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>> Hello everyone my name is Kashia Rosenau and want to welcome you all to the webinar series for the autism intervention research network for physical health the AIR-P airp thank you all for joining us today so before we begin i would like to address a few logistical details I'll provide a brief introduction of our group of speakers today and we will also reserve time to answer questions at the end of the presentation because of the number of participants your audio will be muted throughout the call however you can submit questions at any point during the presentation via the chat box on your webinar console the entire webinar is being recorded and will be available on the AIR-P website which is airpnetwork.ucla.edu. There will also be a short evaluation survey at the close of the webinar so we invite you to provide feedback on this webinar and also to provide suggestions for future webinars in the interest of time let's get started so we first want to acknowledge the Health Resources Services   Administration as the funding source for the AIR=P. And now i want to turn it over to our Autistic Researcher Review Board um it's my honor to introduce Dena Gassner. So please join me in welcoming Dena and ARB autistic receipt sorry researcher review board. Easier said than done right Kashi a

welcome everyone again my name is Dena Gassner and i am happy on behalf of my fellow co-chair Patrick Dwyer to invite you to our webinar today you see a list of names there there's a whole lot of us who contributed to this and really quickly i'm going to introduce those folks to you slide please so Patrick is my partner in crime he's the co-founder and co-chair of the r arc or autistic researchers committee and he's the facilitator of a local durham divergent peer supported community group and his current research looks at sensory processing and attention and autism using questionnaires behavior eye tracking tasks and he's also working on exploring attention to threat and autism neurodiversity and intervention attitudes with autism and education   fine Jackie Ryan is a part of the autistic i'm sorry her uh current research is uh autistic adults perspective of participatory autism research which she is going to be working on today and understanding autonomy and choice from the perspective of autistic people with intellectual disabilities plus community-based participatory research to enhance self-determination slide. Stephen Capp is going to be joining us from the uk his current research is on examining a social justice model of autism community-based participatory

Steven Kapp is going to join us from the U.K.   He is researching autistic and nonautistic individuals and their fidgeting.

    I'm Dena Gassner.   I'm the incoming coach.   Not trying to keep up with T.C., who was the inaugural coach last year.   I'm a national board member for the RQS.   I'm a wife, mother, a grandmother and an autistic individual.

    I'm currently trying to finish a dissertation on the examination of autistic individuals and their interactions with Social Security disability.

    Heather Brown, helps to contribute to today's activities.   She is at the University of Alberta, understanding the experience of camouflaging and autistic women and how it

affects well-being and looking at and describing the mathematical skills of autistic adults.

It predicts mathematical strength on the spectrum.

Ari Ne'eman is helping us today as well, he is a visiting scholar at the Lurie Institute for Disability, policy at Brandeis. He is an executive board member, co-founder and past Executive Director for ASPAN.

Morenike Onaiwu, I don't think I have said her last name. I'm sorry if I said it wrong. She is a scholar at Rice University and part of the Institute for Exceptional Care executive board.

This includes developmental disabilities and reproductive justice, cross-cultural narrative theory, nontraditional and stakeholder leadership, underrepresented populations and transitional research.

TC ways man is the co-founder of this committee that's presenting this for you today. She is an editorial member for autism in adulthood and cofounder of autism training academy.

Her current research is on autism and universal design training for faculty coleading with Dr. Kristen Gillespie-Lynch. There is your beautiful face, T.C.

Zach Williams has also been a huge contributor, the incoming secretary for the INSAR ARC. His current research is on characterizing the subjective experience in neural underpinnings of sound sensitivity in autistic adults.

Also, the development and validation of novel measurements for the autistic population.

Now, I'm going to turn it over to Patrick. Thank you, everyone.
>> Thank you, Dena, for that introduction. Now you have heard who we all are individually and collectively, of course, we are autistic autism researchers, which means

we are able to draw on a variety of different perspectives, the perspective that comes with being a researcher with that academic knowledge.

We also come from various different points in our careers, which adds to the researcher knowledge.   Then, of course, we have our personal lived experiences as autistic people.

There are also other sources, other perspectives that may be less obvious.   Many of the members of the review board are family members of autistic people.

Some are parents of autistic people as well as being autistic themselves.   We are all part of the autistic community, which means that beyond our own experiences, we also are a part of this community with people with shared experiences in developing their own concepts for understanding those.

We are different from many of the ones that we use in research.   All these different perspectives we think are really helpful combination when it comes to reviewing research ideas.

Of course, we are not claiming to be and we are not representative of all autistic people and as researchers we are in many ways quite a privileged group.

That's one we reason we want to encourage collaboration with community stakeholders outside of our review board, which is something that some of those on the board will be talking about later.

Next slide, please.   So our review boards really wants to prioritize the focus on improving autistic people's well-being.

As you can see the framework there that I won't fully go into details.   Next slide, please.

We also have some other key priorities for research in this domain of autism and physical health.   We want to see more focus on intersectionality and all the different

intersections that one can look at there.

It is also aging.   That's an under-researched area in general in terms of autism.

Aging is particularly important to health.   Provider and system barriers and medical care and how those barriers are interacting with autistic differences in communication and perception.

Moving beyond simple descriptive explorations of occurrences, and more mechanistic and, therefore, actionable understanding of what's going on at different levels.

