

# Science Strategic Planning Survey

August 2017



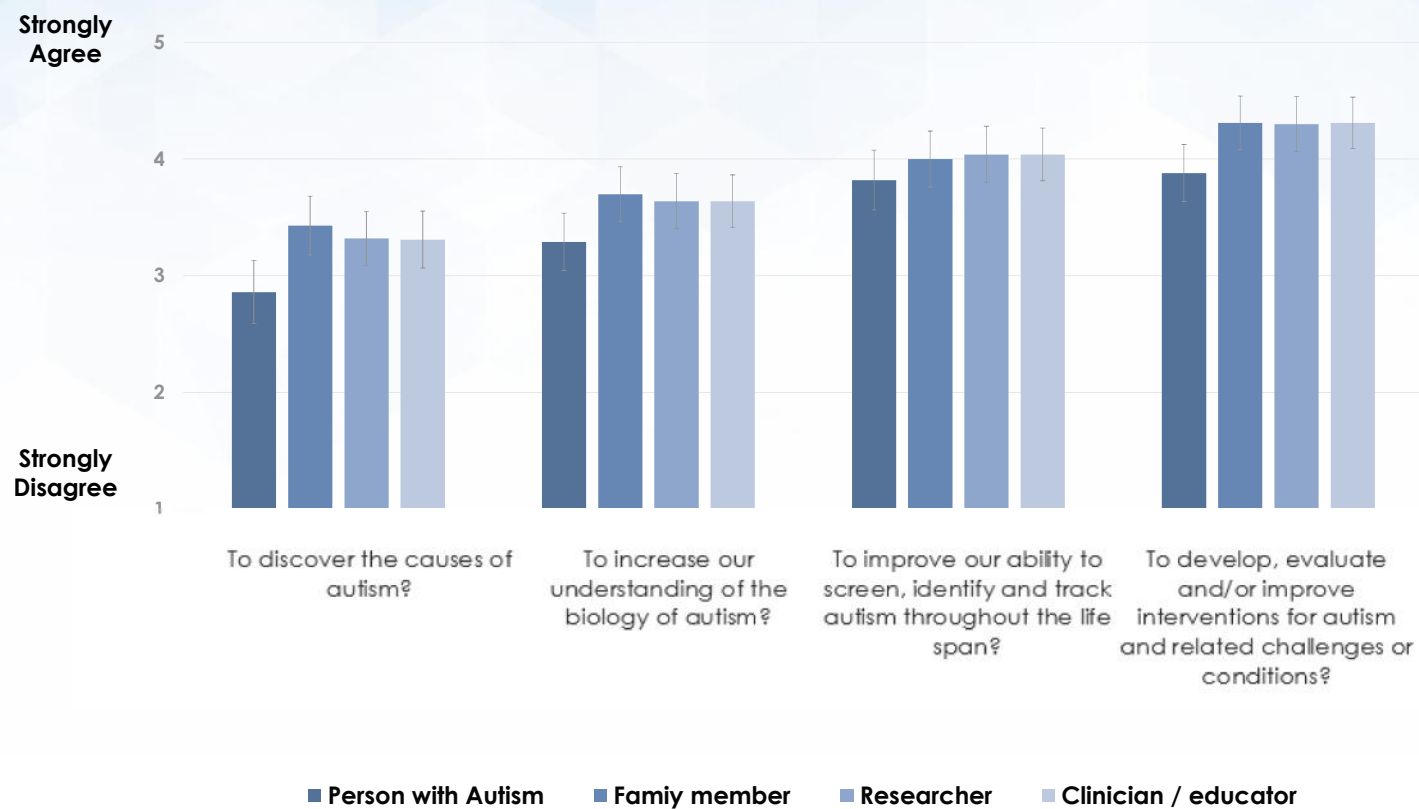
## Survey Respondents – 6,005 total

	n	%*	% Female	Median Age Band
Person with autism	485	8.1%	62.5%	Upper 20s
Family member	4400	73.3%	81.0%	Low 40s
Researcher	401	6.7%	62.3%	Low 40s
Clinician / educator	1306	21.8%	85.8%	Low 40s
Other	670	11.2%	76.5%	Low 40s

