

# Encouraging participant-centered autism research: what we know from potential participants

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**The authors have no known  
conflicts of interest or financial  
relationships to disclose.**

# Objective

To understand  
**motivations and research interests**  
in families affected by autism  
in order to improve  
**research recruitment and retention.**

# Methods

Conducted by Interactive Autism Network (IAN)

- **IAN Research** [www.ianresearch.org](http://www.ianresearch.org)
  - Research study; validated and verified ASD registry  
Total Consented: 50,000+  
ASD: 20,000+; Family members: 30,000+
  - Subject recruitment services (recruitment, survey hosting) and data sharing for researchers. Hundreds of researchers helped.
- **IAN Community** [www.iancommunity.org](http://www.iancommunity.org)
  - Shares research and evidence-based content about ASD with families, participants, and other community stakeholders.
  - ¾ million visits; 2.6 million page views annually.

# A Participant-Powered Research Community

A PARTNERSHIP OF Kennedy Krieger Institute SIMONS FOUNDATION AUTISM SPEAKS It's time to listen. NIH National Institute of Mental Health

**ian** interactive autism network  
LINKING THE AUTISM COMMUNITY AND RESEARCHERS

PARTICIPATE IN AUTISM research

Login

share research discover

"Every child is different. And unless we as parents tell the researchers what is specific to our child, how will they know?"  
-IAN Participant

**Participate in ASD research. Join IAN.**

Autism spectrum disorders (ASD) are identified in 1 out of every 68 children in the United States. Other countries observe similar rates with an increasing number of children and adults living with the disorder worldwide.

Families and individuals with ASD play a critical role in helping researchers and clinicians better understand the disorder. IAN Research provides a secure online setting where those affected by autism are active participants in ASD research.

By participating in IAN Research, you can help make new discoveries and empower advocates to improve the lives of children and adults with ASD.

**Who can participate in IAN Research?**

Individuals with ASD and their family members are eligible to participate.

The following ASD diagnoses are included in IAN Research:

- Autism or Autistic Disorder
- Asperger Syndrome
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder - Not otherwise Specified (PDD-NOS)
- Pervasive Developmental Disorder (PDD)
- Autism Spectrum Disorder (ASD)

**Participate in the largest online autism research effort.**

**JOIN NOW**

**Participants in IAN Research:**

- Complete online study questionnaires collecting important information about ASD diagnosis, treatments, services, and other related topics.
- Receive special notices about local, regional and national studies looking for families like theirs.

explore **iancommunity**

Families, researchers and anyone impacted by ASDs can take part in the **IAN Community**, a comprehensive online library and meeting place focused solely on ASD research. Visitors can learn about the latest research, become more informed consumers of research, and join in a worldwide collaboration of people dedicated to finding answers.

A PARTNERSHIP OF Kennedy Krieger Institute SIMONS FOUNDATION

**ian** interactive autism network  
LINKING THE AUTISM COMMUNITY AND RESEARCHERS

EXPLORE OUR ONLINE community

Search the site... SEARCH

CONTACT US ORDER BROCHURES EVENTS BLOG DONATE

ABOUT IAN ABOUT AUTISM ABOUT RESEARCH RESEARCH SERVICES NEWS SIMONS SIMPLEX COMMUNITY AUTISM INPATIENT COMMUNITY

**Is Autism Rare in Girls?**

Researchers, including those from IAN, are making discoveries that challenge assumptions about autism and gender.

LEARN MORE

**E-NEWSLETTER**

Stay informed with the IAN Quarterly E-Newsletter

Your Email Address

Sign Up

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**TAKE PART IN AUTISM RESEARCH**

Participate in **ianresearch**

Families and individuals with autism spectrum disorder play a critical role in helping researchers and clinicians better understand the disorder. Find out how you can participate in Interactive Autism Network (IAN) Research in a secure, online setting. By participating, you can be...

**RECENT POPULAR CONTENT**

- Romantic Relationships for Young Adults with Asperger's Syndrome and High-Functioning Autism
- Autism in the Teen Years: What to Expect, How to Help
- Feeding Problems in Children with Autism
- Social Skills Interventions: Getting to the Core of Autism
- Dogs, Horses and ASD: What Are Animal-Assisted Therapies?
- Very Late Diagnosis of Asperger

[www.ianresearch.org](http://www.ianresearch.org)

[www.iancommunity.org](http://www.iancommunity.org)

# Methods

- Anonymous survey administered in Checkbox©
- Two versions:
  - adults with ASD
  - parents of a child or adult with ASD
- August 1, 2014 to August 11, 2014
- Survey links:
  - emailed to
    - IAN Research registry participants
    - IAN Community e-newsletter subscribers
  - posted on
    - IAN Community website
    - IAN Community Facebook page

# Participants

- Completed surveys = 1,263 – four groups:
  - Adults with ASD = 141
  - Parents = 1,122
    - Child <13 = 514
    - Teen 13-17 = 347
    - Adult ≥18 = 261
- Group comparisons by  $\chi^2$
- Exclusions:
  - did not affirm ASD diagnosis
  - did not indicate age-category of individual with ASD

How likely would you be to participate  
in the following autism-related  
research studies?