Next slide, please.   Our primary goals would be promoting autistic people's health and well-being.

Secondly, promoting an evidence-base that is rigorous and inclusive and that's sensitive to what the community needs.

We really hope what the AIR-P is doing can help inspire other research networks and organizations to use similarly innovative models to increase autistic collaboration.

Then, again, fostering collaborations between AIR-P sites and projects including autistic people and caregivers and some of my colleagues will be talking more about that later.

First, we also have this goal of ensuring that results of AIR-P research are communicated in a way that is not only accessible to the community but also respectful.

I'll take a few moments to talk about that first.

We can move on to the next slide, which is a title slide.   We can move straight on to the actual content too.

Thank you.   So when it comes to respectful terminology, I think it is interesting to go back to the late 1990s when on autistic.org, you saw this thing called the institute for the study of the neurologically typical.

This very amusing parody was taking the language that we use to describe autism and other developmental disabilities and instead of applying it neurotypical, it was talking about neurotypical syndrome as this disorder characterized by all these symptoms.

This tragically affects the big chunk of the human population that has no known cure.   There were these wonderful little condescending remashes interspersed like many neurotypicals, to compensate for their disabilities, interact normally with autistic people.

This is a parody.   It is making some very serious points here.   When it is doing something like the DSM-IV, describing the disorder using the same language and terminology we use to describe autism, it is pointing to areas in which neurotypical people's behaviors and actions are contributing to the difficulty that is a lot of autistic people are experiencing.

It is saying that neurotypical people have an impairment in the ability to make peer friendships.   Because they are interested in making peer friendships with other neurotypical people, not autistic people, they, in fact, lack understanding of those who are different, that they have an obsessive rigidity for social convention.

It is not perhaps autistic people who are inflexible, maybe it is neurotypical people imposing these rigid social conventions that's the problem there.

It even goes on to point out that there are victimization talking and laughing at neurotypical people.   It is a parody but making a serious point that we can actually do a fairly good job of using the exact same sort of deficit language and terminology that we typically use to talk about autism to talk about neurotypicals.

Does that mean that neurotypicals are deficient or disordered?   No, that's not the point.   The point is to say that maybe these judgments of disorder and deficit are not

strictly objective.

That it is more complicated than that.   There are challenges, yes.   It is not clear they are solely due to what autistic people consult.

If we move on to the next slide.   I would say that the terminology is best exposed as reflecting these unacknowledged subjective value judgments.   We should actually probably be striving toward a more neutral descriptive terminology.

This is just acknowledging characteristics and challenges that are there rather than getting into questions of contributing responsibilities.

Next slide or further on the same slide, really.   The other issue here is that the terminology could actually be harmful.   Not only might it reflect subjective value judgments.

If you are going around calling people disordered and deficient, that could be impacting their mental health and self-esteem.   Perceived acceptance of autism by others is related to mental health.

When we can't use mutual descriptive terminology, it is better to err on the side of using strength-building terminology.

Move on to the next slide.   Here is a number of specific suggestions to try and make this more comprehensive.

Instead of the term disorder that's saying everything that's wrong is due to the autistic person's characteristics, you can just say disability, acknowledging the reality of the challenge, much more neutral.

We can also when it comes to autism spectrum disorder, say disability or just leave off the disorder and just say autism.

Another option would be to say autism spectrum development, and this comes from the principle that if it is something that's acceptable to say of neurotypical people,

probably that means it is acceptable to say of autism.

This is sort of a general principle I find useful if I'm ever not sure of a particular phrase or term is respectful.   I drop out the autism or disability label and instead put in neurotypicals are some specific group like an marginalized ethnic group and see whether it still sounds okay.

As you go down the recommendation list, red flags, symptoms, risk, these are also fairly subjective terms.   We can instead say things like characteristics, indicators, likelihood, probability, just more neutral terms.

Instead of restrictive, we might say focused.   Similar meaning.   Instead of saying the autistic person is being rigid and inflexible, it is good to consider that maybe both the autistic person and the neurotypical people or society around them might be being inflexible.

Usually, inflexibility isn't a problem if it is only one person being inflexible.   Other people presumably can be flexible about that.

Instead of comorbid, co-occurring.

Instead of terms like problem or challenging behavior, you can say distressed, which puts more emphasis on the first-person experiences of the individual themselves or you could just be more specific, say exactly what it is that's a problem.   Challenging is such a big term.

Similarly, these functioning levels, severity is extremely vague and more specific descriptions are helpful.

If you want to be vague, say something about the support needs of the individual, for example.

Next slide, please.   Of course, another major terminology controversy here is that between person-first language and identity first language would be saying something

like person with autism.   You want to emphasize the person or the individual.   Make sure that the disability isn't characterizing or taking over their whole identity.

This is something that actually a lot of people react against.   They were putting out, we, do we go around saying things like person with femaleness.   We don't.   We can be comfortable with using terms like women?

Could it be our desire to distance the person reflects some sort of stigma?   Is it reflecting negative attitudes?   Do we take pride in our neurodivergent and different identities.

If we could move on to the next point on the slide.   There is a middle ground position.   Person on the autism spectrum is not necessarily the preferred term of a lot of individuals but it is a good compromised position that is not offensive to anyone.

The most important principle here is that you always do want to respect the identifying language preferences of any specific individual.

