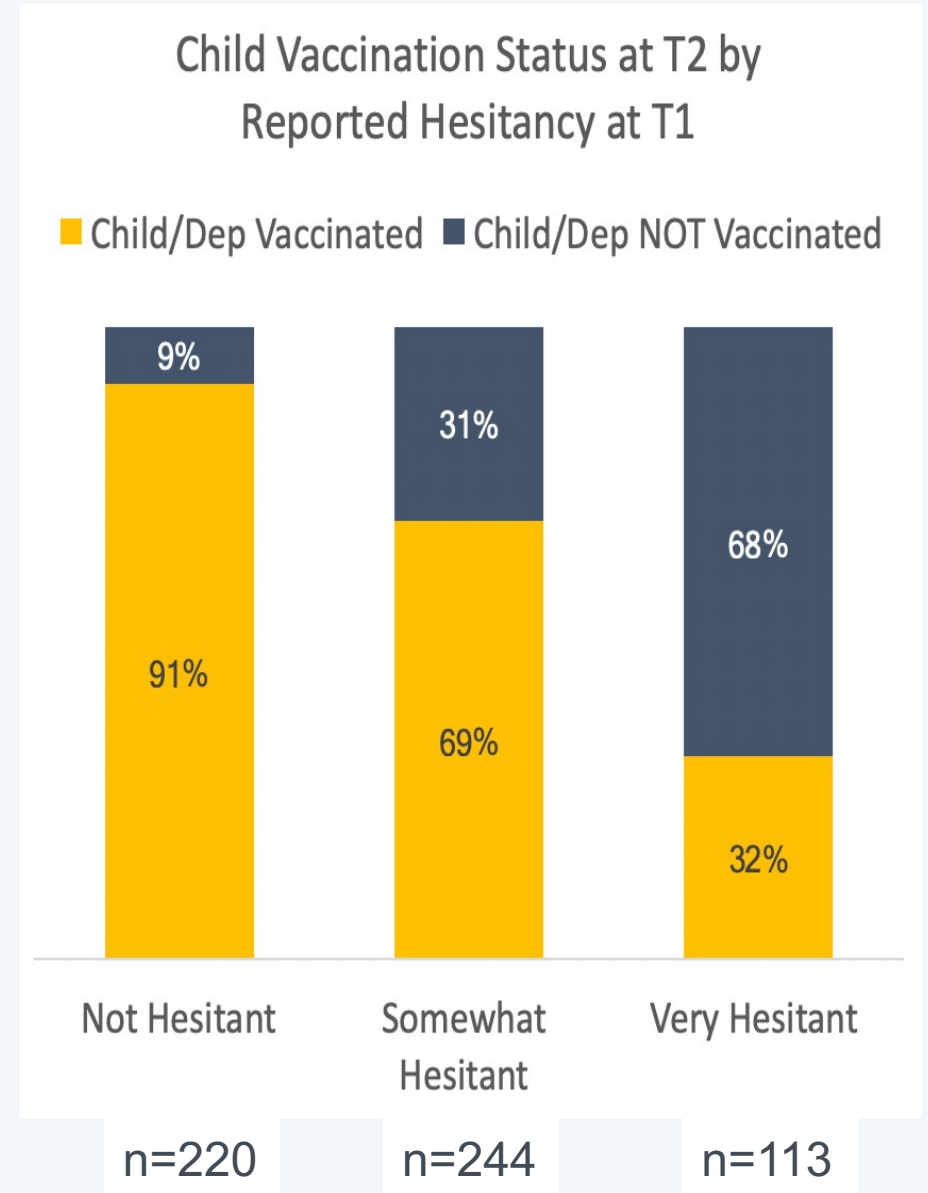
Strategies to reduce COVID-19 Vaccine Hesitancy

- **Very hesitant** caregivers (53%) indicated that nothing would increase their comfort level.
- **Somewhat hesitant** caregivers wanted more time to evaluate vaccine safety (84%) and effectiveness (77%).