# Research Topics Ranked by Percent “Very Likely” or “Somewhat Likely” to Participate

## Adults with ASD

1. Associated mental health conditions\* (92%)
2. Genetics of autism (88%)
3. Sleep (86%)
4. Education (82%)
5. Motor skills (82%)

## Parents of Adults with ASD

1. Transition to more independent living (91%)
2. Associated mental health conditions\* (89%)
3. Community services (88%)
4. Effects of autism on the family (87%)
5. Genetics of autism (86%)
6. Health care (83%)

\* *e.g., ADD, OCD, anxiety*

# Research Topics Ranked by Percent “Very Likely” or “Somewhat Likely” to Participate

## Parents of Teens

1. Associated mental health conditions\* (90%)
2. Genetics of autism (90%)
3. *Transition to more independent living (90%)*
4. Education (90%)
5. Behavioral therapies (89%)
6. Effects of autism on the family (89%)
7. *Sleep (86%)*
8. Community Services (84%)
9. Speech and Language (82%)

## Parents of Children

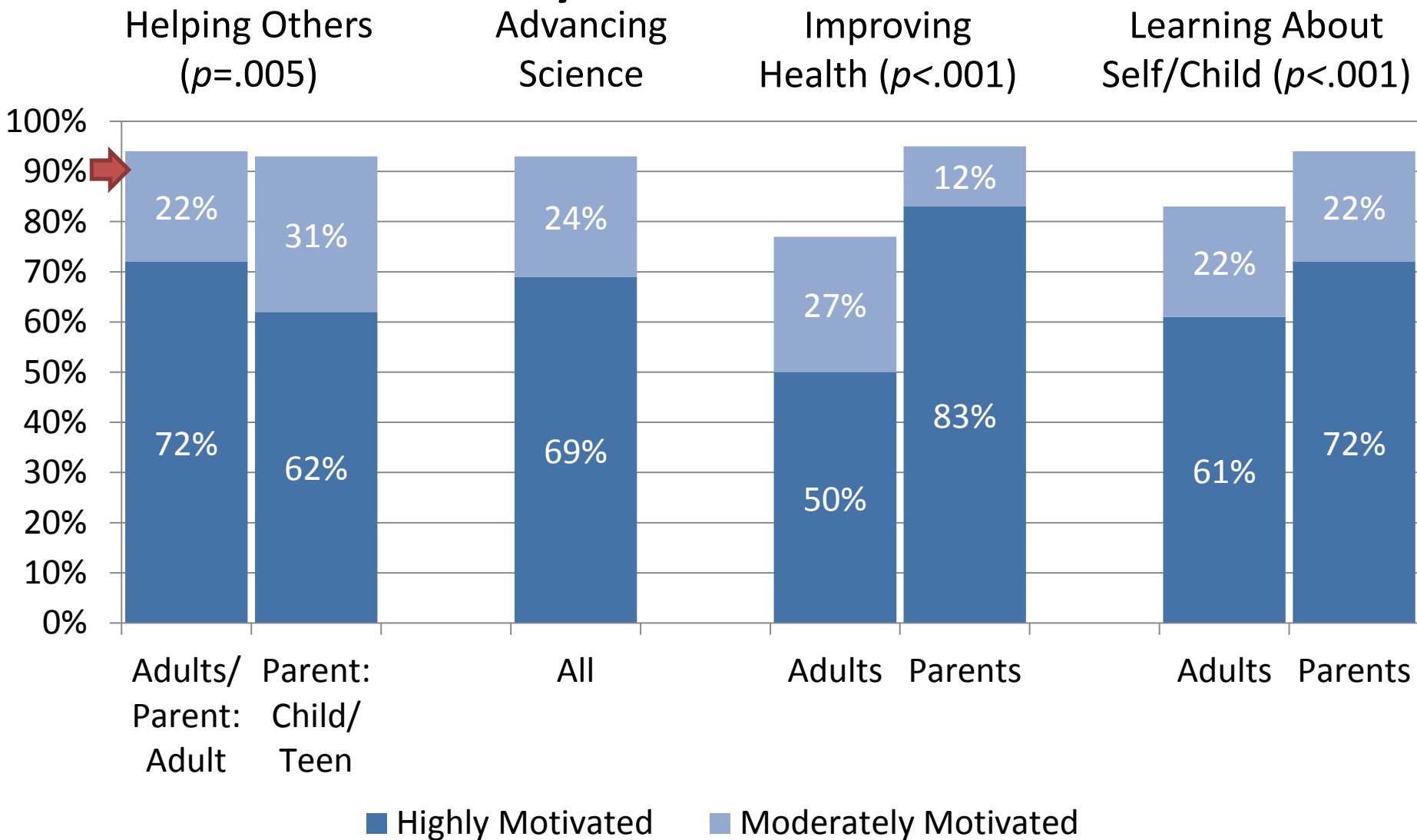
1. Behavioral therapies (93%)
2. Associated mental health conditions\* (92%)
3. Education (92%)
4. Speech and Language (90%)
5. Genetics of autism (89%)
6. Effects of autism on the family (88%)
7. Community Services (81%)

