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MADELINE HALEY:

Hi, everyone! Good afternoon. I will give it a minute or two for people to start popping in and I will go ahead and introduce our speaker.

Alright. I think people will be kind of phasing in and out. I will go ahead and get started.

Good afternoon, everybody. My name is Madeleine Haley and I would like to welcome you to the Autism Intervention Research network on physical health, the AIR-P July 2022 webinar.

Thank you for joining us today. Because of the number of participants, your audio will be muted throughout the call but you can submit questions at any point in the chat or in the Q&A function.

So, I will – just a friendly reminder, please be respectful when communicating in the chat and asking questions. Please note questions or comments pertaining to the presentation will be addressed.

The webinar is being recorded and will be available on the AIR-P website which I will put in the chat.

I think Dana, if you do not mind putting that link to share with everyone, I think I have it was only hosts and panelists.

You can also view the presenters slides to follow the presentation in our Google Drive. Which I will also put in the chat, right now.

There will be a short evaluation survey at the close of the webinar which we invite you to complete to provide feedback on this webinar and suggestions for future webinars. Let's go ahead and get started.

We first want to acknowledge the health resources and services Administration as the funding source for the AIR-P, and it is my honour to introduce our presenter for today, probably needs no introduction, but Doctor Dora Raymaker is a Research Associate Professor at the Portland State University Regional Research Institute for Human Services in the School of Social Work, and the Co-Director of the academic autism spectrum partnership and research and education, AASPIRE.

And the associate editor of 'Autism in Adulthood'. I will let you take it away.

DR DORA RAYMAKER:

Thank you for inviting me. This is enormous treat for me because system science is my favourite thing in the world, it has been my special interest since before I had a name, and I am so glad to talk to you today about systems stuff.

I am at Portland State University's regional research Institute. I am research faculty. I am an alumni of PSU's system science program and codirector of AASPIRE and I initially came in from the community side.

I'm also autistic and part of community. I have a foot in all the worlds. My research interests are community engaged research and practice, systems thinking, measurement, and all of the really messy dynamics at the intersection of science, society, and technology.

In application, what I'm most interested in right now is how to improve employment outcomes for autistic adults and extending anti-ableist and neurodiversity practices in research, and in the world.

In general, I'm all about science for social change.

Today, first I will lay out some basic systems concepts. I will give you a really, really small taste of some methods that could be useful to you in your work.

Then I'm going to talk about leverage and intervention, how do we find places to intervene in a system that might have the most impact?

A really short wrapup, and we will have a discussion. I have about 40 minutes of talking. I think we should have 15 minutes of discussion at the end.

Some basic systems concepts – what do I mean when I talk about a system?

The simple answer is a system is a set of parts that relate to each other, such that they create a whole that have relation to the environmental that could have open or closed boundaries.

With open boundaries, things outside of the system can influence it, and with a closed boundary, it is self-contained and nothing goes in or out.

Today I will be talking about a particular type of a system which is complex systems. What is that?

A complex system is a system that has such complicated interrelationships between those parts, that it's not possible to effectively predict its behaviour. Or to understand it by examining its parts.

Complex systems have some properties that make them hard to understand such as nonlinearity and feedback. The part in the system often influence each other simultaneously.

Irreversibility, you cannot unspill the milk. Emergence and self organization. One of the classic examples is ant trails. If you look at individual ants, you have no clue they can create a thing called an ant trail, it is an emergent property and self organization of the individual level that's hard to see how it works.

They are adaptive, if you make a change to the system, it will often change its behaviour in response

to that. They have tipping points.

Those are places where the entire behaviour of the system completely changes.

So, an example we have seen with that has been throughout the pandemic, every time in the graphs you see a S shape are inflection points where the behaviour of system has changed from going down to up, or up to down.

There are many challenges in working towards intervention in complex systems. Particularly, if you cannot predict the behaviour of the whole look by examining its parts, or their individual relationships, how can you understand it?

If you cannot understand it, how can you actually intervene in it to change its behaviour?

What we need here instead is a holistic or non-reductionist approach to problem solving. In other words, we need to think systemically, and in whole systems, even if that might be due to the massive complexity, giving up the goal of trying to control it.

Just a side note – this is distinct from thinking systematically which is also useful, outside of the scope of this talk.

This is a quote by Donella Meadows was an important systems thinker and I love her work because it's very accessible and very poetic.