Vaccination status (July 2021)

- 70% of children/dependents had received at least one dose; 81% of caregivers
- **Increased COVID-19 vaccine uptake** for the child/dependent was associated with:
 - ✓ Parent being vaccinated, lower COVID-19 vaccine hesitancy at T1, and increased concern for the child/dependent's health & public health ($p < .01$)
 - ✓ Lower general vaccine hesitancy and knowing someone with severe COVID-19 at T2 ($.01 \leq p < .05$)
 - ✓ No association with demographics or neighborhood economic disadvantage



Mental health needs and service status in young adults with autism

Background:

- Depression is a common problem for adults with autism.
- Little is known about depression-related service and treatment utilization in this group.

Study Methods:

- Surveys were completed in March 2020.
- **Over 300 adults with autism** ages 18 to 35 completed online surveys about current depressive symptoms and information about treatments received.



PIs – Ryan Adams
Institution – Cincinnati Children's



PIs – Julie Lounds Taylor
Institution – Vanderbilt University Medical Center



PIs – Somer Bishop, Shuting Zheng
Institution – UCSF

Mental health needs and service status in young adults with autism

Study Results:

- **Almost half of the young adults** met cut-off for current depression.
- Among **currently depressed young adults**, around **84% reported having received treatment for depression** with **59% currently in treatment**.

Table 5. Commonly mentioned barriers to depression-related services among the currently depressed.

Themes	Frequency (% out of 54)
Financial and insurance issues	32 (59.26%)
Accessibility of care/a good fit	15 (27.78%)
Professional's lack of understanding	10 (18.52%)
Logistics (e.g. scheduling, transportation)	7 (12.96%)
Difficulty describing and explaining feelings	5 (9.26%)
Symptoms preventing them from seeking care	5 (9.26%)
Side effects, majorly medications	3 (5.56%)
Family members' lack of understanding	1 (1.85%)

One individual might mention multiple barriers in their responses, and each of those barriers was coded and counted in the frequency table. Thus, percentages add up to more than 100.

Mental health needs and service status in young adults with autism

Conclusions:

- Most adults with autism with depression are being diagnosed, but not all.
- Reducing barriers to treatment is important, as well as more research and training for how depression in adults with autism may need different approaches for diagnosis and treatment.
- Males with autism and depression may be underdiagnosed.

Next steps:

- The researchers plan to survey participants several more times to monitor depression symptoms and treatment over time.
- More research is needed on other known barriers to care, including racial disparities, LGBTQ+ status, and socioeconomic differences.



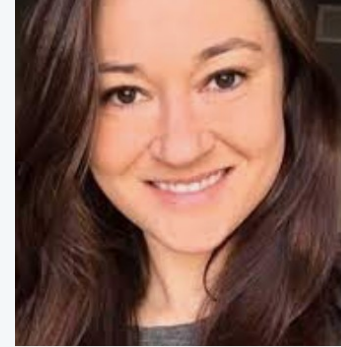
Camouflaging autism: Do autistic teens hide their traits?

Background:

- Camouflaging is a set of strategies that individuals use to hide or mask their autistic traits.
- In adults, camouflaging is associated with higher rates of depression & reduced feelings of acceptance.
- Little is known about camouflaging in teens with autism.

Study Goals:

- Explore how camouflaging differs in teen boys & girls with autism.
- Understand how camouflaging is used by teens with autism compared to their neurotypical peers.



PI – Courtney Jorgenson
Institution – University of Missouri



PI – Stephen Kanne
Institution – Weill Cornell Medicine

Camouflaging Autism: Do teens with autism hide their traits?