\* *e.g., ADD, OCD, anxiety*

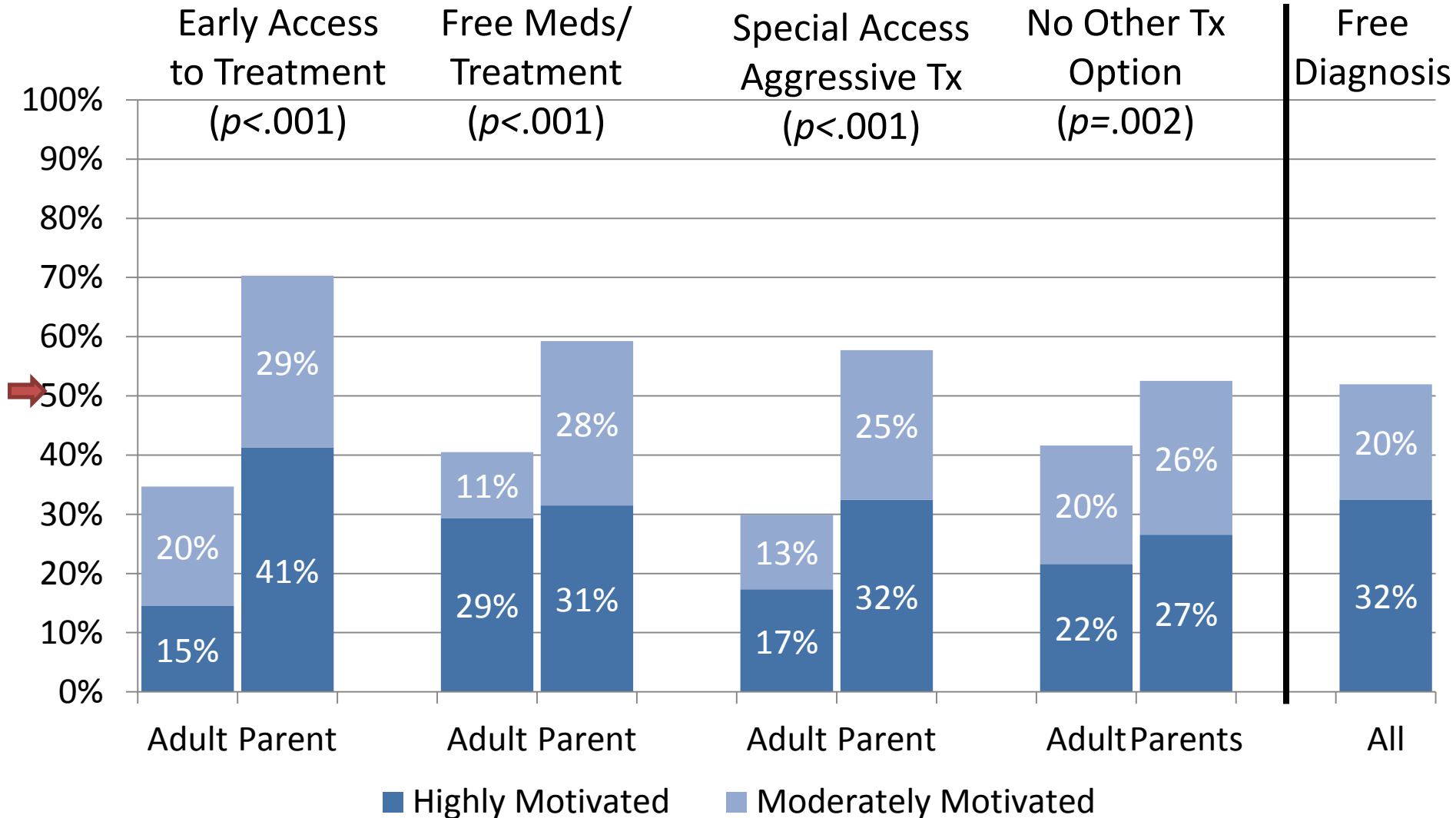
How much would the following  
**motivate** you to enroll in a future  
autism research study?