Next slide.   A lot of these terminology considerations seem to be related to this idea of neurodiversity.   And neurodiversity advocacy.   We don't have time to unpack the ins and outs.   There are a lot of questions of what this term means and it tends to complicate debates and disagreements about the subject.

It just adds a lot.   It doesn't necessarily help that neurodiversity has multiple meanings.

To start with the descriptive, factual sort of angle here, neurodiversity means that all minds and brains are different.   When Judy Singer and Harvey Bloom and the independent living autism lister were initially developing this concept, they said we use biodiversity to say different species in ecosystems, why can't we use neurodiversity for different minds and brains in society.

Then you can use the term neurodiverse to refer to a group that has people with a

diversity of minds and brains.   This only makes sense when applied to groups people would argue.   Any individual has only one mind or brain.

That being said, sometimes the term neurodiverse is a syndrome that most would consider as an indirect usage.

Neurodivergent means having a mind or brain that is deviating from societal standards in what's considered normative in a way of disability.

This can be applied to groups or specific individuals.   I am myself autistic.   You can also use the term neurominority if you are referring to specific groups.

Next slide, please.   But neurodiversity is not just descriptive.   It is also prescriptive, actually can we go back to the previous slide?   I got ahead of myself.

If you go back up to the quote at the top from singer, why not propose that just as biodiversity is essential to ecosystem stability, so neurodiversity may be essential for cultural stability.

That is definitely prescriptive.   It is not just descriptive saying that neurodiversity is a great thing.   We are shuffling back and forth.

Neurodiversity is preferring to this whole political movement that is proposing normalization for autism.   It is talking about support for autistic people and promotion of well-being.

Advocates here don't believe that acceptance should be conditional.   Acceptance should just be a right, that everybody should be able to feel that there is nothing wrong with who they are as a person.

This is definitely not just about autism.   It is supposed to be broader than that. You see a lot in the ADHD world and with learning disabilities, many different minorities.

I said there are a plot of misunderstandings about neurodiversity and what it means.   One of these really seems to resolve around just what it means to reject error.

Neurotypical people, they learn skills, right?   They are constantly learning not just in childhood but throughout adulthood as well.

Neurodiversity advocacy is not opposed to teaching people useful, adaptive skills. It is just opposed to the idea that that should be used to say there is something wrong with who they are.

We can teach people skills without trying to change them into somebody else, if that makes sense.

Another key point mere is that the opposition to cure only applies to things that are perceived to not be medical problems.

If something is a medical problem, then taking a medical pure oriented approach is totally acceptable.

This is a very important point to make in terms of physical health and physical health conditions, many of which will, in fact, be medical problems.

So, for example, I think most advocates would tend to agree epilepsy, gastrointestinal problems are genuine medical problems.

You also see an interesting middle ground where anxiety might be something where you don't want people to feel there is something wrong with them.

Because of an elevated, clinically significant anxiety level.   On the other hand, maybe the individual would want to get their anxiety down to where there is sort of a gray area.

If we can move on to the next slide, I find it really helpful to reflect on different models that are used to describe disability and where neurodiversity fits here.   This medical model that you see on the left, that is this idea that disability and challenges are solely located within the person.

I have already opined that reflects subjective value judgments and you want to

cure the person to normalize them.

The social model in the strong form is pretty much the exact opposite. Here, we have this interesting distinction between disability and impairment. Impairment is the thing located within the person and not directly causing the disability. The disability is coming from society, from society's failure to accommodate and include people.

So, for example, a neurodivergent person who has skills but who is unable to obtain employment because of an atypical social presentation at job interviews, that disability, that barrier that's presenting them from accessing employment is coming from society.

The solution to that would be to reform society to put in place some alternative job assessment that would allow them to get employment.

This strong version of social model breaks down sometimes because it is not clear if a particular neurodivergent characteristic is going to be -- it sometimes seems like it could be disabling in pretty much any environment you can think of.

This is where we come to this middle ground of interactionist or ecological approaches, social, relationship approaches, many different names for more or less similar ideas here.

This is the idea that both characteristics of the person and their environment could contribute to disability.

Therefore, we could either try to reform society or to change the individuals, not necessarily by curing, if the problem is not a medical problem.

Perhaps by teaching adaptive skills. So the neurodiversity movement, I would argue, fits in this interactionist middle ground. Certainly, that is what we think they are officially proposing.

If you look at what neurodiversity advocates say about adaptive skills, I think you

can see the neurodiversity movement in there.

Hopefully, that provides some useful concepts.   I know that that was a huge amount of information in a very short time.

Thank you for bearing with me.   I am happy now to hand things over to Jackie Ryan, who will actually be talking about the topic of our webinar for participatory autism research.

>> Thank you, Patrick.   I'm going to be presenting on a small study that I did while I was a visiting student at the University of Edinburgh.   I was looking at the experience of autistic adults in the U.K. and their experiences of participatory autism research.

It is an umbrella term that encompasses a variety of participatory approaches to include autistic people as more than subjects.

For example, at advisers, collaborators or partners.   These could include community-based participatory research, action research, participatory action research, et cetera.

This study was developed during my study term at the University of Edinburgh.   I was looking to update the findings of a 2014 study by Pellicano in terms of the autistic people's perspectives, research community engagement in autism research.