Study Method:

- Small pilot study with 2 online surveys
 - Teens answered questions about autistic traits and whether they tried to hide those traits to fit in socially.
- **140 participants**
 - 78 were autistic (almost all from SPARK); 70% identified as male.
 - 62 typically developing; 44% identified as male
 - Ages: 13 – 18 years old

Camouflaging includes behavior such as:

- **Monitoring your body language** to appear interested in someone else
- **Taking steps to improve your social skills** by watching others or learning from TV, films or books
- **Copying the facial expressions** of others to fit in
- Feeling like you are **pretending to be a certain way** in social situations

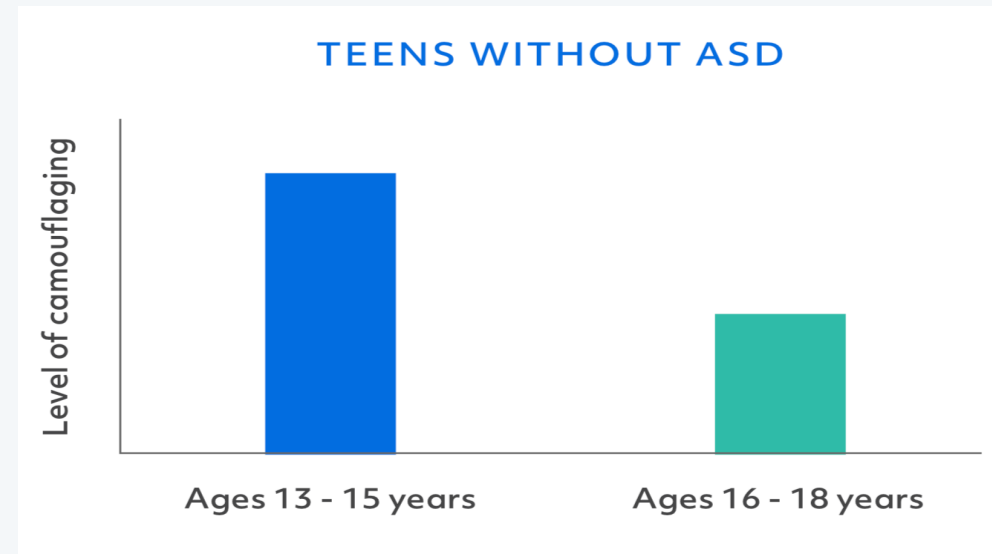
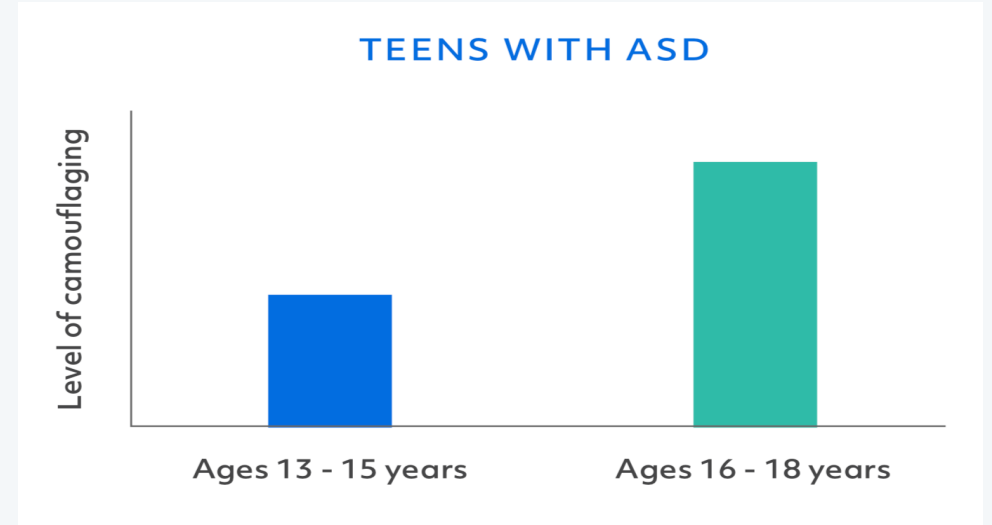
Camouflaging Autism: Do autistic teens hide their traits?

Study Results:

- Camouflaging is associated with autism, but teens who do not have autism also try to hide certain behaviors & traits.
- **Girls**, with and without autism, **camouflage more than boys**.
- **Age also plays a role in the level of camouflaging**, but the pattern differs in teens with autism compared to typically developing teens.

Why does this research matter?

- It is **important to hear directly from teens** about their experiences.
- **Understanding social development in teens with autism** may help improve supports to build peer relationships and interactions.