# Key Motivators



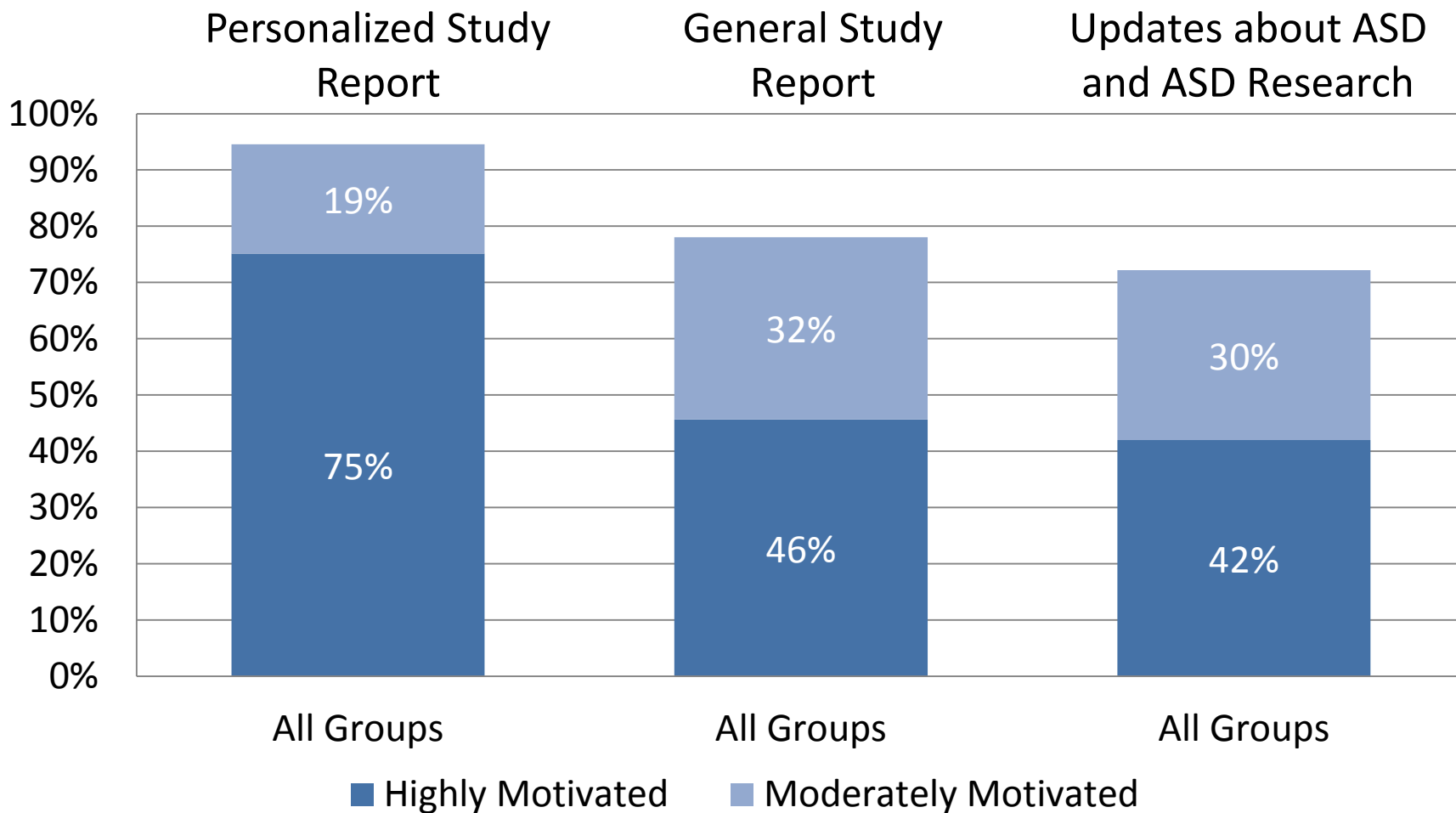
# Access to Treatments and Diagnosis



