Kimberley Carpenter: I would love to introduce my amazing panelists, so I'm just going to go around and, Anne, since you have your microphone off, can you introduce yourself and just share in what way you are a stakeholder and how you are involved in autism research, please.

Dr. Anne Grego-Nagel: My name is Dr. Anne Grego-Nagel. I am I'm autistic. I'm also a human factors engineer, so I come out of the world of applied research and applied science and currently, I work for Autism Speaks, and as a human factors engineer there working on the science team. Thank you.

Kimberley Carpenter: Zach, can you introduce yourself please?

Zachary Williams: Sure. Hello everyone. My name is Zachary Williams. I am also autistic and currently, I am a first year resident and a research track a psychiatry residency at UCLA.

Kimberley Carpenter: Hari, can you introduce yourself and share how you are a stakeholder and how you're involved in research?

Hari Srinviasan: Hi everyone. I'm Hari Srinviasan. I wear multiple stakeholder hats. I'm a PhD candidate in neuroscience at Vanderbilt University, where I research sensory systems in autism. I'm also in varying roles in a blunch of other research projects. I've also had the diagnosis of autism and ADHD since Age 3 and recently diagnosis around movement. My flavor of autism impacts me on the communication and sensory motor fronts. I bring multiple perspectives, scientific, advocacy and live perspectives to the table. Thank you.

Kimberley Carpenter: Thank you so much Hari and Danai.

Danai Kasambira Fannin: My name is Danai Fannin, and I'm an associate professor at North Carolina Central University, and I'm a speech pathologist. I train future speech language pathologists, and I'm also adjunct in Duke's Head and Neck Surgery and Communication Sciences Department and collaborate with the Duke Center for Autism and Brain Development. My research focuses on early identification of child language delay or disorders and bias mitigation in clinical settings once people are identified as autistic, and then access to care for people who've experienced right hemisphere stroke, they tend to have pragmatic language disorders, which is relevant to some of the autistic traits that we see as well. Most importantly, I'm a parent of two autistic children Ages 14 and 15, one of whom has intellectual disability. That really grounds my approach to research and that's my stakeholder role on this panel.

Kimberley Carpenter: Thank you guys all so much. I'm so excited. We're going to get started with our first question, and if it's okay with everybody, I'll just go in that same order to make it easy because that's how you're on my screen. The first question is, how has your lived experience as an autistic person, a parent of autistic children are both shaped the questions that you ask in your own research or the way that you review other people's research? We'll start with Anne.

Dr. Anne Grego-Nagel: Because my autism, I do read from a script on these stuff. In my job, I'm not a creator of research, but I'm a consumer of research, and I'm in the unique position to recognize research that may improve the lives of autistics and their families. My autistic experience includes speech and social challenges, sensory issues, trauma, and GI problems, and I use my lived experience to understand and empathize with other autistics, their caregivers and parents and I'm also looking for ways for ideas to improve my own life. I'm very much a systems thinker, and my brain enjoys when solutions combine research from different areas and I'm going to give you an example of how this happens in autism. Eating disorders, especially anorexia are a major cause for long term hospitalization for autistic women and eating disorder clinicians found that about 20% of those anorexia treatment have autism. Traditionally, anorexic treatments aren't as effective for those with autism and like autism, anorexia has a genetic component, and researchers have found a genetic overlap between the two conditions. Neuroscientists have discovered how the brains of girls with

autism respond to food sensitivities different from autistic boys, and that this brain activity may lead girls to develop strategies as children that are deadly as adults. All this information or all this evidence has been used to develop treatments tailored for the autistic brain. In Great Britain, the success of these trailer programs have decreased the time of inpatient care by six weeks. I've just given you examples that come from genetics, neuroscience, clinical work, implementation science research. Rarely do the results of one particular field of research improve our lives, but it's when all the research streams come together that we see improvements for our quality of life and part of my job is to help to advocate for those combinations to take the research from the researcher and implement it into clinical and life improvements. Thank you.

Kimberley Carpenter: Amazing. Thank you so much Anne. Zach, we'll go to you next.