Throughout the slides, I put in links to things and citations so if you want to look up any of these sources, you should be able to get them from the slides.

This comes from her 'Dancing with Systems' and she says, "We cannot impose our will upon a system. We can listen to what the system tells us come and discover how its properties and our values can work together to bring forth something much better than could ever be produced by our will alone.

We cannot control systems, or figure them out. But we can dance with them."

Systems thinking, systems science gives us some clues as to how we might dance with these systems.

I will bring this down into the concrete now. I will talk about issues of complexity in autism employment intervention research, which many of you may be aware of these things, but it's very – it's a messy real-world setting.

There is no employment laboratory, employment is something, by definition, you do in the real world.

There is a huge amount of heterogeneity of autism characteristics, of autistic people, we are people. (Laughs) We are all of the things people are.

Of workplace cultures, of job fields, of particular jobs inside of those fields, all of that. There is a huge interrelatedness between employees, employers, supports, and services, they are all influencing each other at once.

There is also an influence of public perception, public policy, attitudes towards autism, things that might be in the environments that are also influencing because it's an open system.

There are also complicated intersections between autism and other marginalized identities. People might be facing discrimination based on race, or gender.

There is the fast unpredictability in people's own lives or the lives of their employers where people have perfect job, and it goes out of business, unpredictability in the broader economic environment.

I have seen reductionist or traditional approaches to employment research and I try to deal by simplifying. One thing I see a lot is narrowing demographics.

Job types, job settings. We might talk about transition age, youth in a particular high school program, going into entry-level jobs.

Or he might talk about Intel, the company can and working there. Restricting into certain types of autism characteristics.

I have seen attempts to simplify by focusing on the autism person by focusing on the intervention. It's a lower hanging fruit to intervene in our lives than it is to intervene in a business or a company.

Assuming limiting outcomes to those that can be measured more easily. The outcome is: did you get a job and did you stay in it for three months, as opposed to looking at bigger picture, more systemic things like, "Are you happy at your job? Is it a good fit? Do you have good worklife balance?"

I see a lot of ignoring or assuming stable environment or context, or ignoring some real-world application and dynamics over time.

This example I will pick on this example a little bit a bit as we go on in the talk. Will teaching someone how to behave in a neuro-typical matter in a human resources interview have any positive impact? Or no negative impact on that person's ability to be successful in their job or the future of their career?

Another way of saying that is, is the typical human resources interview actually a point of leverage?

So, what is leverage? Leverage is a place to intervene in a system. Going back to Meadows, they say, "Places within a complex system where a small shift in one thing can produce big changes in everything else."

Another way to think about this is if we understand how the structure of system is generating its

behaviour, that gives us clues as to how we might be able to change that structure in order to change the behaviour.

Getting more effective, and acceptable interventions, for less effort.

And also, maybe even a better understanding of what outcomes to target in the first place. Because from a holistic perspective, did you get a job – that might not actually be the right outcome to look at.

How do you do that? There are many, many ways, system science is a big field, systems thinking has a lot of tools. I will give you a small taste of a couple of approaches and a couple of specific tools that might be immediately more useful.

So, systems thinking is an approach to inquiry. It can be contrasted with the typical reductionist approach that is pretty much the dominant way of approaching science and inquiry.

It's a holistic, non-reductionist approach. It focuses on the relationships of parts, and the feedback between them, over sometimes long, because it can take a while for all of those tipping points to tip and all of those inflection points to happen.

Instead of looking at the component parts in isolation.

It includes consideration of the environment, it is inherently transdisciplinary. If you are talking about employment, you are not just talking about an educational intervention, you are talking about occupational psychology, you might be talking about the field in which the employment is, in the first place.

It assumes there are many potential solutions to complex problems. You are not looking for one answer – you are looking for something that works, it's very pragmatic.

The drawing is from (Unknown Name) subsystems methodology, it's a very useful tool. I have a student of mine who calls these people as starfish people and I kind of like the starfish people rather a lot.

Here's a starfish person and they are perceiving it as a big, interrelated messy pile and saying, "I spy complexity and confusion, but I can organize exploration of it as a learning system."

In order to do systems thinking you have to start getting good at thinking in multiple perspectives and multiple layers. Multiple perspectives is every type of perspective.

It could be stakeholder perspectives, it could also be the perspectives of multiple disciplines, it could be multiple worldview perspectives, because even if it's a worldview that you are not going to privilege in your work, it's important to know it's there because it's part of the larger system.