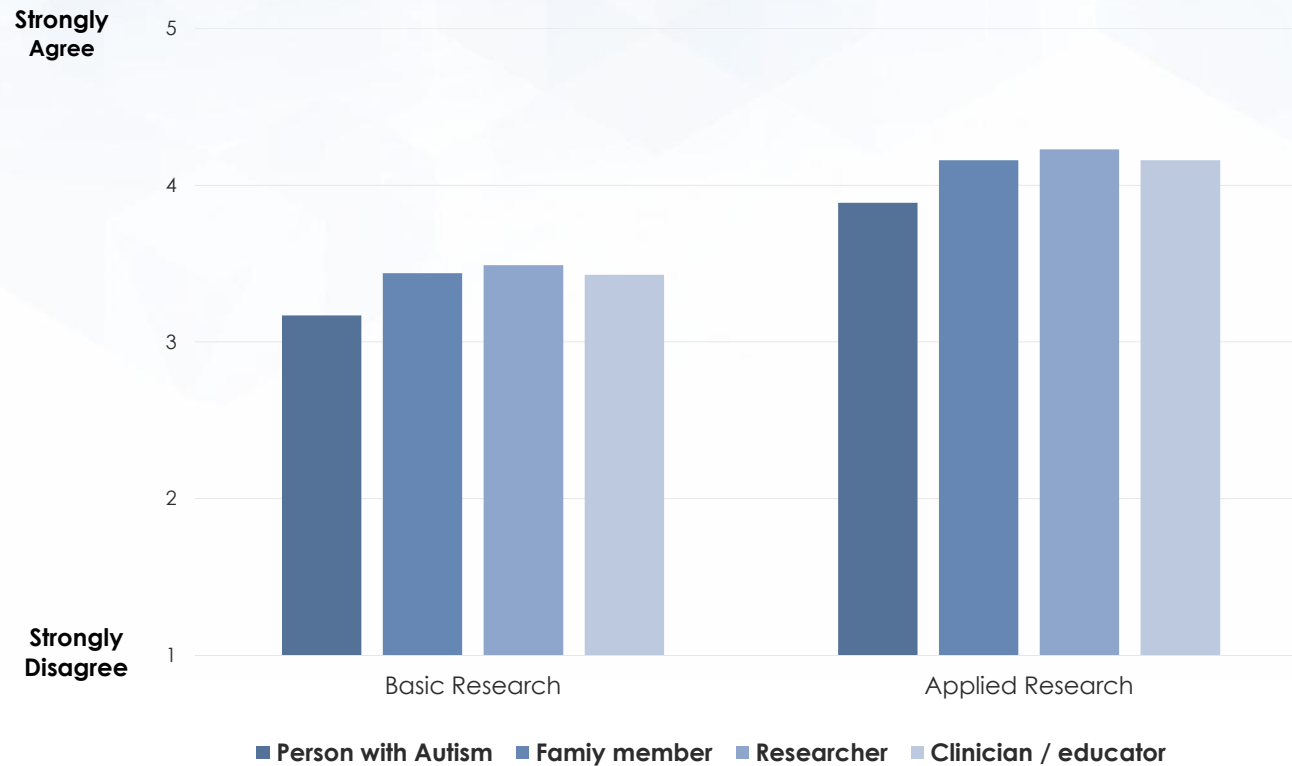
\* Total higher than 100% because some respondents fit more than one descriptor. e.g. person with autism/researcher, family member/clinician, etc.