Zachary Williams: Sure. I would say, much like Anne, my loved experience very much shapes the research I do and several of my identities, not just as an autistic person, but also as a medical provider and a participant in other biomedical research all greatly shape the questions I ask in research and the research that I review as well. I mean, primarily as an autistic person, though, I would say that I care that all the research I do is something that other autistic people find meaningful, which generally, boils down to the fact that the work is more applied and close to having a tangible impact on the lives of other autistic people. If you go and Zoom, and ask autistic people what matters to you in research. They're saying, we want answers. We want things that are going to be helpful for us now, near translation. I think that generally is what I tend to research, something that is going to be a well received thing within the autism community. As a medical provider, I often tend to find medical and psychiatric settings top of mind. This is where I am all day in the hospital and so the studies that I'm most interested in conducting are those that make changes to the way autistic people receive health care in those settings. Then I've also had the opportunity to be a research participant in all studies, not just autism research studies, which I do a lot of, but also, interestingly enough, several, like clinical trials that were not at all related to autism, like being in the Moderna COVID vaccine trial, for instance. Being a study participant has mostly given me a front row seat to how not to run a study in a lot of cases. But being a study participant is also great to learn all the little tips and tricks of what other people are doing well and how to make studies maximally participant friendly, which half of which is just giving people snacks, breaks, and good directions. But there are other little things too that do very much help.

Kimberley Carpenter: Awesome. Thank you so much Zach. Hari.

Hari Srinviasan: There is a thunderstorm going on in Nashville. It's really loud, so I'm hoping everyone can still hear me. Back to the question, strength wise, I break persistence, creativity, curiosity, and the ability to bridge academic research, lived experience, and policy. The challenge is balancing being both subject and researcher, staying objective while acknowledging my own vulnerabilities. Given my own communication and sets our e-motor challenges, I'm acutely aware of the gaps created when research samples the easiest to test participants. As a result, a big chuck is getting left out of solutions that come from research. It's like designing a remote using athletes, then wondering why the folks with motor challenges struggle with it. But if you designed that same remote for the motor challenges folks, it would easily work for athletes. That's the mindset I bring to my work. From inclusion, so science represents the full autism spectrum, not just the most convenient slice, sue solutions coming from research benefit at all. As a graduate student, my academic research focuses on areas that align with my research lab. But beyond that, I try to contribute in small ways to nudge other areas forward, like on collaborative projects, on advisory boards, nonprofit boards, by writing. Coming to the second part of the question, how I evaluate other research. Bottom line for me is translational value. There were approximately 11,000 papers on autism published last year. We are drowning in research papers, but how many actually added to improving autistic lives. In peer reviews, I'm also seeing a tendency to rebrand old ideas with clever new labels. I'm increasingly seeing terms like kinder, gentler, or neurodiversity affirming attached to almost every study, which

seem more marketing lingo than meaningful innovation. Substance must come before style or volume. A lot of research also sits in theory, which is nice at an intellectual level, but autistics needs solutions, and too often research takes forever to make it out of theory. CBT, for example, has been around since the 1980s, but took decades to make it out as a real world practice. Thank you.

Kimberley Carpenter: Thank you so much Hari, and we could not hear the thunder, so all was well. Danai.

Danai Kasambira Fannin: My experience as a parent shapes my questions because I'm always thinking about the practical outcomes and real-world accessibility, quality of life and all of this can be done with basic science. I review a lot of journal articles, and trying to pull that out of the authors, I think is really important because, as a parent of autistic children, I read a lot of articles, and I'm, I know what you're getting at is important, but who cares. I don't right now until you tell me, and of course, I will give them the language to make it so that we will care people at consumers of their science. I'm really involved in definitely trying to make or help basic science matter or be useful for people and not just amongst the thousands of articles that Hari talked about. Having that lived experience of wanting to improve the lives of my children is that plus working in research allows me to see the nuances and systemic gaps. When I'm trying to balance my lived experience advocacy for autistic people with objectivity, it can sometimes be tricky. But and in those cases, I'm always trying to check for my unconscious bias and navigate what I think is really important when these research methods or research findings and or policy progress is really slow. But I think I'm definitely invested in continuing research with human participants and across with the more challenging to collect, as far as data is concerned, populations, ones with intellectual disability, ones with communication disorders, ones who are non speaking they've been excluded from research studies. Black people have been excluded from research studies as well, and I'm Black. That lived experience helps gives me a different perspective as well.

Kimberley Carpenter: Amazing. Thank you, Danai. All those answers were so insightful, and I'm going to reach out to all of you for some ideas about how to move things forward. Our next question is, how do you think current autism research priorities align or fail to align with the needs identified by autistic people and their families? We'll start again with you Anne.