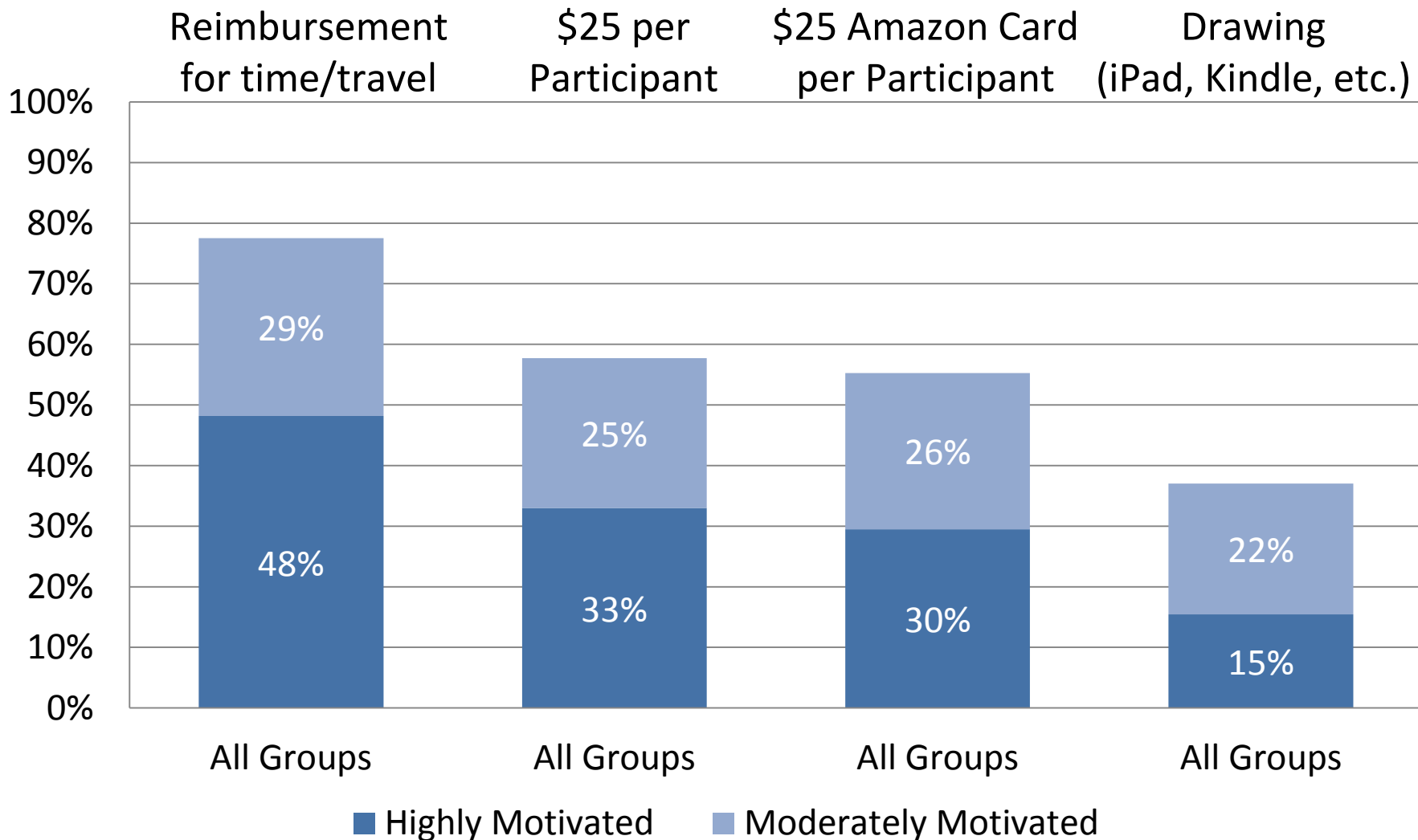
How much would the following  
**incentives** motivate you to participate  
in a research study?