General health problems in young adults with autism

Background:

- General health symptoms, such as fatigue, sleep problems, dizziness, headache, and constipation are the most common reasons for outpatient medical visits in the general population.

Study Goals:

- Describe the current and lifetime prevalence of “*somatic symptoms*” in adults with autism.
- Better understand how these symptoms are related to autism severity & other symptoms, such as anxiety & depression.



PI – Zachary Williams
Institution – Vanderbilt
University



PI – Katherine Gotham
Institution – Rowan
University

General health problems in young adults with autism

Study method:

- Online surveys asking about autistic traits, co-occurring conditions, and somatic symptoms.
- **290 adults with autism in SPARK**
 - Ages: 18 – 26 years
 - 61% female assigned at birth
 - Average age of autism diagnosis: 12.2 years



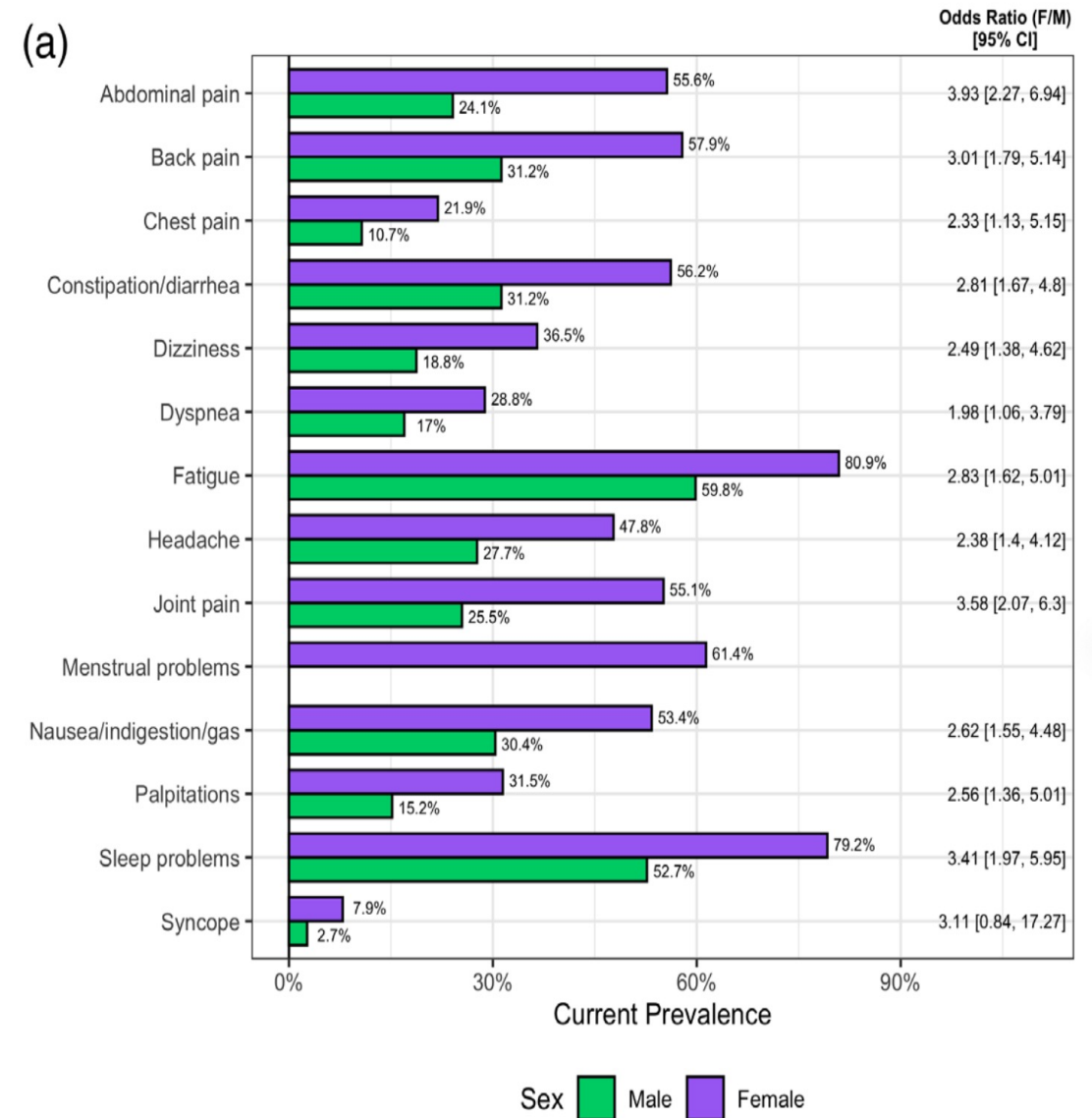
General health problems in young adults with autism