Basically, has anything changed in the five years since then?   I was supervised by professor Sue Fletcher-Watson.   I collaborated with Kabie Brook, an autistic activist in Inverness, Scotland.   Next slide, please.

So autistic people have not been involved in research as they would like to be. There are differences in priorities between the autism community and the autistic community.   For clarity, when I talk about the autistic community, I am talking about actually autistic people.

When I'm talking about the autism community, I'm including researchers, family

members, professionals, allies.

So the autistic community is a subset of the autism community.   So the two groups have different research priorities.

With the autistic community being most interested in research to improve quality of life, yet autism researchers have been reluctant to engage autistic people.

In fact, a recent study by Hollin and Pearce say that researchers describe engagement with the autistic community is difficult due to political differences.

Interestingly, autistic impairments which exacerbates researcher reluctance to engage with the autistic community.

Next slide, please.   So our main research question was, what are the perspectives and experiences of the autistic community of participatory autism research or PAR?

We supported that by asking these questions.   What do you think about PAR? What are some of the barriers to PAR?   What has worked well in your experience in PAR?

How could PAR be supported in the future?   What do you wish autism researchers knew about being autistic?   How would you like to be involved in autism research?
>> Next slide, please.   So we used an a synchronous focus group platform called Colavito to collect the data.   The questions were posted.

Participants had one week to answer the questions and respond to other participants answers.   The dialogue was carried on throughout the week.

Then we used brawn and Clarke's thematic day it analysis and we achieved consensus between the two main researchers via e-mail discussion and review by our supervisor.

Next slide, please.

So we identified two main themes.   That of respect and authenticity.

So the theme of respect related to valuing autistic individual's time, attending to their accessibility needs, including autistic people with co-occurring conditions and other intersectionalities.

Using sensitive language and providing accurate information about autism.   This theme is exemplified by this comment from a participant.

They said, I feel like we spend so much of our energy educating people about the same dozen or so things.

I also find it rather ironic and just painful that people who are researching autism still need to hear these things.

I would suggest that researchers simply spend time with autistic people, even if it is only online and listen to the things that we say.

The theme of authenticity related to trust, open and honest communication, ethics, tokenism and recognition autistic people can have more than their lived experience. This theme is illustrated by this comment from a participant that said.

I would love it if all research had to go through an autistic ethics review board in the same way other ethics boards worked.   Next slide, please.

Finally, this research supported earlier findings that autistic people are not involved in research as they would like to be.

The findings also endorsed the AASPIRE Practice Guidelines for the inclusion of autistic adults as co-researchers that Dr. Kapp will be presenting next.

The findings aligned with topics identified by Fletcher-Watson et al. In 2018.

Interestingly, our findings contrasts with Hollin and Pearce findings with difficulties in engaging with the autistic community and research stem from autistic impairments.

One of the participants talked about her ability to mediate disagreements in studies she has taken part in.

The study had several limitations.   We had a small sample size.   We were only recruiting participants who lived in the UK.   We did not include any autistic people who had higher support needs.

Also, interestingly, I was really excited about using this a synchronous online platform.

I thought it might meet the need of autistic people.   The people that participated in this study actually didn't like the platform.

They found that it required too much initiation to use it.

So that's what I found and learned when I was studying in the UK.   Now, I will turn it over to Steven Kapp to talk about the AASPIRE guidelines.   Thank you.

>> Thank you, Jackie.   Yes, thanks for leading into this and mentioning the AASPIRE practice-based guidelines I'm presenting on including autistic adults as co-researchers and recommendations from these guidelines.

So as background to the guidelines are in this is actually research that I have done in partnership with Dr. Kristen Gillespie-Lynch, Associate Professor.   We shared primary authors of the study about expertise of autistic people.

Arguably, autistic adults' expertise about autism can fall under the least relevant of our findings.

In general, there is experiential expertise, which is expertise from the lived experience of being autistic.

This would direct that experience for the people.   Empirical evidence we found relevant to this.   We have open-end of questions.   We also have quantitative data.

In this case, we had an open-ended question about how would you define autism in your own words?

We saw that through content analysis that autistic adult people were more likely to

define autism experientially, from the inside.

This is including referring to perception or other aspects of emotion or cognition or any aspect of the brain or genes or biology.

These are things that are more internal.   Whereas, autism defines by behavior, especially someone on the outside.

You can more easily observe someone's whole literal behavior and maybe more easily be directly involved in that.

Whereas, the inside of something again not only do we have directions but [Speaking Away From Mic].

There are all sorts of reasons that may underlie our actual behavior.   That might be the true autism that a way a lot of autistic people say, neurodiversity term.

Autistic adults, you know, the term that we coin and use, that's what we are talking about.

And then Mrs. Autistic people are more likely to define autism in a balanced way that incorporated neutral differences as well as potential positives but also incorporating challenges.

It was unusual for people to talk about autism only positively.   Usually, strengths and weaknesses of people are mentioned.   This was, I think, more in line with the neurodiversity framework, autism as a difference.

Also, there is a traditional expertise of autistic people that this was autism awareness scale, which goes back to the 1980s and has been revised as scientific knowledge of autism, has been updated over the years.

It relates to scientific understanding of autism and autistic participants reported the most knowledge on this measure.

Higher knowledge related to lower stigma.   Actually, the higher knowledge was

especially for autistic adults exceeded the other scores on items that were more strength related because of the understanding of autism.