Dr. Anne Grego-Nagel: First off, I'm going to on this question, let me explain my terminology. When I say the autistic community here, I am including autistics and their families and caregivers because I'm going to talk about other communities too. That's the reason why I'm doing that here. This group, the group of the autistic community, their priority is quality of life and all dimensions of life and accessibility and autism researchers priorities vary. Clinical and applied researchers, which include your medical and your treatment providers are pretty closely aligned with the autistic community. The autism science community, which often includes geneticists, neuroscientists, and now data scientists, they are judged on generalizable results that impact the whole community. They're looking for something that links me to a five-year-old kid, and our situations might be very different, but they're looking for the thing that runs through both of us often. This group is measured by publications, grants, and intellectual property created, and the quality of life issues may not be very important to them, or they might be very important to them. But those aren't going to get them tenure or a big grant. For many basic researchers, the quality of life issues just aren't visible to them. The further a researcher gets away from working directly with autistics and their families, the less they may understand the priorities of that community. I review a lot of grant applications. That's primarily what I do for various agencies. Reading these applications can be really depressing because the goals of certain fields is to find something wrong, and their solutions are never solutions that are going to help me. The solutions are to create more research. Now, when I ask for examples of research that doesn't align with our priorities, I'm usually given social and psychology research that uses college students as subjects. Please remember that most of that research that involves college students is often self

funded research from graduate students or junior faculty at universities without a large autism research infrastructure. Using college students and covering is usually very affordable research for these people trying to get their degrees. We need this research not necessarily to prove our lives, but to help train students to become researchers and clinicians. I often hear the complaint that research is not improving our lives, and that is understandable. But you also have to understand, too, that there's another community in between the researchers and the autistic community sits the autism treatment practitioners. We do have some amazing research that's come out in the past 30 years. But if treatment centers are unwilling to adopt the newest evidence based practices, that research can never really improve an autistic's quality of life. Now, I am hopeful because I'm seeing research impacting treatment in Europe and Australia and Canada, and even Africa. We're beginning to see it being done regularly in other countries. In other countries, they often discuss autism using the autism plus model, where they take co-concurring conditions. They do not lump co-occurring conditions into the definition of autism. It will be autism plus GI issues, autism plus intellectual disability, autism plus anxiety. By also looking at that way, hopefully we will not have as many people left out of research. By actually focusing on what we're doing. This has really allowed communities to go beyond causation and blame and more toward accessibility, better treatments, and especially pain relief, especially if you know kids who have GI issues. All that's pain relief. Thank you.

Kimberley Carpenter: Thank you so much, Anne, Zach.

Zachary Williams: This is fairly similar to Anne's response, frankly, but as I mentioned previously autistic people are most interested in research that results in near term benefit. Again, this is improved supports or services or improvements in quality of life for autistic people who are alive today. This is a focus on studies that are assessing interventions, not necessarily interventions for autism, but interventions for the things that autistic people want intervened on things like GI issues, things like their AEHD, things like anxiety, anything that would be a measurable improvement in quality of life if it were intervened upon. Of course, we don't have lots of these interventions. There are probably like three trials out there for medications to improve AEHD in autism, for instance. But again, we want the resources to have more trials for these things. Of course, are the funds being diverted to that? No, not really. Again, we have much of the money autism research is spent on other fields. We have some things like health services research and epidemiology that can also affect clinical practice in other more indirect ways. That's great. But even more of that is spent on things like clinical translational neuroscience research, descriptive clinical association studies, genomics, animal models, multi-omic group discrimination, some of this data science stuff, deep phenotyping. All of this provides less value from a community standpoint. It's not to say it's bad research per say, but if we want money going to making autistic people's lives better, then this just may not be the right way to do it. Especially if it's a zero sum game, which is because funding just can't be spent in two places at once.

Kimberley Carpenter: True. Thank you, Zach. Hari.

Hari Srinviasan: Is a research progress on many fronts. When I say many, I mean it's vast. We need work on communication, sensory processing, and executive functioning on brain and body domains such as mental health and co-occurring conditions on biomedical areas like pharmaceuticals and underlying health physiology. On lived support needs, including education, employment, and daily care on systemic influences such as policy and participation and on technology from assistive tools to artificial intelligence, yet priority seems conflicting of this range. Social research gives the illusion of underplaying the importance of biomedical advances, while biomedical research seems to remain stuck in theory or a role models with no clear path to real human health outcomes. Meanwhile, we spend too much time debating which autism subgroup is growing fastest, who deserves attention and resources, whose voice is loudest, and which treatment can best monetize disability. We get stories of extremes. Superpower ignores the harsh realities of the most impacted. Total deficit and misery sees no path to solutions, and segregation often becomes the easy answer, an echo of the ugly laws when