Different priorities. There might be different reasons for wanting to do things. Being able to see all of

those at once is part of that holistic thinking.

There's also the system layers. There's an idea of, there's a system you are looking at, and above it, there is a supra-system or meta system and below that there is a sub-system.

Going back, we've got more starfish people here. I like this drawing a lot.

It shows both the multiple perspectives of observers, and those layers of the systems. They talk about it in terms of the why, what, and how.

For observer number one who might be a realtor, the supra-system, their why is achieving a higher price for the property. They are working on improving the appearance of the property, that's why. They are doing that by painting the house.

To observer number two, who might be the house painter, there supra-system is the system from the other person, the system they are concerned with and interested in is the paint in the house and how they will do that is one of the subsystems is by hand painting.

Systems thinking also deals with this idea of generative causality. In traditional reductionist approach as we think of causation as does X lead to Y, in general causation we ask a different question entirely of: what about X leads to Y?

This centres the dynamics, the structure, and the whole. Correlation and association start to lose your typical importance.

So, why? Why do we care? Again, if structure generates behaviour, then understanding the structure teaches us something about how to modify the behaviour, in other words, we are getting that leverage.

So, this is a big approach. Here is a concrete tool. With causal loop diagrams. They are a means to identify and map these causal structures.

They can provide a lot of insight into the behaviour of your system. And into the leverage, including if it fits a known pattern. There is some system structures we actually – they come up again and again. People have identified where the leverage fits into them.

They can help communicate and articulate complex, nonlinear feedback systems. Very cool – this process of making causal loop diagrams has been adapted for use with stakeholder groups, who have no formal systems training.

Your keyword to look up there is "Group model building" and another keyword, if you are interested, this comes from system dynamics.

So, causal loop diagrams have a formal language. They have variables written in text. Those are the

parts of the system that change.

They have causal links which are lines that connect and make a relationship between the variables, and heavy direction of influence.

They have a polarity. Do they reinforce or balance, as this gets bigger, this also gets bigger. And vice versa. Or balancing if this gets bigger, then this get smaller, and vice versa.

They joined variables. There may be delays which are broken into boxes and the influence of one to another is not immediately felt.

They have loop identifiers which synthesizes what that causal loop is about with name, direction, and a polarity. You can see if it's reinforced, there's more balancing.

Here's an example from an autistic burnout study. This comes from interviews, Internet sources can and our expertise.

At one point, I was playing with burnout and causal loop diagrams. This is the way to read this. You pick a place. I will start first with the resource drain at loop and I will start with resources to mask autistic traits, the more resources you have to mask your autistic traits, the more people will give you social and financial rewards for behaving typically.

The more there will be expectations put on you to behave in that manner. The more you will have to continue to mask. The more you continue to mask, the more tired you get. The more tired you get, the less energy you have. The less energy you have, the less resources you have to mask your autistic traits.

That is the resource drain a loop which is a balancing loop – oops. Sorry. I am a little twitchy on the keyboard sometimes.

That's a balancing loop and that's the resource drain. This also has this little loop which is a reinforcing positive loop called the runaway pressure loop.

I will read this starting with expectations – as expectations increase, the need to mask your trades increases. As you are masking, the expectations also increase.

What we are talking about here is a reinforcing feedback that is an exponential curve. Because these two loops operate together, not alone, you end up with a behaviour that is the growth and collapse type of behaviour where it goes up until it runs out of energy, and crashes.

The system will grow faster than the available resources can keep up.

OK. I want you to put a pin in that because I will come back to it. I will switch gears a little bit to another big holistic approach which is action research.

Again, it comes out of the systems field. Though, it has become very big. It was an approach to inquiry that began with Lewin in the 1940s.

Today, there are many, many ways of doing action -- research but they have the same core idea, the subjects of the research are also the co-researchers. It places the subjects of the intervention inside the system of inquiry it says, "OK, you are part of this, too."

It is research for the purpose of making wanted and positive change, that is, research for the purpose of action.

It's also a means to include stakeholder perspectives that might otherwise be marginalized. Especially for emancipatory branches that were explicitly designed to shift power.

Pausing a moment for shifting power. After giving explanations to a class, the students came back and said, "Take away message is, do not ever do systems work alone..." (Laughs) I thought that was a good insight. Multiple perspectives are really required, in my opinion.

Do not do it alone is a great motto because if you're not looking at all those perspectives you will miss out on some of the parts that could be crucial to the behaviour you are looking at.