If we go to the next slide, please.

AASPIRE is an acronym for Academic Autism Spectrum Partnership in Research and Education is a leader in community-based participatory autism research. I'll go into the framework of it.

It was formed in 2006. I joined ten years ago. It is co-directed by Christina Nicolaidis, a professor in internal medicine, medical doctor, and also a mother of an autistic now adult, child at the time, and Dora Raymaker, who was at the time working toward a graduate certificate.

Before the master's degree. Now, Ph.D. and so Christina was the academic co-Director and Dora was the kind of community co-Director. Did I say Dora?

So Dora was autistic and Christina was not. For AASPIRE, community-based participatory research means equal partnership with the autistic community and it includes the lay autistic community, not just autistic researchers like this review board.

But also lay, not academic, co-researchers, and studies that I have partnered on have been health care, employment, autistic burnout and outcome measurement.

When I joined, I didn't yet have a master's degree either.

So I was considered a community partner. Now, I'm something like an Assistant Professor in Americanese. I am from L.A.

By the terms that my university uses, I'm called a lecturer. I do research and teaching. The closest thing to tenure that I already have in our system.

And so I'm now no longer a community partner but an academic partner, even though I'm [Speaking Away From Mic] partner.

Somehow, I forgot to replace the -- it should be the academic -- it should be our

practice-based guidelines slide that was published in the autism [Speaking Away From Mic].

Anyway, free of charge.

So if we go to the next slide, please.   So there is the proper citation.

So the inclusion guidelines, they were actually for including autistic people as both co-researchers, which is the main point of this talk, but also as research participants.

So, generally, just to quickly cover autistic people, including the most research, the general principle is to protect autistic participants or human subjects while maximizing the autonomy and inclusion of autistic adults.

So, for example, only accessing, assessing the capacity to participate if necessary. Someone is participating independently online in the survey.

I don't think -- we don't think they are in the capacity but need to be assessed.

Only including proxy reporters like parents and caregivers for an autistic adult if necessary, if that adult can't participate.

The adult should be given or participant should be given opportunity for support to participate.   They can still, as long as they are actually the one giving their views, it is okay to have support.

Also, it is important to create an accessible data collection processes and materials, including with the process with participation and surveys, interviews, et cetera.

You can read more about this in our paper.   Also, in our collaboration on our website.

Next slide, please.

So the first, kind of, guideline for including autistic people as co-researchers is to match the goals, the research partnership has with the approach that's taking to the

level of engagement.

It should be transparent about the level of engagement with, you know, autistic -- with the autistic collaborators in the outside world.

Three main levels of engagement that we discuss are equal partnership, so community-based participatory research is a type of that.

It's been done with other marginalized groups.

The type of emancipatory research, trying to search the goals that the community wants to directly empower the community.

And the process itself is empowering, because it is about sharing power equally.

Whereas, typically, the researcher it's have more power than the lay co-researchers.   Not every person in the community is academic.

Sometimes when you are an academic, it can also shade your perspective.

I can speak from personal experience.   Although, I can also speak from literally my personal experience as an autistic person.

It's important to have autistic people with all sorts of experience, background.

Another level of engagement is authentic collaboration or engagement.   An example is stakeholder participation.   This is a level where the autistic collaborators would have more -- it's more than just input.

It is more meaningful than something that you say something and that could be totally discarded and might not have any influence.

Arguably, although we are professional in a sense that we have different types of academic researchers, this could be something that the review board.

The areas are a bit gray.   Then, there is another level of engagement that's basically consultation.

This might be one time or ongoing.   It is kind of just giving input.   They can do

what they want with it.   It is not necessarily having that strong of an impact.

Next slide, please.   So the next principle is about, you know, some of these are my own words, of course.   I am partnering with suitable people and well-defined roles.

I am paraphrasing.   So it's important to identify partners who share a long-term vision, share the same long-term vision for what they want to see for, let's say, the autistic community, what they want to see from this research project.

We prioritize the group's goals over individual gain or whatnot.   Partner, I think we'll get into that.

To partner with autistic people with different types of lived experience including not just about autism but also different intersectional issues, different educational backgrounds, different racial and ethnic background and gender backgrounds.

Maybe who have experience living or currently live in a group setting or, you know, who could potentially receive certain therapies or have different experiences with services or whatever it might be.

It might be AAC users or non-speaking or other disabilities and what have you.

Partner with autistic people with diverse levels of community connection was not just leaders.

Also, potentially if there are different autism or autistic organization self-advocacy organizations.

Also, people who are not tied to any particular organizations and might not even be all that involved in the autistic community outside of AASPIRE.

And everything in between.   Again, it will shade people's experiences and perspectives and what have you.   We are trying to represent the current experiences and --

Also, partner with nonautistic people who agree to share power.   This could be

practitioners, researchers who have relevant expertise and experience for the study.

If it is about health care, then having nurses and doctors may be quite relevant and necessary, even.   So everyone needs to put aside their ego and seek to achieve --

Well, potentially a consensus.   But whatever means of working together that's agreed upon.   We in AASPIRE seek to achieve a consensus.

You don't need to necessarily have a formal application process.   If you do, you know, you should probably make and review it as a team.   Do everything you can as a team.