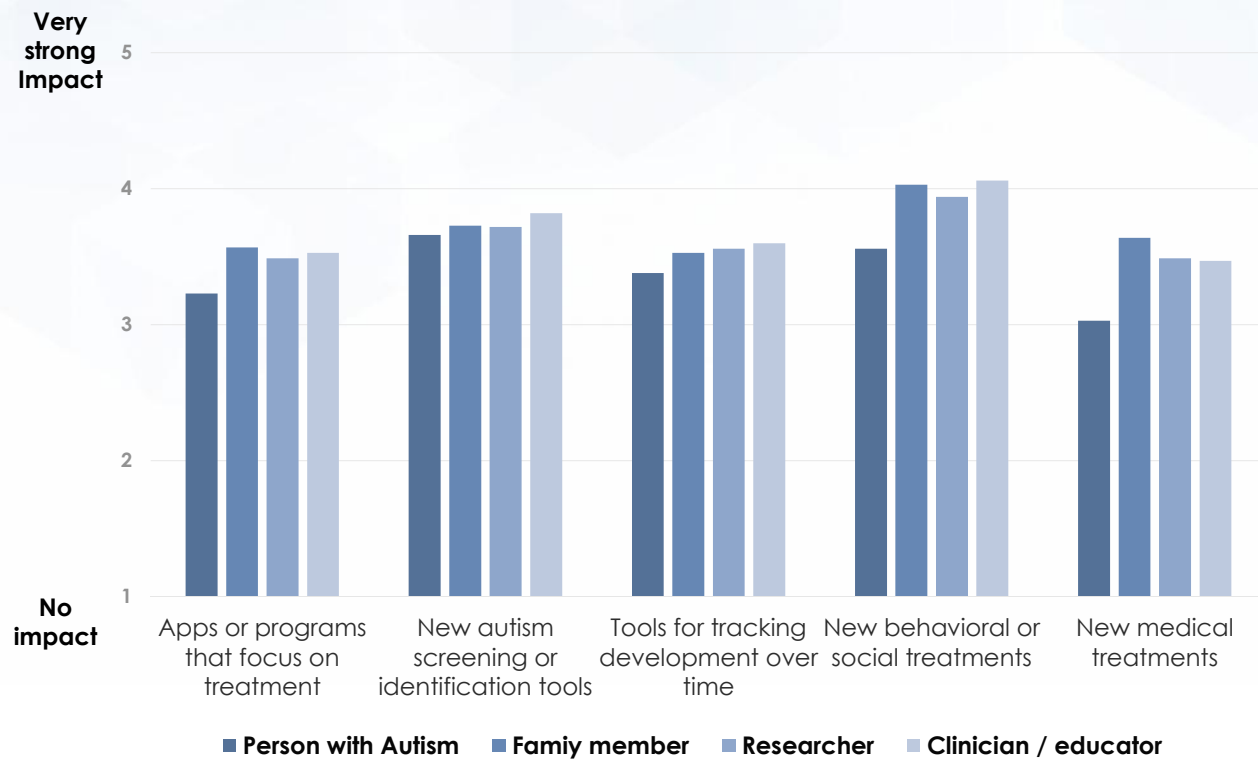
# What should be the mission of AS Science?



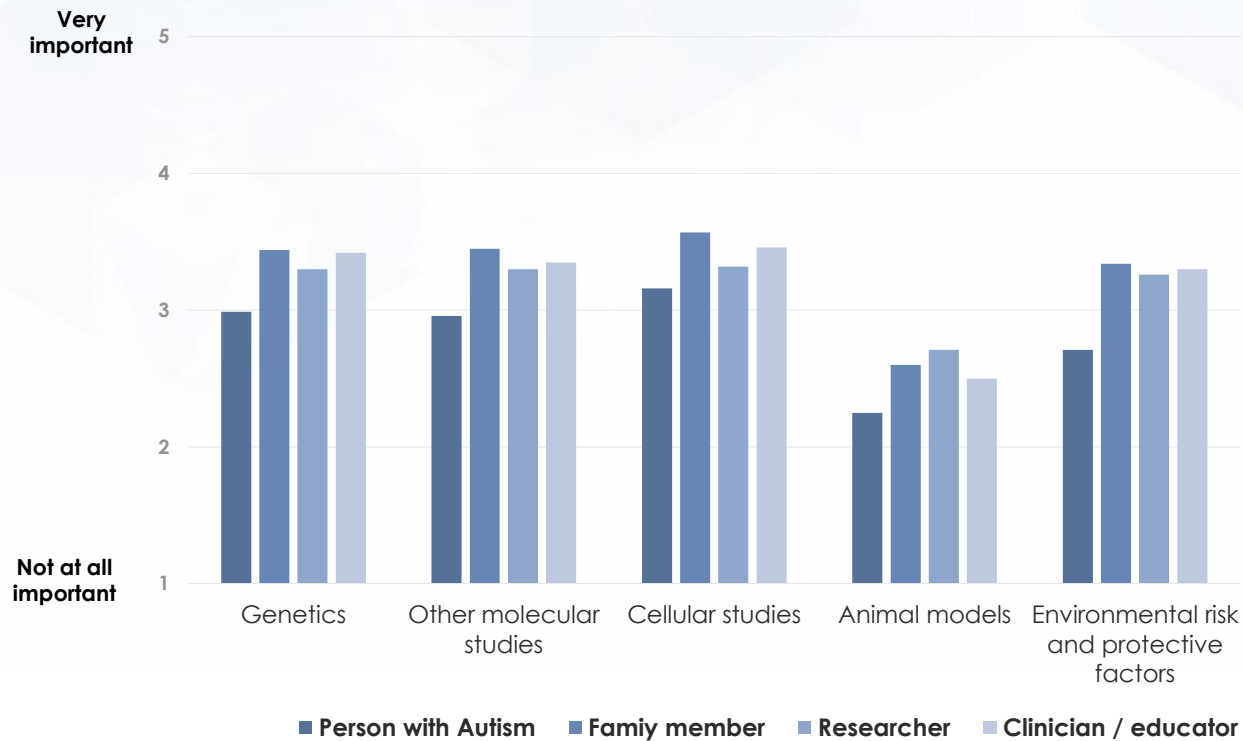
# Should funding basic and applied science be part of the core mission?