# Getting Personal



# Doing good and doing well

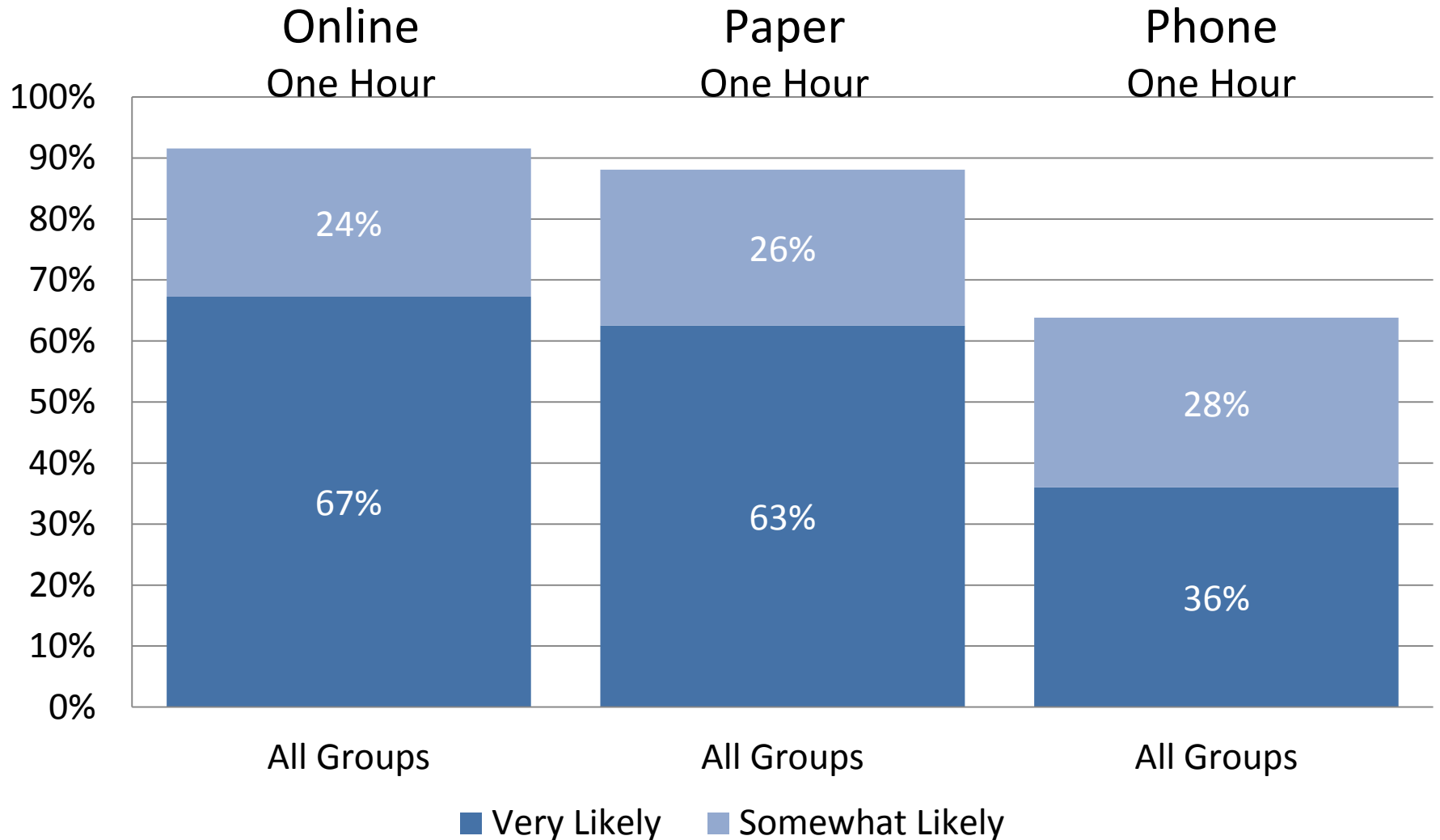




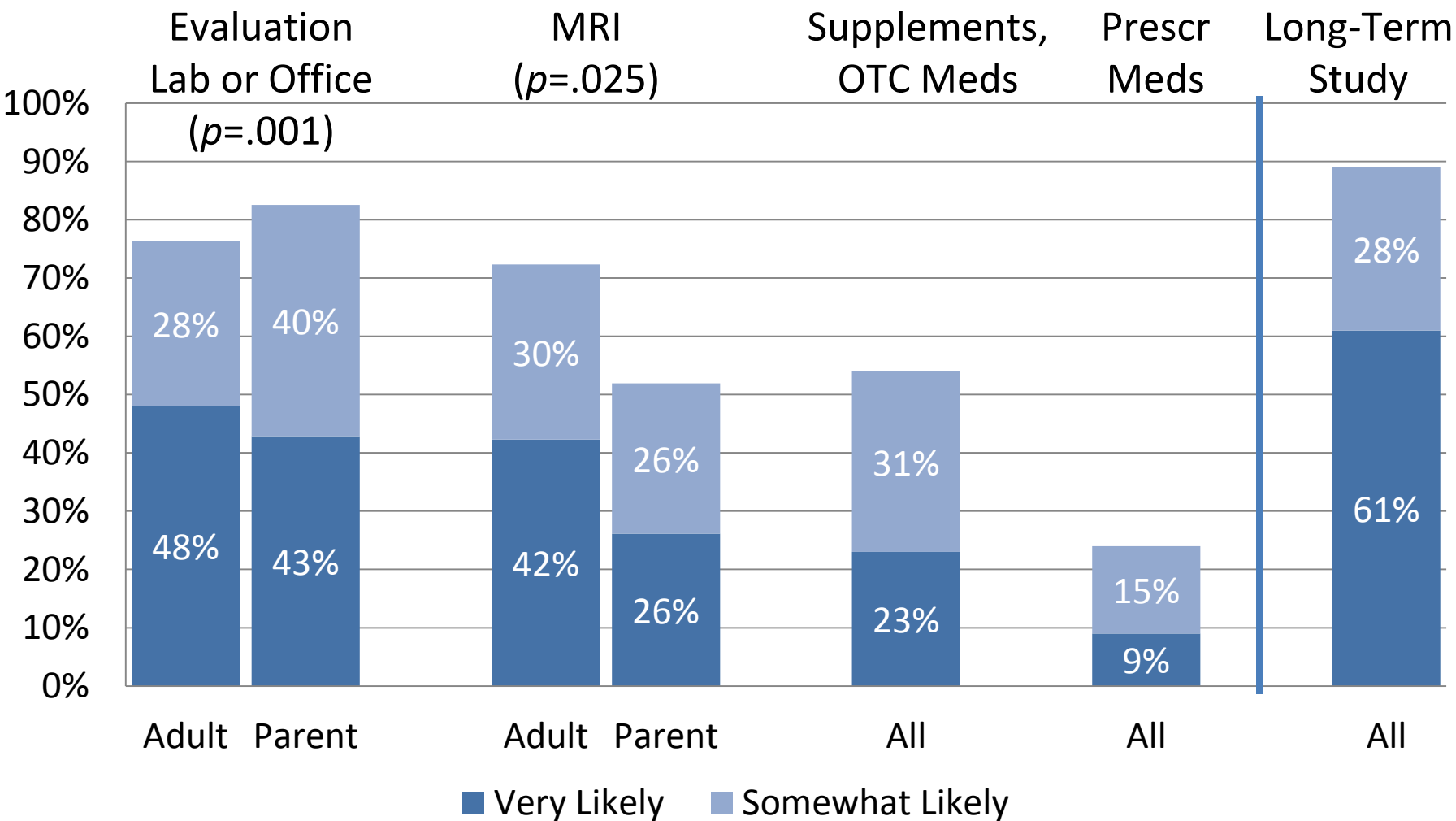
How likely would you be  
to participate in the following  
**autism-related research activities?**