disabled people are not allowed in public, so society didn't have to confront its failures. A 19-year-old is treated like a 91-year-old boxed up in a care facility till they die. In the meantime, we add confusion by introducing new diagnostic terms every decade as if reclassification alone could solve those issues. Motion is not movement, but both strengths and challenges can co-exist. We must support autistic strengths by opening more doors of opportunities, but we must also find real solutions to the challenges of the more impacted so that they can approach those doors of opportunity instead of being always locked out. Yes, ideally, we need the competing groups to acknowledge their interdependence and work together rather than treating their goals as competing priorities. That day will come, but what we forget is that collaboration and shared responsibility within the artistic community itself can move the whole field forward. Many artistic are in positions of privilege and power in higher education, in research, and in policy. They are in a unique position with real insights to help build solutions that reach those with greater challenges, and those challenges often span both social and medical fronts. Progress for some must and can become progress for all artistic. Thank you.

Kimberley Carpenter: Thank you so much, Hari. Danai.

Danai Kasambira Fannin: Everyone said a lot of what I would have said, and I wish that there two things could be true at the same time. We do need the basic science but it shouldn't be that something is prioritized at the detriment of this quality of life support for daily living type research. But we know that's not how the funding dollars work necessarily. Across medicine I would like to see considerations for autistic people integrated into these studies. In a class that I took last semester on implementation science, we were talking about advances in blood pressure medication, and the professor asked, what types of questions should researchers be addressing at the implementation level? I said, a question would be for those patients with ARFID, so the avoidant restrictive food intake disorder. Or people who physically can't swallow the pills. As speech pathologist, we work with dysphasia, so that's a swallowing disorder that you could get for many reasons, but a lot of time it's dementia, degenerative diseases. But also, your child with ARFID who will not take pills. What alternate methods of medication delivery are there? Is there an injection, a patch? My professor said, of all these years of teaching, no one had ever brought that up. I was really surprised about that. But that's because they have had one speech pathologist in the class. But that's the whole purpose of these interdisciplinary team and perspectives from stakeholders, people on the research teams who are autistic and think about things that parents like me think about every time we go to the doctor. Is she even going to be able to take the medicine. I think across all of the co-occurring conditions that can happen with autism, it would be nice if medical providers and researchers were thinking about that as well.

Kimberley Carpenter: Thank you so much, Danai. That's so true. Our next question is, what are some best practices or tools that you wished more autism researchers employed in their research? Recommendations for increasing stakeholder involvement without increasing a new burden, making changes to measurements, things like that. We'll start with Anne. Thank you.

Dr. Anne Grego-Nagel: Probably not the best to start with right now because I'm also going to ask the researchers to do things. One of the best practices would be to use autistic and family participation in the development of the research question. If we can start at the origin of the research project, we can actually address a lot of the needs of the autistic and family communities, and research is rarely viewed as a partnership between the researcher and the autistic family and communities. When it is considered a partnership, it really strengthens the research and also makes a lot easier on that implementation side and on the innovation adoption side. We desperately need right now from researchers is their expertise to call out bad research and misinformation. Researchers actually do this every day in seminars, but they don't do it necessarily in the bigger audience. They're very polite and very congenial. But we really need the research community to stand up to good science and especially in their research journals. I work a lot in advocacy, and so I am addressing these questions

daily. Unfortunately, there are a lot of bad actors who are promoting science, treatments and technology that are not evidence based, and the evidence is weak. The science may be nonexistent, and the funding is very self serving. This is the community that's referred to as the autism grifter community. This group preys on the hopes the desperations, and the confusion of families by promoting services and treatments that don't work or that promote bad science. Rarely do I really see people standing up to say, no. That doesn't work, and then why? This is where the researchers also could help a lot. They really need to get better at communicating the technical aspects of their methods and the science they use. They need to be able to monitor and call out bad researchers by making it clear what are good standards. We really need to be willing to discuss research that parents find on the Internet and explain it. Autism research is very complicated and it is highly technical. Autistic and their parents and their families should not be expected to have to master all the science. I am currently watching as research is being used to attack the community, both the autistic community, the parent communities. Researchers should have been fighting against bad science equation long before now and been fighting not just in their own academic communities. They do in the academic communities, but they don't do it further out. But they really do need to communicate with the communities and advocate for better funding for things that I never saw whenever I would go and I would sit with families to advocate for funding for research, rarely did we have researchers there. Someone just mentioned about the priorities of funding. I'm going to be honest, we have no clue what the priorities for funding research are right now. It is a very chaotic world and the funding aspects. But if researchers can do anything right now, it is to learn to communicate better. I have autism and is considered a communication disorder. But a funny thing when I'm with a lot of researchers, I'm rarely the worst communicator in the room. Thank you.