Part of that is considering whose knowledge is being legitimized, and whose is not.

In the knowledge power loop, those who have knowledge have the power to then define what knowledge is.

These emancipatory approaches to action research are really about breaking that up and changing that, and say, "OK, we will give other people knowledge and power." What is that going to do? How is that going to disrupt the way we do research?

In knowledge power feedbacks, they are part of what research questions we may ask. How we design research, whose knowledge is considered legitimate, who the research participants are, and whose data is captured, how the findings are interpreted and framed during dissemination.

You bring in community, and what's going on inside of that has the potential to change.

There is a lot of continuum to engagement and action research. I do community based participatory research. It is by far not the only way.

You can think about the continuum of depth of engagement from advising to community leadership, frequency of engagement, will you just meet with your community person once or are they part of everything?

Leadership engagement, is it directed by the academics, or the community? Some collaboration?



Team engagement, what is your balance of academics to community? There's a whole continuum of that.

There are other dimensions, but these are some to think about. All are good – pick what is going to suit your project and be very, very, very transparent about it, both to and any community partners you have, and to the world.

Here's my example: I do community-based participatory research, and it's an emancipatory approach developed in public health. It has a set of very formalized principles.

Community members are considered a co-researcher at every phase of the research process. Lived experience and community knowledge is valued on the same level as academic expertise.

That's part of busting out that knowledge power loop. Giving other people knowledge and power, privileging different types of knowledge. At AASPIRE, we use community directed research priorities can all the research we do is something the autistic community has said we want.

This is just my slide because I love my team and I'm incredibly proud of them. This is a little picture. It does not diminish my love anymore.

We have been working for 16 years, we have a lot of different perspectives, while mostly we have autistic people, we also include academic researchers, family members, healthcare providers, disability service professionals, people who have specific expertise or lived experience in the areas we research.

Last tool – that was a big approach. Here is a specific tool. This is critical system heuristics and it is a set of questions for stakeholder groups to use in order to think critically about what they are doing, why, and who has the power.

You could use this with an action research team or use it with stakeholders, it's not connected to anything specific.

In this method, stakeholders answer from their own perspectives. It's really good at exposing things that might otherwise have been marginalized or unsaid, untroubled.

It's good at revealing and examining the worldviews of people who are involved in your project, or intervention. Which often, people do not examine their mental models, or share them with each other.

For example – it might help you with, do the potential recipients who have a proposed intervention, do they feel the same way about it as the scientists who designed it?

There are boundary issues. Motivation, what is the impetus for doing this thing? What does it come from? Power, who has control over it, and how?

Knowledge, whose expertise and experience is feeding into this? Legitimacy, what is being centred, and what is being legitimized?

It has these three boundary categories which are stakeholder, concern, and difficulty. For each boundary issue, there is a perspective under the boundary category.

For the boundary category of stakeholder, the motivation comes from the client, the power comes from the decision-maker, the knowledge comes from the professional, and the legitimacy comes from the witness.

And that is turned into 12 questions. So, that is one for each of the four boundary issues, and three for the three different perspectives.

I have put a link in here to where you can find more information and find these questions.

I have not had the chance to use this in my research yet. I have just run through it in some scenarios. I was pretty impressed with how it actually does elicit worldviews and mental models, and put a lot of things on the table that might have previously gotten missed.

In the literature around this, you can also see how it's been used to bring forth thinking critically about things that have been previously marginalized or silenced.

OK. The last big block here that I'm going to talk about is... intervention and leverage. How can we use this, these holistic strategies, how do we use systems thinking to actually find leverage and make effective interventions?

Just a reminder, Meadows slide again, leverage points are places to intervene in a system, there are the places in a complex system where a small shift in one thing can produce big changes in everything.

Because I love Meadows and this link here will take you to this rich picture.

So, these are points of leverage that Meadows has defined, and this rich picture is great because it really shows how not all leverage is the same.

So, we've got the system on one side of the (Unknown Name), and on the other, we have the things we can do as an intervention.

Really close to this where you have to do a huge amount of work in order to move that lever, we've got things like changing your parameters, your buffer sizes, the materials that go into something.

A little further out we've got all of our feedback loops. And our dynamics. So, if you change the way things flow through those dynamics, you might not have to do quite as much work to shift that system.

It's still a fair amount of effort.

Further out, if you start actually changing the structure of the system, if you change the way it's built, you have leveraged to build that system. That is looking at changing the rules, the structure, and goals.