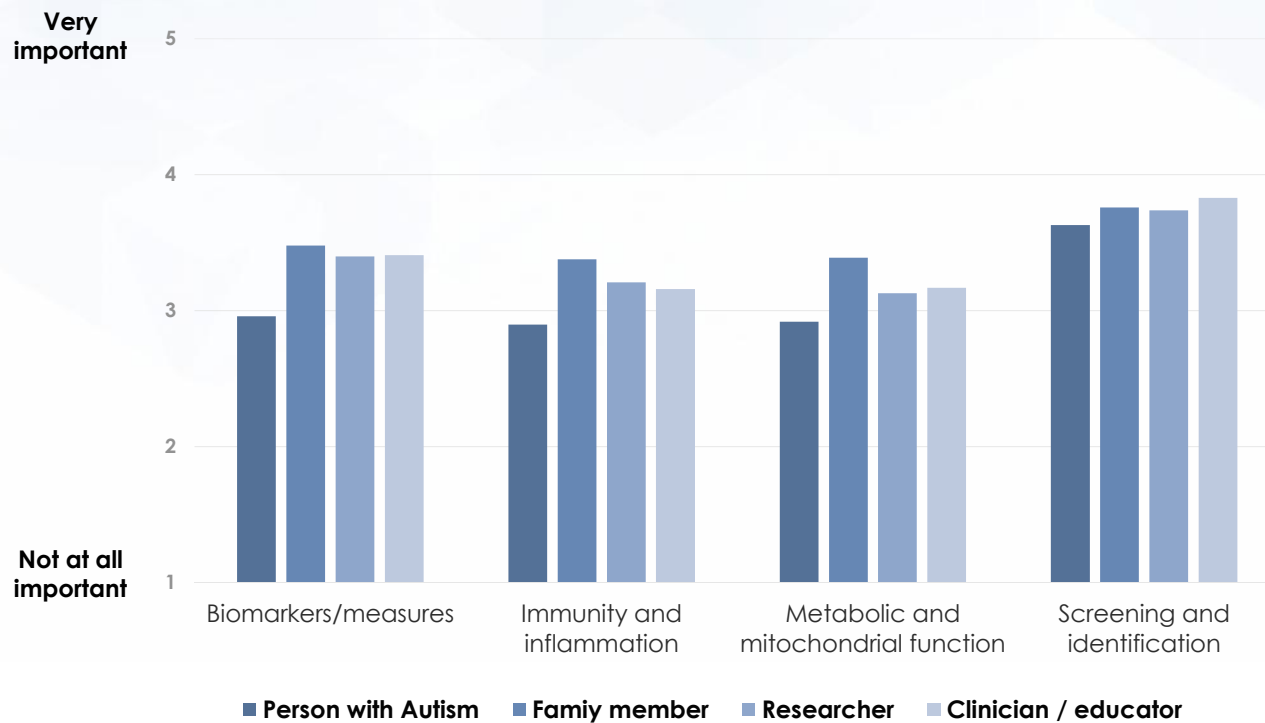
# What products or improvements would positively impact the lives of individuals and families affected by autism?