Kimberley Carpenter: Thank you, Anne. Zach.

Zachary Williams: Sure to follow that up, I think that I want to double down on researchers should communicate better. This time, though, to their participants. Really, one of the things that I think that researchers could do the best is that they need to make the research study on the whole, more accessible. Cognitively accessible to their potential participants, their past participants. It will pay off to make people understand what you are doing, why you are doing it, and when you are going to be doing it. That mostly means understanding what you are putting forth in your printed and spoken materials, and then how to understand what people are and aren't getting from that. What I usually find most helpful is actually to explain more. You oftentimes, as the researcher who has spent all of your time and effort on this study, just knows so much more about the study than everyone around you that you know, things are implicit that like, this is what happens next. This is where you go. This is what you do. Of course, people are coming into the study, not knowing any of that. I am an over explainer. But I have found that usually, autistic or not, the participants tend to find excessive directions helpful. You don't always need to give everyone excessive directions. But my strategy tends to be provide excessive directions optionally. Here are the directions, and then if you need more directions, click here, and then there's the excessive directions behind a little like, click here for more. That has been so helpful in my general experience because people just don't get lost as much. They don't ask me for more. They don't get confused. Not that this never happens, but it just does generally make people find that they understand what I'm doing. I get thanked for my emails, which is shocking. But then it does make people feel like they are really in control of what they are doing, where they are going, and breathe less confusion, which just makes people happier about doing the study in general. One of those things that I did actually learn from being a participant funnily enough.

Kimberley Carpenter: Amazing. Thank you so much, Zach. Harry.

Hari Srinviasan: The last question was the big picture. The first step is shifting from a mindset of how do we study autism to, how do we make studying what is impossible for everyone? This question immediately makes us think participatory research must be the solution, but we need to be honest about who is actually able to participate. Many high support autistics were never given early access to

alternative communication methodologies or technologies aligned with their motor, health, and sensory profiles. In many cases, what was tried early on was incompatible with their apraxia or sensory challenges, so it failed, and the assumption became that communication itself wasn't possible, which means they literally can't take part in research as a child, as a teen, as an adult, or even when they are 80-years-old. This is a third to quarter of the autistic population we are talking about. Instead of apologizing for excluding them, let's first invest in solutions that make participation possible, both long term and immediate. In the long term, ensure access at every age to communication that works for them, understanding that it's never too late and you're never too old to learn to communicate. That way, they get to not only participate in research, but also in life broadly. The immediate adaptation is making today's research protocols flexible enough so people can participate now. We can adapt equipment, simplify task demands, develop adaptive protocols, rethink research environments, building from the participants comfort zone and measuring what the person can give you, not what the paradigm demands. In my research, accessibility was the design principle, not an afterthought. My VR-based sensory integration task is simple and intuitive by design. It can be used across the lifespan and accommodates a range of communication, motor and cognitive differences. It relies on movement and feedback rather than long verbal instructions or button presses to measure perception and chiming. The goal isn't to dumb down the science, it's to open the door wider so more people can be part of it. It still yields robust data. My task may still not capture the entire spectrum, but it significantly broadens participation. I think of it as a good start. Another area we need to rethink is exclusion criteria. When I first entered graduate school and began reading papers, I was shocked by how many studies excluded participants for co-occurring conditions, medications, and more, creating an artificial, pure autism sample that hardly exists in real life. What I mentioned about autism plus really intrigued me. I need to read up on that. Ultimately, research inclusion isn't just about recruitment, it's about design. The future of autism research depends on building tools, environments, and expectations that fit real people, not the other way around. Thank you.

Kimberley Carpenter: Thank you so much, Harry. Dana.