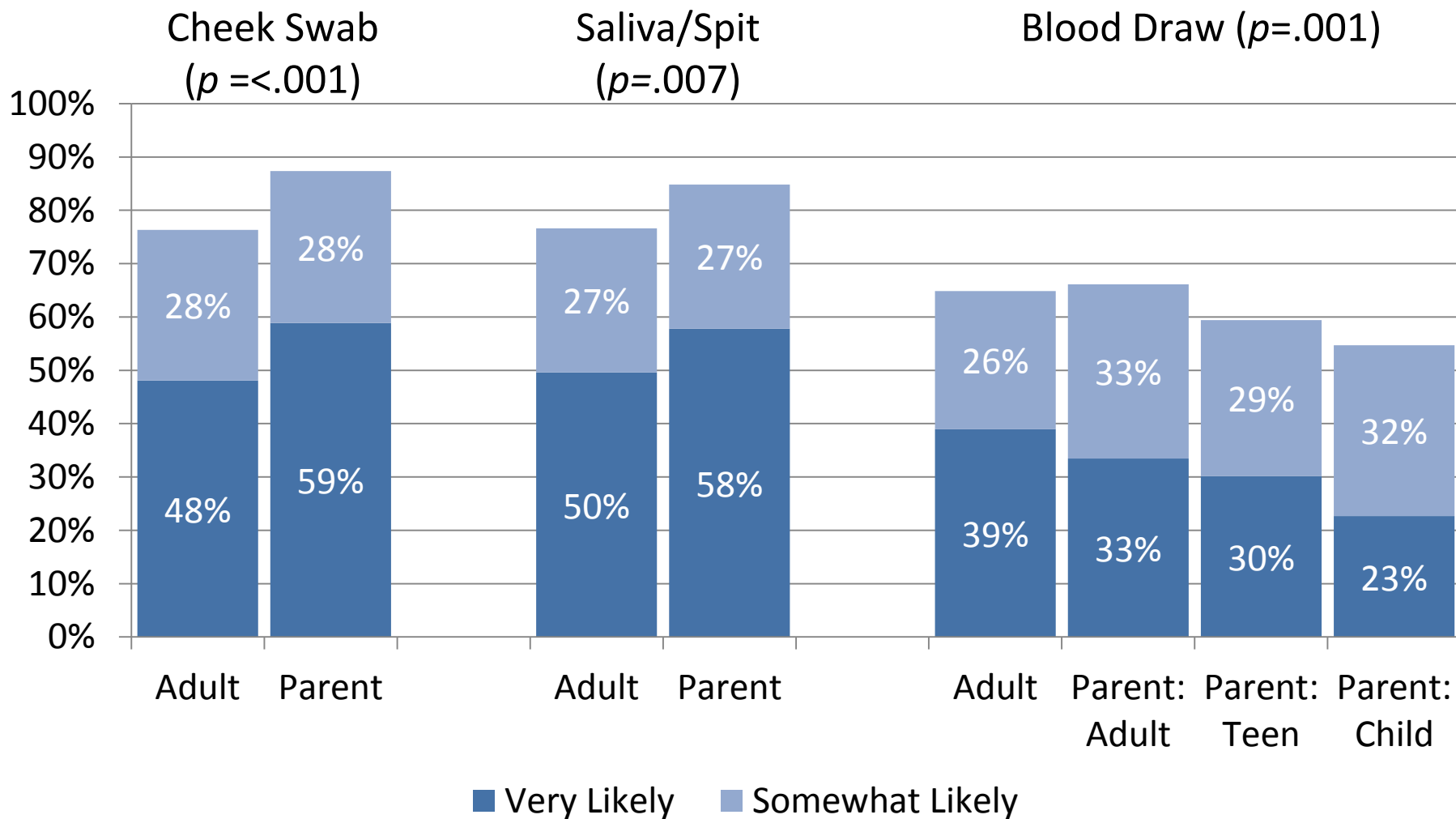
# Survey Modality



# Other Autism-Related Activities



# Genetic Samples



How much time would you spend traveling one-way to a research study?



How much time would you spend participating in an autism research study?

# Travel Time and Participation Time

## Travel Time One Way\* ( $p < .001$ )

## Participation Time

Up to	Adults	Parents
1/2 hour	79%	89%
<b>1 hour</b>	<b>63%</b>	<b>62%</b>
2 hours	45%	32%
3 hours	27%	17%
3+ hours	21%	12%

Up to	All Groups
1 hour	99%
2 hours	89%
4 hours	77%
<b>4 to 8 hours</b>	<b>55%</b>
8+ hours	37%

\*Balance includes home only, online only, shorter travel time

\*Balance includes shorter participation time

If you had the opportunity to tell autism researchers how to improve autism research, what would you tell them?



# From Adults

“I would consider participating in anything that did not pose risks --- e.g. I am reticent to sign up for medication study...”

“Don't forget about the less studied groups, especially adults and girls.”

“Don't leave potential participants dangling with no information.”

“Include individuals with Autism as actual MEMBERS of the research team to help design attributes & research protocols from conception to research study conclusion.”



## From Parents

“Make it as convenient as possible for the participants. My child has a lot of anxiety and aggressive behavior in new or uncomfortable situations so we would be less likely to participate if we have to take him out of our home.”

“Make the logistics as easy as possible.”

“We are on the front lines every day...listen to us. Make research as easy and productive as possible, and share the results with us as they pertain to our child(ren).”

“Think about adults. There is nothing for adults. Everything is for children.”

# Key Takeaways

- **Research participants are research partners**
- **Design research with participants in mind**
  - location, convenience, study topic
  - procedures and methodology
- **Recognize the individual**
  - personalized feedback
- **Recognize sense of purpose and altruism**
  - frame study rationale in terms of benefit to others
  - frame incentives in terms of reimbursement



# Acknowledgements

- Individuals with ASD, families, researchers, and health care professionals who make IAN possible through their generous contribution of time and effort
- Simons Foundation