All the way out at the end of this, consciousness and mental models. If we change the entire paradigm, that is going to really, really shift the system.

Of course, as we all know, paradigm changes are pretty hard. Things get more difficult the further you get up this. But also, the more impact you potentially have.

I told you to put a pin in the burnout causal loop diagram. Here is an example of identifying possible leverage, first at the physical events level.

Here, I want to look at the runaway pressure loop. I mean – when you work hard, you expend energy and get tired, and there are some things that are harder to move than others.

The runaway pressure loop is one that might have a chance of getting intervened again.

So, I want to first look at an idea of changing a physical loop or that buffer level. I'm looking at expectations. These are the expectations somebody continues to behave in a neuro-typical manner.

-- Thinking about what happens if we put a constraint on that and reducing those expectations. Maybe we want to bring in our interventions to bring some limiting variable that comes in from the outside that says, "We will not put quite as much pressure on the expectations to do this masking."

Indeed, we did find that people in our study talked about that as a way of relieving some of their -- autistic burnout. There was this theme of reduced load for people talked about breaks, social withdrawal, reduced activity, mostly as ways to reduce or mitigate their burnout once it had started.

It was definitely there. I'm not convinced there is a whole lot of really strong leverage especially because you have to get pretty tired for you get to this point.

I want instead move up a level to look at some of these systems structures changes. What if we change the rules of this system? I'm looking here at masking autistic traits. What if we do not do that? (Laughs) What if we do not ask people to mask?

What does that do to this entire system? Does that maybe collapse it and make it no longer a thing that, you know, it breaks up the whole system?

So, we had asked people to talk about what they thought might actually prevent burnout in the first place. That was one of the big things they actually said was, "Being autistic, not masking helps." Attending, unmasking, using this, one person said, "The biggest thing of all you can do to prevent

burnout is to start identifying what you do when you mask, and stop."

Even little things like eye contact which many of us do, or pretend to do this, to allow yourself to not be sociable if you do not want to be.

Switching my example to employment, this is not a causal loop diagram, this is a dump of research findings.

In the middle here, these are all the things in our employment interviews which were 45 autistic people with skilled training, 12 supervisors... disability services professionals, and some experts in various system-level things.

This is kind of what they told us about, first of all, what does success actually mean? Not just getting a job, all of these other things. Good worklife balance, sense of workplace community, feeling valued, and around here are a bunch of things that we learn from people are what led to those types of successes.

So, I want to concentrate – I told you I was going to pick on that interview example. I want to concentrate on flexible hiring and job crafting, because none of our 45 autistic employees, the majority of whom had what they considered to be "Successful skilled employment" said that acting normal in a job interview got them their success.

In fact, they told us their success hinged on flexible hiring and doing things that bypassed all of those traditional human resources interviews.

For example, they talked about skills demonstrations and about getting jobs based on internships, or on networking, they talked about getting an entry-level job, showing how good they were, and being hired because they were amazing.

They talked about fitting niches and everything besides a regular HR process, as what led to their successful employment.

When we talk about the goals of the system, what about instead of saying, "The goal is to behave in a neuro-typical white in a certain human resources interview," if we are looking at this holistically, increases the masking variable in the burnout system.

That entire burnout system was an offshoot of the employment study because people talked about that happening.

What if we change the goal of the system from that to having more flexible and unconventional HR hiring processes? What if the goal is actually to allow things like skills demonstrations?

Or what if we change the goal to increasing the number of supervisors and hiring managers to understand autism? So, if you do end up in a typical HR interview, not having eye contact or needing

clarification on questions is not going to cost to the job.

Or what if we change the goal even one step further and approach a paradigm shift of: what if we create neurodiversity friendly workplace environments?

Have not had a chance to create any of these interventions yet.

When I first got my Masters, the first thing I did was went out to change the world, as one does, right? (Laughs) This is my example of identifying leverage at that consciousness mental models paradigm shift level.

So, this is not a causal loop diagram but it is a diagram of dynamics. This is my map of traditional science and how there's a pretty strong relationship between science and society where science gives society its three findings, society has values, priorities, funding priorities of mainstream culture that feeds back into what science gets funded. That loop continues.

There is a pretty strong relationship between society and community, where society pushes its values, policy, public perception, and funding onto the community, the links elsewhere are pretty weak.

We give raw data to scientists to make interventions on us but that is about it. We try to advocate for change, but we do not have any legitimacy.