Danai Kasambira Fannin: I have one suggestion I would have as far as a best practice for including stakeholders, the fair compensation issue. That means if everyone has the same role in a study like a community engagement committee, the compensation should be the same, not like, for example, paying a PhD researcher $500 an hour while the representative of the autistic community gets 25. We've really seen this in grant applications, and it's up to the reviewers of these grant applications to alert the applicant to this discrepancy. If they're all there to be a part of the research team doing the same task, there should be a going rate for that. People shouldn't be paid more just because they have a PhD to do the same thing. The measures, of course, should be culturally responsive and relevant, and you get that information from your stakeholder participants. I know of researchers who are working on survey question types that are more effective in getting answers from neurodivergent people. I think it's important to always remember and respect different perspectives within the autistic community. I was on a neurodiversity affirming committee run by autistic people, and they set ground rules the first day saying that we're not going to quibble over language, meaning that they won't let the debate of identity first versus person first language derail the goals of the group. Several social justice movements have been destroyed because of infighting about minutia like that, and language is very important. I'm not saying that that's not important, but I tell my students we have clients who want to use identity first, clients who want to use person first. I personally use identity first for my children. But I'm not going to tell a family, no, you need to be using identity first language, so as not to alienate stakeholders in your research. I think we need to truly listen to everyone that we invite to participate and realize that even though there may be a study that says the vast majority of autistic people think this, I want to see who's interviewed the vast majority of autistic people because that's a lot of people. I know how research works and sample sizes and how things can generalize. But when we're talking about things in such a wide range of presentations and life experiences, I think it's

difficult to put everyone in the same box. When we have these autistic people, family members on the same research team, we should expect different perspectives and make sure that we're respecting everyone.

Kimberley Carpenter: Amazing. Thank you so much Danai. Then building off of this theme, actually, how can researchers develop trust with autistic participants and their caregivers?

Dr. Anne Grego-Nagel: I'm just going to go through a few things that researchers might need to do. Researchers really need to listen to autistic, their parents and their caregivers and be respectful of how that person wants to communicate and don't rush their communication. That's really taking the time and just to listen. It It is not easy as a skill to develop sometimes, but it's very important. Researchers need to understand that the experiences of an autistic person and their caregivers, their parenting is always changing with cultural, societal systems, and diagnostic changes. Researchers need to identify their biases and understand how much the field has changed in the past 30 years. I am floored and shocked, and I very much grade down when I see a grant application that is quoting a lot of research from the early 2000 before 2013 when we changed the diagnostic code of autism. Because it shows me they can't define what population necessarily. Things like that, we have to adapt to what the current times are and understand how much the field has changed. One thing that I'm seeing a lot lately, I hadn't seen for a while, but I'm seeing researchers need to never blame a parent or even hint that autism is somehow a parent's fault. I thought we had moved past this, but the past year, I'm seeing a lot more of this, and it's very scary. It's also very sad because we had moved past the refrigerator mom period, and so to move back into it is very sad for our community. Then one thing that if any of you have sat on a committee with me, we've come across a grant application like this, you know I will get going on it. I'm going to try to limit my words here. But researchers need to never suggest research on an autistic child that would not be done on a non-autistic child due to safety concerns. This happens more than you would expect, especially regarding technology and wellness treatments. It is often framed that the condition of the child with autism is so bad that it is okay to understate the negative effects of the treatment. I can go on for this for a good hour. I know Kim has seen me do that. I'm going to leave it at that. Thank you.

Kimberley Carpenter: Thanks Anne. Zach.

Zachary Williams: Sure. This goes in a little bit of a different direction, but I think for developing trust with autistic participants and their caregivers, I would hope that for a lot of researchers, there are actually people right in their vicinity that might be able to help them do that. By this I mean, they can leverage their academic and community partnerships. Most researchers are part of academic institutions that already do things related to autism. This means they might have an autism clinic, they might have an IDDRC ln program these, like, disability related institutional, government funded programs, and maybe the researchers aren't hooked into those programs. But I think what they should do is lean into those affiliations or partnerships and figure out to what extent they can actually become members of those things, associated with those things, or just talk to the people who are running those things and get endorsements from them, get understanding of who those people's community partners are. Talk to those people, get understanding of what those community partners priorities are. Get endorsements from those community partners. If there is some conflict there, understand why. Because, of course, in that case, then there may be some reason why the research that this person is doing is not up to par. You don't need to just get the trust because you're getting the trust you need to get the trust because you're walking the walk. At that point, then there is some actual improvement to be done.

Kimberley Carpenter: Amazing. Thank you so much, Zach. Harry.