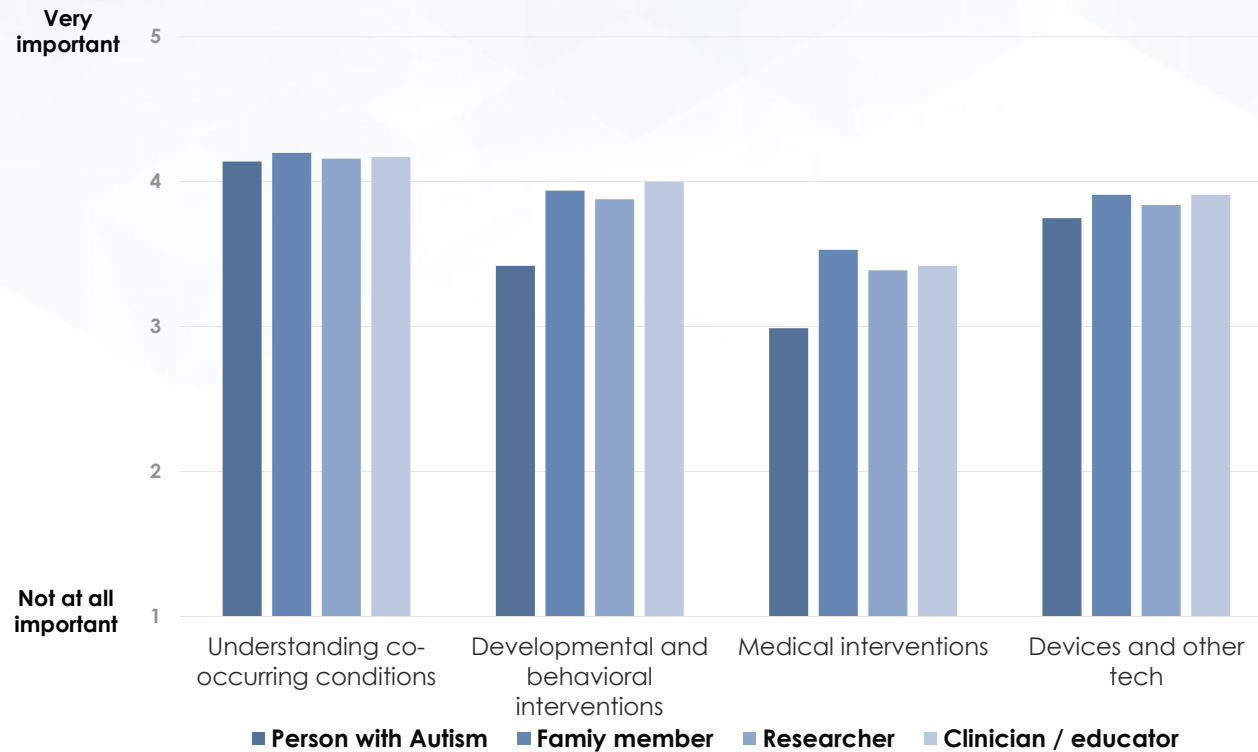
# Please rate the level of importance of the following research topics to Autism Speaks Science? (1 of 4)