Next slide, please.   So another principle is to create processes for sharing information and power, including for procedures for communicating inside and outside meetings.

For example, in AASPIRE, we have templates for e-mails and they have clear headings and sections within the e-mails, for example, they will say, what actions are expected to be taken.

If any, it might just be for your information, any details.   The deadline, any stipend applicable.

Then, within meetings, to provide clear agenda in advance and other materials for the meetings sent in advance.

And time management and what have you is not always a strong-suit of all of us. Help us stay on track, respectively.

And offer accessible methods for participation.   It could be multiple simultaneously as needed.

For example, when AASPIRE was first founded and over the first -- until quite recently, until the last year or so, I believe, we met by text chat with Skype and then it has moved to Zoom because of the preference of an individual.

It is not really a preference.   Really, access needs are needed from preferences. Sometimes actually access needs for some autistic people make things more inconvenient and difficult for non-autistic people.

At the beginning, text chat was more accessible to all the autistic or at least as accessible to all the autistic partners.

Things are written down.   You don't need to process visual cues, et cetera, which made it more difficult for some non-autistic partners like Christina, who is used to the more -- the sort of talking out loud sight and sound together and the video chat or at least teleconferences or whatever.

But, now, we have a partner with an intellectual disability, a partner who is blind, and a partner who is an AC user who types to communicate.   So three separate people.

And so we need to provide the option to speak in the meetings or have sound and to have closed captioning for any sound and speech and what have you.

We still have text chat, if needed, for those.   Someone reads what's written aloud. People who one method is not accessible can still participate.

It is important to have the method for making decisions.

Next slide.   The example of AASPIRE.   We have something called a five-finger method.   We covered that in the paper in 2011.

Actually, I was just joining.   But AASPIRE has a paper about it.   You can see that it is basically, you might love it.   You might like it.   You might need to talk about it further.   You might dislike it or you might hate it so much that you are willing to kind of veto it.

We need to come to a consensus in AASPIRE to be able to get everyone to agree

to live with it.   Almost always at least through discussion.   If there are any fours and anyone dislikes it but they are willing to live with it, we still need to discuss it.

If everybody love it is or likes it, we just move on.

If anyone has questions but they dislike it but can live with it, obviously, if they hate it, we discuss it and try to get it to work for everyone.

As long as everybody has a one, two, or even the like it but can live with it, four, we can move on.

Usually, through discussion, everyone comes to like it.   Next slide.

There is not too much more.   I think this is the final slide.

A bunch of quick principles that I put together.   There is the importance of building and maintaining trust.

So solidify and share goals.

It is important for researchers to demonstrate, nonautistic researchers and nonautistic practitioners and professionals to demonstrate that they value lived experience.

So autistic partners and co-researchers can feel comfortable sharing their own personal experience and the experience of others and what have you.   Even if they don't have as much technical knowledge and academic traditional academic expertise or what have you.

It is important to listen to the group and one of the group's decisions and report back on the progress and to formally self-evaluate the collaboration.

We do that really formally every once in a while.   At the end of every meeting, we have a key change exercise, what we did well.   We don't have the time to cover it.

Even so, we generally will send it out by an e-mail to discuss it further.

We share, disseminate findings together.   People that work on the study always

have the opportunity to be a co-author and to collaborate on presentations.

We encourage skill building to essentially help people like Dora and I become academic partners potentially, which also means now we always have this kind of community counsel.

Since Dora is also an academic now, the community counsel, of lay autistic people, it is important.   They have an important voice as well in making decisions with the AASPIRE coDirectors and with the staff.

Manage power differentials.   When people like Dora and I, when we become academics, we shouldn't substitute for community partners.

Actually, I have made way by no longer being a community partner, we need to [[   ]] more other community partners.

Critical to fairly pay community partners, which is especially important when non-autistic staff or just any staff or research participants are paid.

It is a non-funded project and no one has any money for it, then we can commiserate.   Usually, researchers have some funding for our time in some respect.

We used to be paid, community partners were paid $25 for two-hour meeting ten years ago.

Now, minimum wage is higher than $12.50 an hour in many parts of the country. Also, as we have gotten more grants and been able to pay more, now we pay $25 an hour.

So it is $50 for two hours.

You know, I don't know that there is any magic formula to what the going rate is. What we can pay people.

Anyway, thank you very much.   I think that about wraps it up for me.

I think that I am done.

>> Dena, I think that you had something to say on this slide or Patrick, on this.

>> Absolutely.   I'm happy to do that.   This is our commercial break for the end of the session.   We just wanted to let you know that we are very excited that we have full capacity at our first year of this sig.

It is called building the strength of autistic psychological Lars by addressing systemic barriers to autistic success in academia.

In the first year, we are going to be looking at primarily three groups of participants. We were going to be looking at the experiences of autistic researchers, the observations of their colleagues as they collaborate with autistic researchers and the employers or supervisors as the individuals who are autistic are experiencing the application process and that transition into first year adjustment for Graduate School.

Each year, we will be adding more time to this.

The second year, we are going to be looking at the actual experience of Graduate School, beyond the first year, up until graduation.

The final year, we are going to look at employment.   We are very excited about this.   We are building on the research that's already been done by some of the people you heard today.

Our primary keynote speaker for that day is going to be Sandra Jones, who has done a lot of work in this area already.