Hari Srinviasan: I feel trust starts with respect, respecting communication differences, being transparent about study goals, and sharing results back in accessible formats. But it doesn't end

there. Trust isn't the checkbox. It's a relationship built on understanding, accountability, and responsiveness. Let's take Arnstein's ladder of participation as a mental model. At the lowest ranks are tokenism, where autistic people are technically included, but have little real influence. It's like being asked to be on an advisory board to give your input, but then just ignoring that input. True trust comes at the top runs where their input helps shape the research questions and they become co-creators, not reviewers at the end. It also means sharing findings in clear usable ways. But trust also depends on what we choose to study and how we study it. Autism research has fragmented camps, the two visible ones being medical versus social, and each camp seems to view the other with suspicion. The truth is autistic people's needs cross all of these boundaries. Many researchers end up being wishy washy, as they don't want to offend either camp which actually reduces trust further from both autistic people and from families. People want researchers who can bridge perspectives with conviction, not avoid them out of fear. Building trust means having the courage to work across interests and center what truly matters to autistic individuals and their families, even if it doesn't fit neatly into one cap. Finally, trust grows when researchers meet people where they are in schools, clinics, community spaces, or online, showing that participation is built around their realities, not academic convenience. Trust doesn't come from neutrality. It comes from integrity, from choosing relevance over rhetoric, and continuing to show up even when the conversations are hard. Thank you.

Kimberley Carpenter: Thank you, Harry. Danai.

Danai Kasambira Fannin: I think that treating the stakeholders as colleagues is really important on the research team. I mentioned that before as far as the fair compensation. Equal pay for equal work, but not just compensation, just listening to what they're saying and considering it, valuing it the same way we value all of the team members. Following through on the promises that will give feedback or results is really important. If you have the luxury of having a research team, making sure that they are reflective of your participants. If you're going to be looking for bilinguals, bilingual Urdu speakers, you should have someone on your research team who speaks Urdu. You should have people who are from the community on your research team because that's who they will be interacting with. You can do that with the research assistants you hire, the students. Finding students who are also autistic to work on your research team, to help with data collection, and to help with dissemination, to help with reviewing your grants before you send the applications in. You can build trust with the community just by if someone walks in and realizes there are autistic people who work on this study. I think that is really powerful.

Kimberley Carpenter: Amazing. Thank you so much, Danai. We're to our last question. In the last few minutes of our panel, what advice would you give to autistic individuals or to parents or caregivers of autistic individuals who are curious about pursuing careers in autism research or are interested in contributing in any way to shaping the future of the field?

Dr. Anne Grego-Nagel: I'm going to discuss an area of research, the research area that is not always discussed, which all my colleagues have already discussed. But one way to participate in research is to become a strong community reviewer for grants and different policy programs. This requires a person to develop a deep understanding of all of the spectrum and all of the different needs, or at least empathize with them to try to understand it. It also requires an understanding of the research and the people in it. I also encourage parents, if they want to get involved in research, to read research on subjects that interest you. The one thing about autism research, it spans a wide variety. If you find an article that interests you and it's behind a paywall, write the author. They will often send you a copy. I strongly encourage people interested in research on parents and families to read NeuroTribes. It's an older book, but it will give you an understanding of autism research. Because, as Harry mentioned earlier, a lot of old ideas are being repackaged with new marketing terms. Find research that you like and look at a variety of subjects. I regularly read research by the other panelists. You'll find great researchers in a variety of fields, including not just in neuroscience and genetics, but also in disability studies in education, sociology. There are also some wonderful clinical

studies out there. Research is often done in very specific areas that are not related to autism at all. The researchers might study the intersection of autism and their fields, such as criminal justice researchers studying police interactions and autistic citizens. I know that this is done in San Diego, and I've been following the Blue Envelope program for a number of years now because that's an example of a program that came from police and local communities more than it came from the autism research community. If you can find one area that really interests you, follow it. I recently set an expert panel regarding neurodiverse conditions and school architecture. There were people from around the world practicing in such areas as heating and cooling systems, playground designs, and autism. These folks had done the research. They were producing research in their own everyday world. When you talk to someone who can tell you the difference between the volume tones of air conditioning switch-on systems. He wasn't a researcher in the scientific thing. He was a systems engineer. But he was able to do the research in that field. If you do do that research too, expect to meet people from around the world. If being a community reviewer is of interest to you, please email me because I can put you to work for Autism Speaks, and we do keep a list of community reviewers that we give to other organizations when they call saying, We need a reviewer for this, or We need a reviewer on this pre-doctoral program. Please feel free to do that. Thank you.

Kimberley Carpenter: Amazing. Thanks so much, Anne. That's such a cool panel you have in our work group. Zach.