So, when I asked was: could community-based participatory research, could the change in systems by changing the approach to inquiry, actually change the structure of the system enough to start shifting paradigms?

And this is my picture of what I feel community based participatory research actually does is it strengthens that feedback loop between science and the community.

The community is also, in addition to data, giving its cultural expertise, its resources, its insights, values, priorities, all of its perspectives, its worldviews.

Science is giving the community not just interventions, but research findings, academic resources, credibility, legitimacy, so when the community goes to advocate to society, that link gets strengthened and our perspective, and our priorities might actually start shifting things.

So, did it work? Did it change? Anything.

This is leverage with the mental models and the goal here was a neurodiversity paradigm shift.

I absolutely cannot take full credit for any of this. It is a complex system. The whole community has been working towards this for close to two decades now, or more.

But I do know that AASPIRE and our work, and community based participatory research has had a

role in some of these things.

There has been a big policy change toward anti-ablest language in major autism journals and literature, and there is an article I have linked to here, including autism in adulthood which is the journal I'm associated with, we have autistic community members who are not academics who do every single article.

There has been a huge change in areas of focus of research, there has been a large explosion around research unmasking which is fantastic, and never would've happened without some of this push of community priorities into the scientific process.

We have research and policy, the Interagency Autism Coordinating Committee which is the federal government's body that sets priorities for federal autism funding, now they have a lot of autistic presence on it.

INSAR, the large autism research conference has an autism research committee now. 'Autism in Adulthood', we have inclusion there.

Inclusive research has exploded. In 2006, it was really just as, as far as I know. I know there are dozens of autistic academic collaborations, internationally.

We've had some wins recently on shifts towards autism acceptance, and I see AIR-P as an example of how these paradigm shifts have had influence.

Five years ago, I do not think neurodiversity was being taken seriously, not enough for AIR-P to exist. There is an example of leverage in paradigm shifts all the way out at the heavy leverage end of Meadows.

Just a quick wrapup and we can have discussion. So, these are some take away points.

Complex systems like autism services are difficult, or impossible to understand, predict, or control, particularly using traditional reductionist approaches.

Luckily, we have systems thinking which is a holistic, non-reductionist approach to inquiry, that can help you understand the structure, behaviour, and intervention points of complex systems, and it comes with hundred years of frameworks, methods, and tools, and ways you can actually perceive the holistic inquiry.

Including things like action research, which helps to include stakeholders inside the system of inquiry itself.

Finally, the closer you get to a paradigm shift, the more leverage you will have. So... with that, I want to say thank you all for showing up and listening to me talk about my favourite things.

Also, thank you to the AASPIRE team and our research participants who shared everything with us that went into the little brief and some of our work I talked about.

A plug for the journal, consider submitting. We take articles from anybody.

My contact information, and I have a newsletter. It's usually monthly. You will have to put up with me putting in, you know, reviews and things from my novels.

I also put in updates on AASPIRE's research, studies, findings, recruitment, publications, etc.

If you want to keep up with the work that AASPIRE is doing, that is a good place to subscribe. We are a little spotty with our social media. But I've been good at keeping up with the newsletter.

So, I will now end there. We can have a discussion. Madeleine, could you let me know? Should I unshare my screen? Is there anything you would like me to do?

MADELINE HALEY:

I think you can keep the screen up for now. If anybody has any preference in closing out the screen, please go ahead and let us know in the chat. I think it should be OK.

Thank you! That was such an amazing presentation. I have so many questions and I'm trying to digest and process everything.

We do not have any questions yet, but please feel free to submit anything, or I do not know, if you have any questions or discussion points that you would want to maybe have us think about, yeah. This was amazing.

DR DORA RAYMAKER:

What I would say is I know there's a call to always keep the questions to the topic of the presentation. Systems and this, if you want to ask me questions about any of AASPIRE's work, or I do not know, you can ask me anything really. (Laughs)

I might not answer everything, but you can ask me anything.

MADELINE HALEY:

Thank you. I did see there was a question – can you elaborate more on unmasking?

DR DORA RAYMAKER:

So, masking is the idea of you are hiding your autistic traits. Well, it is hiding anything. Everybody masks.

In fact, if you are talking about burnout, there's been a lot of research done into burnout in healthcare professions.

Masking – healthcare providers, you know, they deal with a lot of human suffering. Then they have to go out and talk to families and do things where they put their own emotions, they cannot show their own emotions. So, they mask.