We are still, very, very much in need of facilitator.   There are two divisions, no takers and people to prompt the questions.

If you are already registered, unfortunately, registration is closed.   If you are already registered and you can participate in either capacity or you can handle both parts, we would really love to hear from you.   Let us know.

I'll put my e-mail in the chat and you can reach out to me if you would like to help

us out.   We are really hungry to have you.   Thanks.

>> A quick clarification from me.   The registration for the INSAR SIG specifically is closed.

If you want to be a discussion facilitator and you are registered for the entire INSAR meeting, not specific the sig, it will still be possible to sneak you in.   Thank you.

>> Thanks, Patrick.   Well, thank you very much to everyone.   Perfect timing on the slide change.

Thank you all very much to all the presenters.   Thank you for your work, your advocacy and for being an integral part of the AIR-P network.

I could probably spend an hour and a half talking just about how amazing it has been as an autism researcher working with the AIR-P members, everybody in our ARRB.   It is awesome for you all to be able to provide more information for others.

So we now have time for some questions and answers.   I'll start.   There was at least one question already submitted.   Please feel free to type additional questions in the chat box and I can read them aloud for the presenters.

I will post a link for a feedback survey in the chat.

There were some answers being put in the chat throughout the webinar.   There was one person who asked a question about resources and being able to connect with others.

They said, what has been the most effective tool for the community of autistic co-researchers to engage between them and with partners broadly?

Then, they also said you mentioned a list serve, which I think Dena provided other information that they are in the process of creating a database.

I wasn't sure if anybody had anything else to add there.

What has been the most effective tool for the community of autistic co-researchers

to engage between them and with partners more broadly?

>> In terms of the database, I can just quickly say some more about that. This is not a resource that exists currently. It is one that we hope will exist soon.

A lot of us on the AIR-P ARRB are also on the INSAR autistic researchers committee. Sorry about all the acronyms there.

Zach Williams has, in particular, been doing a lot of work to develop a database that could be used to try and match researchers and community co-researchers who would be interested in collaborating on any specific projects in terms of helping co-researchers and academic researchers find one another.

That does not exist at the present. We are hoping that after this year's INSAR meeting, we'll be able to focus on getting that up there.

I don't know if anyone else wants to comment. I am not sure if the question was intended to ask about that question of finding one another versus the question of tools to support a collaboration and make it work.

>> Steven, I think, were you adding something? You are muted.

>> I think there is also a tool kit based in the U.K. that autistic people develop. I am trying to remember it.

>> Also, Steven, you mentioned something from AASPIRE earlier that you wanted to share. You could also drop that in the chat as well, if it is easily findable. No pressure whatsoever at all.

I just remember you saying that.

I think that they were asking -- Patrick, you were trying to ask the question about if they seemed to be asking about connecting with other autistic co-researchers or with other partners, more broadly.

I think that they were asking about both, just from the read of the question. How

do they connect with other autistic researchers and, also, how they could possibly connect with other possible collaborators more broadly?

I think the information that you all provided, was asking about maintaining the engagement and communication broadly.

I don't know if anybody has anything else to add on that as well.

I'll also add a link to the survey in the chat right now.

Sorry, Dena, I think you were muted.   You were going to add something?

>> I was just going to say, the autistic researchers have been unearthing each other at INSAR for quite some time.

Depending on your particular research matter, the subject, the focus of the inquiry, qualitative or quantitative, if we have some idea, you know, inform alley, no guarantee.

We kind of know who each other are.   We can maybe help you out if you have a particular interest in collaboration.

I can also say that, you know, in addition to Christina's work and their work at AASPIRE, Teal Benevides has done some pretty significant community participatory research as it applies to autistic experiences with mental and physical health care.

We are about to drop another research article here very soon.   So one of the other ways you can find collaborators is to possibly look for PCORI-funded research.   It is required by their funding stream.

There are a couple of ways you can less formally.   You can come across collaborators some other ways if you are looking for them.

>> Also, in terms of facilitating connections among autistic researchers, whether academic or otherwise, there are some social media groups.   So, for example, there is this Facebook group.

There is another one as well.   It is a private, secret group, not publically findable.

Of course, there is Twitter hashtags and things.

>> Social media is a good suggestion, Patrick.   We have also been trying to really encourage and work more with the AIR-P social media to find more places for individuals to come together.

I dropped the link for the feedback survey, which is also on your screen in the chat.

I also am going to provide the link to the AIR-P website in case that is helpful for individuals.

I'll also provide a link to join the AIR-P network by joining the AIR-P newsletter.

>> Another way, autistic researchers might meet each other.   Did someone see the #autistics in academia on Twitter or essentially elsewhere.

Patrick alluded to Facebook groups.   Technically, the groups are listed as secret. But I think that means maybe their existence isn't necessarily that you have to be autistic in or to join.

I think we can -- maybe this one is probably this.   One is autistic researchers researching autism, did you say, specifically, Patrick?

Then, there is just going to make sure it is not -- autism researchers the other one.

>> The one I posted is autistic researchers researching autism.   That's the one that you can at least see exists.   Autistic researchers autism, I don't think you can see.

>> You can see but it is private now.

>> You can?

>> I think one or both of them used to be secret.   Then, it might defeat the purpose.

>> Just reach out to us.   We'll help you out.