Study results:

- **Adults with autism reported more somatic symptoms** compared to the general population.
- **Most common problems** were fatigue, sleep problems, and back pain; plus menstrual problems in women.
- **50% of women and 19% of men reported moderate or severe symptoms.**

Future research direction:

- We need to better understand the cause of these symptoms, the impact on overall health & well-being, and how these symptoms are addressed/treated by health providers.



Sharing results and collecting feedback



Preliminary data shared with RM families

SPARK Summary Report

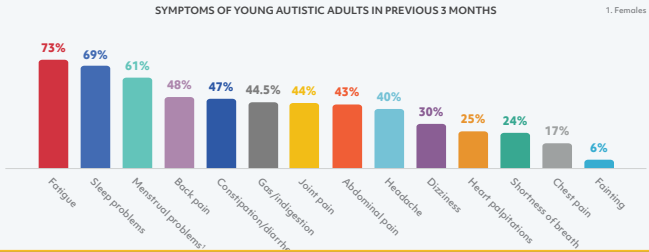
SPARK

Research Match

The Health Problems of Young Autistic Adults

Summary Reports describe results from newly published research using data from SPARK participants.

- Study Title**
Current and Lifetime Somatic Symptom Burden among Transition-Aged Autistic Young Adults
- What was the study about?**
Researchers wanted to find out how young autistic adults compared to the general population in their experience of 14 bodily symptoms, also called somatic symptoms. These symptoms included fatigue, sleep problems, dizziness, headache, constipation, and back, joint, or chest pain. These symptoms are the most common reasons that people see a doctor.
- How was the research done?**
About 290 autistic adults in SPARK completed online questionnaires about symptoms they experienced at different stages in their lives. The participants were ages 18 to 26, and 61 percent were assigned female at birth. Researchers studied young adults because they are less likely to have health problems related to aging.
- What did the researchers learn?**
 - Autistic adults, particularly women, reported more bodily complaints than previous studies found in adults overall.
 - In the previous three months, 73 percent of adults had fatigue, 69 percent had sleep problems, and 61 percent of females had menstrual problems.
 - More than 50 percent of the women and 19 percent of the men reported moderate or severe symptoms. That is much higher than the overall 9 percent rate found by a 2013 study of men and women in the general population.
 - Autistic women were two to four times more likely to have one of the listed symptoms than autistic men, including dizziness, chest pain, and joint pain.



SPARK RM Summary Reports are made available to the entire SPARK community

Upcoming Research Match Studies

- Equity and Access to Care: Barriers to Diagnostic and Treatment Services for Black Families of Children with Autism Spectrum Disorder by Lauren Quetsch at University of Arkansas
- Disrupted eye gaze perception as a biobehavioral marker of social dysfunction: An RDoC investigation by Ivy Tso at University of Michigan
- Mental Health and Social Connection by Annabelle Mournet at Rutgers University
- Cognitive Functioning in Children by Katherine Stavropoulos at University of California Riverside



Publications

- Bhat A. Analysis of the SPARK study COVID-19 parent survey: Early impact of the pandemic on access to services, child/parent mental health, and benefits of online services. *Autism Res.* 2021 Nov;14(11):2454-2470. doi: 10.1002/aur.2618. Epub 2021 Sep 30. PMID: 34591364; PMCID: PMC8578426.
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