Zachary Williams: I think one thing I will do is just very briefly overview a couple of different models of what it means to contribute to the autism field because there are different career paths in here. One is just being a career autism researcher, which I think would really be getting a graduate degree in some scientific field, probably a PhD. That would be a fully committed path after undergrad, going to maybe two or three year post back and then into graduate school and some field that's adjacent to autism, training with somebody who is themselves an autism researcher, maybe doing a postdoc, getting a faculty job. That's a career path that a lot of autism researchers are on. If you are really interested in maybe your whole career about autism, then that's probably the path you should take. But, of course, there are lots of people who may not be that committed to making their whole career about autism but still want to contribute. That's totally fine. You can also do things like becoming a grant reviewer in autism spaces or becoming some community partner in other respects, being a part of research teams, sharing one's lived experience, and being a part-time on that, or sometimes even full-time on the research team depending on your actual position, but not necessarily requiring a PhD to do that because you're contributing in a different way. These latter positions are a lot harder to come by, mostly because the credential you have is your lived experience and usually who you know. But I do think that it's relevant to just say that these are different paths. But I think the thing to know about that latter thing is how to get that is oftentimes about networking and contacting typically faculty in your local area or someone that you know for some other reason in your network with interest and enthusiasm, saying, Here I am. Here's what I'm interested in. This is my background, my lived experience, and why I want to be a part of your project. That can work. I also would recommend for anyone who is trying to get their way into a project based on lived experience, etc. I would say that the more of a pre-existing relationship you have with the person that you're contacting, the better. If there is research to participate in at that center, participate in it. If you are a patient of that clinic, etc., that seems good. Then you are now not only just cold emailing, but you are saying as a person who has experience in this capacity already, and now I'm already trying to level up my participation and now become representative of the patients of this clinic or the research participants and be a community partner with you. That might be helpful. But beyond that, I would also recommend that if you are trying to be someone who is being involved in autism research, not just as a primary researcher, but a community partner, you can do this at not just your local site but any site. It's important to know that you can reach out to people who are doing work that you are interested in and may have credentials in that you have things beyond your autism or stakeholder status to have an advantage in. That will also get you involved, perhaps. People obviously like you to be involved,

for, my God, this person has some reason that they would be an asset to the team. Clearly, people bring people on for that for other reasons and other jobs. Just so you remember this, these are also jobs.

Kimberley Carpenter: Amazing. Thank you so much, Zach. Harry.

Hari Srinviasan: My advice is to remember that change doesn't happen all at once. I often describe it as dropping pebbles in a plant of change. Each small pebble, whether joining a community board, giving feedback on study design, or pursuing a research career, creates frickles. Our collective ripples build on one another, and over time, reshape the field. Don't underestimate small steps. They matter. Second, don't just fight for a seat at the existing table; redefine what the table looks like. That means challenging who gets to be there, how decisions are made, and what counts as expertise. A lived experience isn't an add-on. It's essential to asking better questions and producing more meaningful insights. Remember, college is not the only path. Whichever path you take, know that it won't always be smooth. For me, college was infinitely more accommodating than the school system, but that was my experience. College is more than exams or checklists of accommodations. Who you are surrounded by professors, peers, or mentors, can make all the difference. In graduate school, where you work closely with your advisor and lab, that people part becomes even more critical. When you find environments willing to adapt and people who see your potential, the journey becomes not just possible but meaningful. Your perspective, whether as an artistic, a parent, ally, or an advocate, has the power to shift research toward what truly matters for the community. Each pebble makes a ripple, and together, those ripples can move the field forward. Thank you.

Kimberley Carpenter: That's such a lovely metaphor, Harry. Thank you so much. Danai.

Danai Kasambira Fannin: Similar to the path that Zach described of becoming a PhD-level researcher, there are other positions, like some places call them clinical research coordinators, CRCs, that require maybe an associate's degree. Some of them require a bachelor's, but they're researchers. Some people do that as a full-time job. While some do use that as a stepping stone on their path to further doctoral work or between their bachelor's degree and before medical school, but it is a full-time job for researchers. Then there are also these types of clinical research positions in industry. For pharmaceutical companies, for example, that's not really pertinent to autism necessarily. Usually they're doing cancer trials, but there are companies devoted to conducting clinical research, and therefore, they have positions for people who may not want to be in academia, and they may be conducting trial studies for autism. I also think just emailing people after, as Anne said, reading articles, if there's a study you're interested in, just emailing faculty members, it actually helps. I've made connections by just emailing people. Or maybe I've just been lucky that everyone's been nice and receptive. But it doesn't hurt to email someone your interest and ask, Do you have any positions, or do you need someone to help you to be a consultant on your study or community engagement board? You used to be able to say, Call someone, but email is probably a more effective way of getting ahold of people.

Kimberley Carpenter: Amazing. Thank you so much, Danai. Thank you, everybody, for this amazing panel. I've learned so much, and I'm just so grateful to know all of you.