# Please rate the level of importance of the following research topics to Autism Speaks Science? (2 of 4)

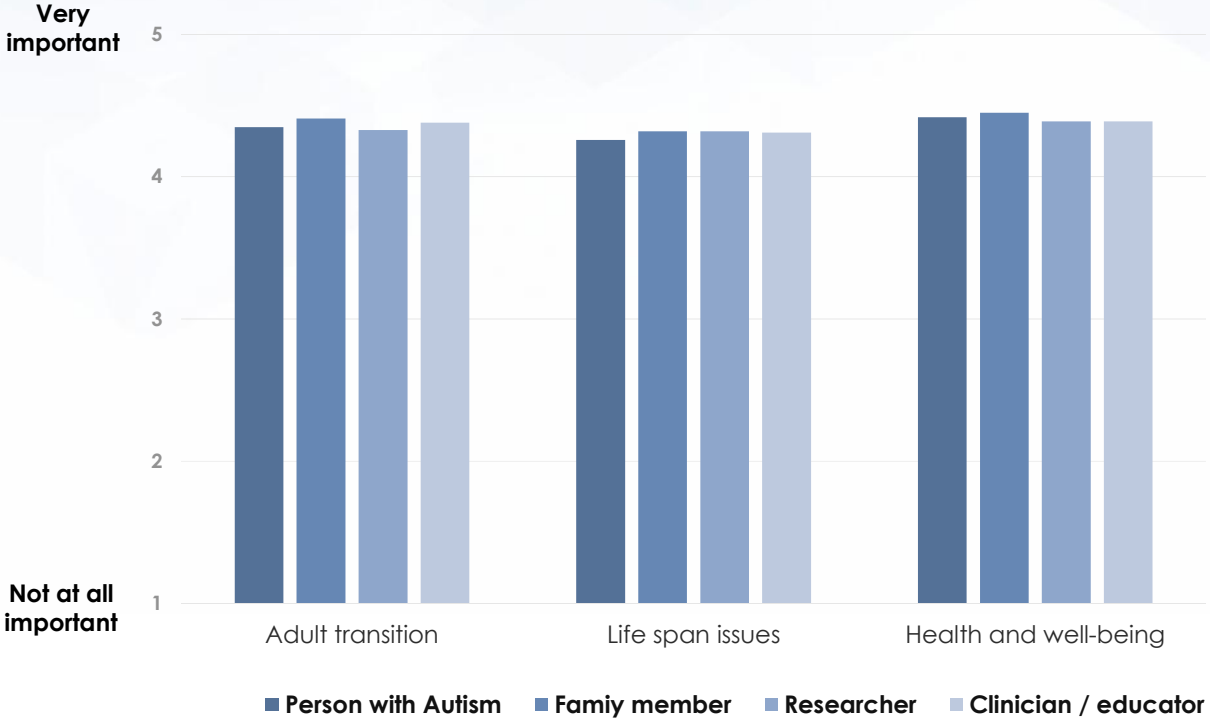


# Please rate the level of importance of the following research topics to Autism Speaks Science? (3 of 4)





# Please rate the level of importance of the following research topics to Autism Speaks Science? (4 of 4)

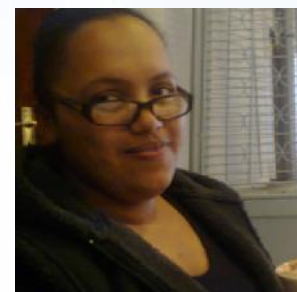


## Content areas rated most important

- Health and well-being



- Lifespan issues



- Associated conditions



- Transition to adulthood





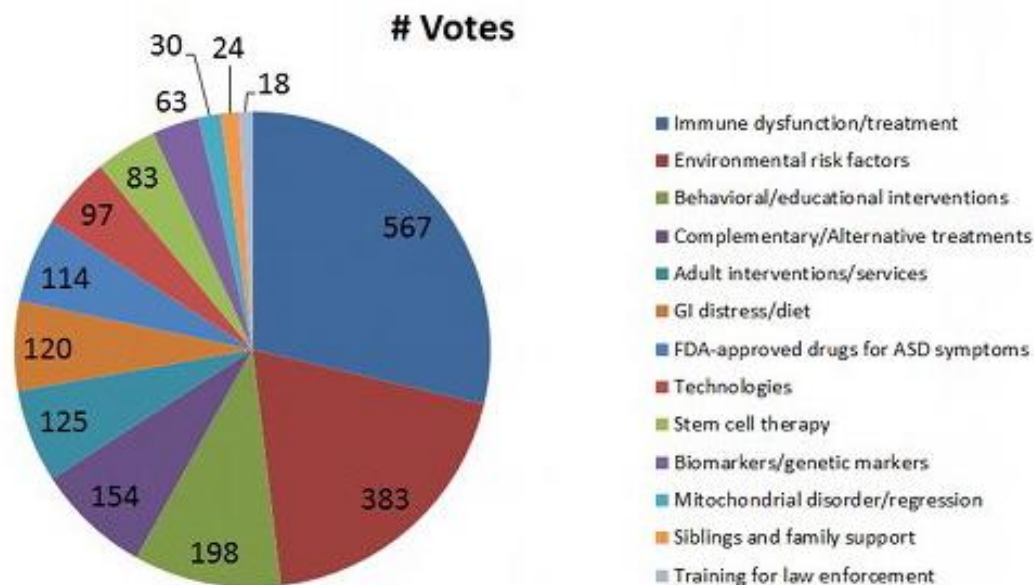
# Changes from the community survey incorporated into 2013-2017 science strategic plan

While survey approaches differed\* ...

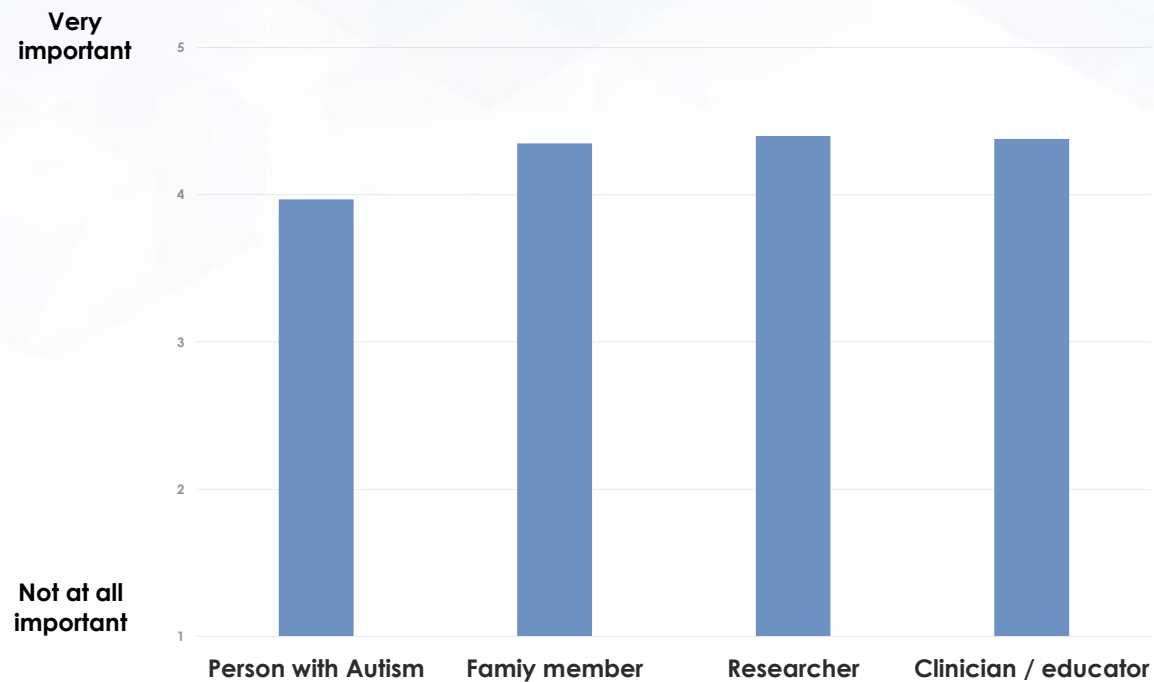
- Immunity and environmental factors received particularly strong emphasis in 2012  
- both areas still rated important in 2017 survey, but more in line with other areas
- Interest in adult transition and lifespan issues increased substantially between 2012 and 2017