>> I'm also learning more about the difference between private and secret Facebook groups.   That's helpful.

Next slide, please.   I also wanted to just in another minute or two, if anybody has

any additional questions.   Please feel free to drop them in the chat.

I also wanted to highlight our upcoming webinar.   Our main webinar will be hosted by our neurology leader, Dr. Rujuta Wilson.   It will focus on the brain and body in motion, understanding and supporting motor function in autism.

If there are no other questions, then I want to thank everyone for attending today. As I said, the webinar has been recorded.   It will be archived on the AIR-P website. So you can view the recording there.

We'll also post the slides there as well.   Please take a few moments to complete our survey so we can learn more about what would be helpful to have for future webinars.

Don't hesitate to reach out if you have any additional questions or you want to connect with the AIR-P or with our autistic researchers review board, the AARB or if you have any questions about the millions of acronyms we have thrown at you during the webinar.

We are all very approachable and happy to help.
>> We have a question.
>> It looks like it.   Given that parents of young autistic children often learn terminology and perspective from within the medical model, do you find it helpful or necessary to introduce other models in beginning autism community collaborations?
>> I can just speak for what I participated in.

We sort of began our first orientation meeting by disclosing that we were going to be looking at these experiences through the lens of neurodiversity.

If anybody had any questions about what that meant, we were happy to show them.

I teach transition to adulthood.   In my class, we exclusively use a neurodiversity

lens, which is quite a cultural shift for many students.

I teach health sciences, not special education.   They are coming from a very medical model, speech pathologist, frequently special educators, hospitalists that are working with people in a hospital environment.

So we are in our own ways, I think, individually just sort of helping people to understand that at least they have options.

We always defer to the individual family or the person's choice of identity as we would any other minority identity status.

We do try to gently nudge them toward understanding the respect and dignity that comes from the neurodiversity lens that might, as a parent, it makes me feel more hopeful about my son's future.

And my future experience was as an autistic researcher.

>> I'll just add one more.   Completely disinterested, not at all about biased thing, because I may happen to be a co-author on this.

Heather Brown, who is another member of our Autistic Researcher Review Board, has an editorial forthcoming in autism on the topic of how diagnosticians can support a neurodiversity perspective from the start.

That gets the point of the parents of young autistic children and introducing them to other models.   Once that comes out, hopefully, in the next very near future, I think you would probably find that a very interesting read.

I am completely unbiased because I'm just a co-author, it is not like I have any incentive to promote this.

>> By the way, I did post the guide by the autistic self-advocacy network for parents of autistic kids, which is great if you want to look at an electronic copy or take the other versions.

Also, in the case of autistic people who are finding out they are autistic for the first time.   They are old enough.   There is an adolescent version, an adult version of the welcome to the autistic community guide.

There is an audio too, a video.   Welcome to the autistic community guides for autistic people.

>> We only have a minute or two left.   There was one other question that came in.   I wanted to see if you could answer.

Autistic adults have historically not been involved in early intervention research and development.   What important contributions do you think autistic adults can bring to this feel?   Can early intervention embrace this lens?   There was an article that was published that I will see if I can find.

I am not sure if anybody wants to answer that.   Autistic adults have historically not been involved in early intervention research.   What contributions do you think they can bring to this field?   Can early intervention embrace an early lens?

>> I would like to think so.

I am very actively trying to work on this.   Dena and Jackie and I are actually all part of this discussion group that's meeting regularly of autistic and nonautistic researchers to talk about these very broad and controversial subjects of early intervention.

There is also research that I would highly recommend that, again, I am collaborating on.   I have some vested interest here.

Rachel and Caitlyn, at the University of California Santa Barbara have done some research asking autistic adults about their perceptions of early intervention.

That will be presented in two different posters of the upcoming INSAR conference.

If you are interested in this topic and attending INSAR, I highly suggest you check

those out.   There are some very interesting findings.

It points towards some ways of performing these things in ways more acceptable to the community.

>> One of the things that I brought up to the committee, the informal group that we are having, is the idea of doing research on individuals who have had positive outcomes without any early intervention.

I am a parent of a 31-year-old man who was told by a major medical center he would never live independently.   He has a Bachelor's degree.

To be very personally blunt, we couldn't afford ABA.   We haven't even gun to examine those persons.   I think there is a big void in the literature there in looking at outcomes that were not necessarily benefited or affected by, if you will, early intervention.

We did a little bit of sensory work for a while.   That became too overwhelming. We did some early speech services.   What we really found out is underlying the autism, we had an individual who presented with very severe learning disabilities, processing issues.

Once we treated him like an individual with a learning disability, he was able to succeed academically.   I am interested to see if we might not be able to examine that other part of this dialogue a little bit more specifically.

>> It looks like we are at time.   I do just want to quickly point out that the amount of resources that have been shared in the chat in the last few minutes is phenomenon.   It gives me a lot of hope there is more information out there for the important topics.

I put the AIR-P e-mail in the chat.   So we have to end now.   If anybody wants to continue this conversation further, please don't hesitate to reach out.

We are here and happy to communicate and collaborate.

We encourage any of you who are interested to reach out to us.

Thank you, everyone, very, very much more attending the webinar today.

Thank you very much to all of our presenters for our autistic researchers review board.

>> Take care, everybody.   Bye.

[The webinar concluded at about 5:30 p.m.]