It's been found that masking in healthcare providers is a mediator for mental health problems, and suicidality.

Masking is not exclusive to autism. It's the general idea of hiding your true anything.

In this context, we are talking about masking autisticness. That could be – it could be very concrete, like, sitting on your hands so you do not wave them around.

It could also be things that are a little bit harder to see... sorry, had an idea in my head and it was gone.

It's really kind of pretending to be something you are not or feeling something you're not. You could be very uncomfortable by sounds, but pretending like you are unaffected.

And unmasking is the idea of like, basically not doing that. (Laughs) So... if you need to do this, do this. (Laughs) You know?

If eye contact is taking an enormous amount of effort for you, stop doing it. I remember what my example was! It's actually how you do things.

Sometimes the autistic way of doing a thing is not the way that somebody wants you to do it. Take a math problem and people want you to follow a certain algorithm, or certain steps.

You might have somebody those steps really do not even make any sense because they are doing math in some kind of synesthetic landscape.

I would often solve my math problems my way and go back. And do them painstakingly in the way the teacher wanted so I knew my answer was right, but... was pretending I was doing it in a way I was not, and people talking about doing that. The all do things in neuro-typical ways because they are being watched.

That was a very long answer but unmasking is the idea of taking off the pretend and just being the real.

MADELINE HALEY:

Thank you! I love the math example. As somebody who also had to do things my own way in math and had to change my way to show the teacher the correct way, I can definitely identify with that. That was a good example.

We have some questions in the Q&A and I will go ahead and read them out loud.



How can existing ongoing research grants integrate participatory methods? A good question.

DR DORA RAYMAKER:

Participatory methods are probably a little bit easier than talking about integrating holistic system science approaches.

You are a little lucky because at this point in time, participatory methods are used very broadly. Not with autism, not with disability, that's still in a very early stage. It's been used with communities of colour and communities based in specific geographies, those things for a long, long time.

I would say, just include them. The CBPR police exists – I am the CBPR police. So, the advice I would give you, which I also said in the talk, is to be very transparent.

Do not claim to be doing a participatory method you are not 100% doing. If you are doing something else, just explain to something else you are doing and say it's based on, or a type of participatory action research.

Yeah. Just be very careful that you are being transparent about what you are doing.

One thing you will have to be, or two things to be aware of, one is that it will take a lot more time than you think if you do not have a participatory group you are working with.

So, building trust and figuring out how you work best together, and teaching, teaching or community partners enough about science so they can participate in them teaching you about the community, so you are not constantly sticking your foot in it. (Laughs)

That all takes a long time. If you are starting a new group, be sure to build in time because the CBPR police will look at it and say, "This is not feasible," in a timeline sense.

The other thing is it will also cost you some budget. So, compensating your community partners, making sure there is enough money for reasonable accommodations, you might want to make sure you have enough money for CART captioners, ASL interpreters, or anything you might need.

And accommodations also take time and you might have accommodations that is – meetings have to go slower.

When you are crafting your grant, be sure to build in time and money that actually supports the true inclusion of your community partners. As far as the approach and the methods, there's a lot out there at this point. A lot of resources, a lot of precedence, the NIH even has their own study sections, and sections of the NIH that are concerned, specifically with community engaged research.

MADELINE HALEY:

Thank you. Alright. Next question... another good question of thank you for the presentation, can you

please share how you ensure quality cooperation with autistic individuals with different levels of cognitive abilities and communication needs?

DR DORA RAYMAKER:

So... we just kind of do it all, I guess. (Laughs)

So, we send out materials for our team meetings two weeks in advance. The materials consist of, you know, the slides so people can prepare. There's also a big background of information that has tons of details for people who are like that.

There is an easy read version we make of everything. We have an accessible version of all the prep materials.

We offer a pre-meeting. So, people can come in an hour early and go over everything. With our community lead and project coordinator to make sure they understand it and what's going on.

Our meetings, we do all the accessibility things and run them with... we've always been remote, it's not new to us. We've had a while to work out the stuff.

We've got people and everybody's in the meeting and -- we use the text feature as an accommodation so if you do not speak or do not want to speak, you can participate in the chat.

If you do not read, write, or do not want to reiterate, you can participate verbally. We have somebody in the meeting who takes care of making sure that the conversation threads get merged. It's hard I'm not going to lie, it's hard.