\* "MyResearchIdea" used a crowd-sourcing platform that invited participants to propose research ideas and rate ideas proposed by others.

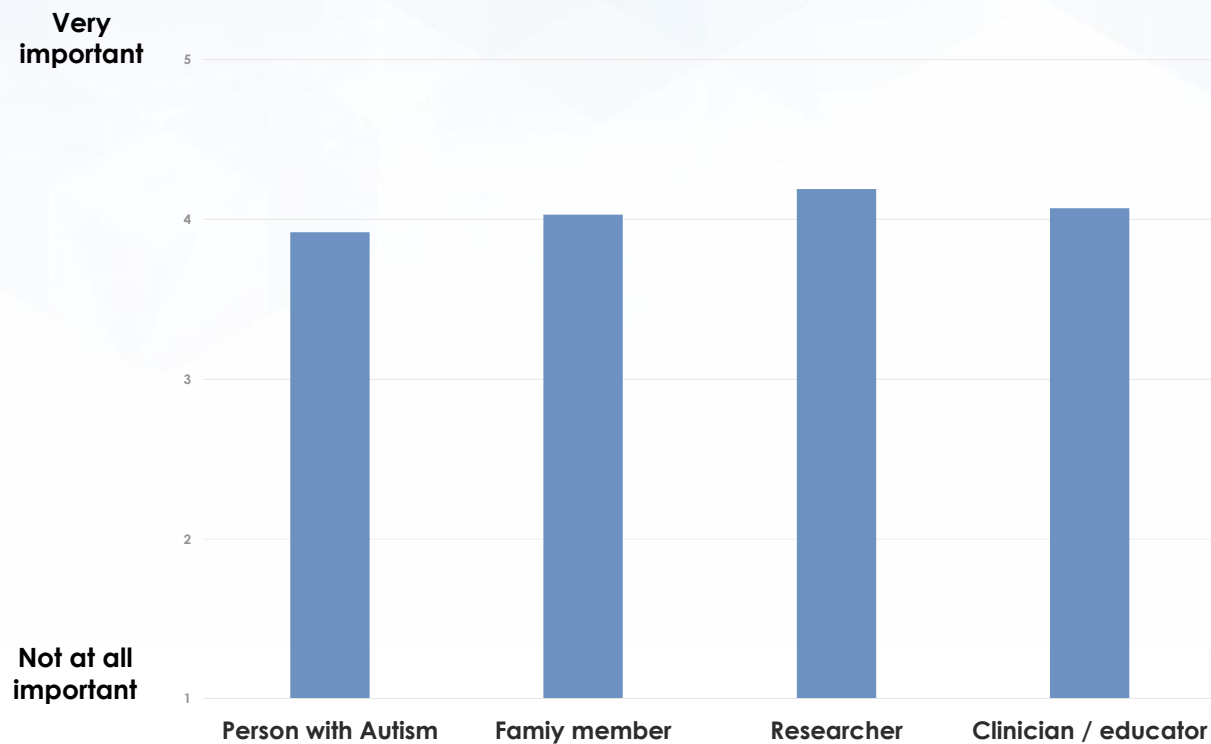
## Autism Speaks MyResearchIdea Final Results



How important is it for Autism Speaks to be involved in funding studies that move research findings into clinical practice or communities?