We provide CART services pretty much always. Any accommodations we might need, ASL, we also have a team member who is blind and we also provide screen reader friendly versions of everything.

Really, it's about thinking about accessibility. I could go on. We have some papers and some resources on AASPIRE.org, there is an inclusion section which has some resources that you can go to.

I would think about it less from the perspective of like, "How do I integrate all of these different things?" Think more like, "OK, accessibility. What do we do to make things accessible for people?"

Also, ask your people. Do not assume. We do a lot of asking people like, when they first come on, what accommodations do you need in order to do this? Do a check in and leave the door open because sometimes once you get into the work, you realize, "I need this other thing." It's a continuous process, as well.

So yes – do all the things!

(Multiple speakers)

Did I mention the time and money thing? (Laughs)

MADELINE HALEY:

I think Zoom comes with its own set of challenges but there is a silver lining in that there is a built in chat feature that accommodates a lot of different communication styles, and that's something that AIR-P has taken advantage of, as well.

DR DORA RAYMAKER:

If you cannot afford CART, as our deaf community members call them the 'craptions', they are not great but not terrible either.

MADELINE HALEY:

Sometimes there is a hilarious typo, but usually it can get the general gist of the conversation. We are at the hour – is it OK if we ask one more question?

DR DORA RAYMAKER:

Sure.

MADELINE HALEY:

If you do not mind putting Dora's email in the chat for the participants that want to reach out with these questions.

The question that I see is – as a fellow systems researcher in an academic setting, I find this work to be fulfilling, it does take more to move to publications. Do you have any tips or recommendations on how to maintain a publication record when working on these messy but impactful systems issues?

DR DORA RAYMAKER:

I do not know I do. I'm not the most prolific person in the world, either.

One of the reasons why I wanted to give this talk – I actually have been a little bit more in kind of mainstream dominant research approaches, because it was easier. You know?

It's easier to get funding when you take the complexity out.

I'm trying really hard to push back on that and say, "No, we need this."

I do not have any brilliant advice because at this point, have not had a huge amount of success. I am stealthing my system stuff.

Anytime I explain it, (Indiscernible) that is one of the biggest challenges we have as systems practitioners is to find a way to explain this to people who are very, very entrenched in reductionist approaches, and in a reductionist world.

Fortunately, public health is a bit more open. One thing that I would just that I'm currently exploring and thinking about is thinking less about autism research and more about public health research, and can we wiggle in a little bit there?

Back to publications, I do not know the publications take any more time than anything. Finding a home for the publication... that might be a little more of a challenge.

I think we do have good options. Autism has options, 'Autism in Adulthood', I think there are journals that are more open to holistic things.

So, I guess I would say my biggest tip is to find journals that do interdisciplinary, transdisciplinary systems focused work, public-health work. So you're not having to revise papers and resubmit them to many places that do not and cannot handle the idea of systems at all.

Otherwise, it just comes down to paper writing skills. I do not feel like they are anymore different. (Laughs) Sorry. That was a bit of a disappointing thing.

I mean, writing takes a while.

I guess I will offer this if it's at all helpful. I try to – before I start writing, I think about what the core of my paper is. Like, what is it that actually care about communicating?

If somebody walks away from this paper with only one they learned from it, what is that? And I'm mentioning that because it can help me reduce the complexity of just what needs to be communicated. And like, "OK, everything needs to be in service of this."

Even though there's a million things in this messy thing and they are all equally important, I will centre that as a way to self organize all the bigger systems I want.

MADELINE HALEY:

Yeah. Thank you, Dora. I think that's probably all the questions we will have to take. Again, Dora's email is in the chat, if you want to reach out with questions.

If you don't mind going to the next slide...

(Multiple speakers)

DR DORA RAYMAKER:

I forgot there were other slides.

MADELINE HALEY:

Here is our contact information and a feedback survey that we ask you to complete. I will also put that link to the survey in the chat.

...

So, here's our social media information. I will give you a minute to process that. Next slide, please.

Here is the information for next month's webinar! Kind of a little more of talking about CBPR, we have Lisa and Maria who are from Kaiser Permanente and known leaders in the gender, sexuality, and reproductive health for AIR-P and they will be presenting on involving community partners in autism research.

The link is also in there for registration and also the survey for feedback for this webinar. So, there is that information. And I think that's everything.

Thank you so much again, Dora. Thank you all for attending. Have a great rest of your afternoon and we will hopefully see you next month. Thanks!

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