# To what degree do you feel it is important to fund the development of young scientists?





# Should Autism Speaks require funded investigators to engage in additional activities beyond publishing their findings?

	% Yes	If yes, disseminate and translate findings for a lay audience?	If yes, promote open source science?	If yes, provide regular progress updates?	If yes, collaborate with external media?	If yes, provide info on leveraged funding?	If yes, provide info on publications and presentations?	If yes, provide aid in future fundraising?
<b>Person with Autism</b>	54.8%	42.5%	37.3%	36.9%	25.6%	26.2%	34.2%	21.0%
<b>Family member</b>	72.8%	46.8%	30.7%	39.8%	25.5%	23.5%	31.9%	27.1%
<b>Researcher</b>	68.8%	63.6%	43.1%	35.4%	33.2%	29.2%	46.1%	22.9%
<b>Clinician / educator</b>	62.6%	55.6%	30.3%	37.9%	23.4%	22.5%	33.2%	23.4%
<b>Other</b>	67.7%	57.4%	38.7%	42.3%	29.4%	32.3%	40.3%	36.1%

**Q10: If Autism Speaks were to devote significant resources to a single scientific topic, where could we generate the greatest tangible benefit to the community?**  
(4,388 responses)

Wide range of responses with three stand-out trends:

- Improving quality of life on a daily basis, with particular interest in addressing sensory issues, mental health, sleep and GI problems  
*“Scientific advances that allow all autistic people to live, work, and enjoy life with fewer obstacles and less reliance on others.”*
- Earlier diagnosis and prevention  
*“How to diagnose as early as possible in order to begin treatments immediately.”*  
*“I think early detection. I’m 71 now. Had anyone known, my life might have been much different.”*
- New therapies that target disabling symptoms without changing broader autistic personality  
*“Therapies that alleviate the deficits associated with autism while helping autistic people play to their strengths.”*



**Q11: If Autism Speaks were to avoid one specific science topic (for any reason) what topic would you suggest avoiding and why?**

(3,059 responses)

- Nearly half of those who took survey did not indicate any areas of research to avoid
- Of those who did reply to question, most indicated opposition to research aimed at curing or preventing autism

*“Stop trying to find a cure. We do not want to be cured; we want to be accommodated.”*

*“Researching a cure or genetic markers of autism. Preventing or curing autism is a form of eugenics, which is an abhorrent idea.”*

*“Prenatal screening. This encourages eugenics and I believe it should definitely be avoided.”*





## Q12: Please provide any additional comments on Autism Speaks Science (1,611 responses)

### Four stand-out trends:

- Supportive  
*"Doing great." "Thanks for all that you are doing for our community."*
- Opposition to cure/prevention/ABA; more focus on acceptance/support  
*"I felt uncomfortable responding to so many of these questions - from your wording (like the use of the word "treatment") to your implications (that autism can or should be "prevented")"*
- Engage more people with autism in research and broader work  
*"Autistica UK is a good model of how to do autism research right. Autism research needs to be driven by and for autistic people to address autistic people's needs."*
- Greater sensitivity to nonstandard gender identity (in response to our M/F demographic question)  
*"Please put more time and effort into understanding how autism can affect gender (not sex, gender) and our perception of it."*
- 



## Take Home Messages – Overarching Trends

### **All areas of research received overall rating of “important” to “very important”**

Comments trend to highly supportive of Autism Speaks funding research across all areas, with an emphasis on applied science

- Applied science areas viewed as particularly critical to the mission of AS science, with basic science areas also viewed as valuable

As a group, respondents with autism rated all areas of research slightly lower

- This lower rating was largely driven by subgroup of respondents with autism who rated all research areas as “not important” with comments describing pursuit of cure/prevention as a personal attack



## Take Home Messages – Topic Ranking

Adult transition, lifespan issues, health and well being, and co-occurring conditions rated highest in importance for future research

Other areas of research viewed as moderately important, with animal models given lowest rating.

- Lower rating for animal models among lay community likely reflects need to better communicate their crucial role for safety and efficacy testing of new medicines
- Lower rating among researchers and clinicians may reflect under-representation of those engaged in basic research



## Take Home Messages – Recommendations for Future Funding



- In assessing the potential to improve lives, respondents gave “strong impact” rating to wide range of products, tools and treatments (both behavioral and medical)
- In recommendations for future funding, respondents gave highest ratings to research that translates findings into practice and community settings
- Respondents strongly supported future funding of early career scientists

## Take Home Messages – Requirements for Funded Researchers

Most respondents supported requirements that AS-funded researchers engage in additional activities beyond publication of findings. These included:

- Translation of findings for lay audiences
- Regular updates on research progress
- Detailed information on related publications and presentations

