

Podcast Part 1: Barriers to Participation in Research in Historically Underrepresented Groups.

F: My name is Dr. Fakhri Shafai I and I am the research and evaluation project coordinator for AIDE Canada.

N: And my name is Nick Denomey I am a second year master's student at the University of Alberta.

J: Hi everyone, my name is Jessica Baraskewich and I'm a PhD candidate in the School and Applied Child Psychology program at the University of Calgary.

L: Hi everyone, I'm Laurel Ryan I have a master's in fine arts and dance history and criticism which is not why I'm here but I am a student in the family engaged research course and I have a grown son who has autism, intellectual disability, mood disorder. tic disorder etc. and that's how I got involved in pediatric clinical research.

F: OK so we're here today to talk about diversity in research and I think it's important that we start with the fact that most research that is conducted in the world is on quote unquote WEIRD people and WEIRD is an acronym that stands for White, Educated, Industrialized, Rich, Democratic nations. So the vast majority of the research in the world that's been published has been on white people from wealthy areas - so now we're going to talk about how do we make it more diverse? We each decided to take on one type of diversity and really delve into why that particular group of people does not engage as much with research.

L: Even within WEIRD we find that it's predominantly - especially in pediatric clinical health research - we find that it's mostly moms who are participating with their children. And I have a husband, who is the father of said child, and he was particularly interested in research and got me interested in research. This was about 25 years plus ago that my son was diagnosed and at the time there weren't a lot of dads who were involved in participating in all of the treatments and diagnosis and therapy appointments and this and that and the other. I think that that is continued but the role of fathers in child rearing even has changed during my lifetime, which is a long time. The role of fathers, you know, has changed I've seen it since the 60s fathers have recently in the last 30 years 40 years become more involved so there's a possible implicit bias for researchers of a certain age to not even think about fathers. As long as they get a parent it's all good. There are few studies that look at the wide swath of types of fathers and so even though many of them may fit into the WEIRD category, they still are not well represented in research published in the English speaking world. Yeah, so some of the barriers that fathers cite - there was one particularly well cited study that looked at 300 fathers and most of the fathers said that they just weren't asked. So particularly making sure that your research recruitment doesn't just say "parents" because 'cause there was a study down under that looked at, "Oh well if we say parents will be fine" but no, you absolutely need to personally - not personally -but definitely invite fathers as fathers to participate in the research. And many of the barriers also are that research studies may

require a lot of time and historically this is meant time off work for males as the major breadwinners and this is you know lots of assumptions but this is generally, maybe an assumption we might be able to make about the WEIRD demographic. And also that pediatric health visits, which is where a lot of people get introduced to research studies, are mostly - 3/4 of them they found - attended by the mother alone. So those are just some of the barriers and then if you start slicing and dicing groups of fathers into different ethnicities, kids who have fathers who are incarcerated, kids who have particular conditions, you know that's when you have added barriers to their (father's) participation.

N: Even though the Indigenous population makes up such a large amount of Canada's 30, 30-something million group, they are often not asked to be part of research. And there are several barriers that would result in not taking part in research and one of them is the history behind the relationship between the Indigenous people. And the Canadian population, and as many of you know, the Indigenous population has been mistreated for several centuries even farther back than that and there have been attempts towards reconciliation but a big part of being a participant in family engaged research is the value of trust. And this trust between the Indigenous population and the rest of Canada is not completely there - we're not quite there and it will take several generations to deserve their trust after how we have treated them in the past. So this is some major barrier in research with the Indigenous population that what we say may not necessarily be taken as with value because they may not actually believe that if we say we're going to pay them, they may not actually believe that or if we say that they're going to be an equal contributor to the to the project or what they say for the project is going to be taken with equal value, it may not actually be true and they might they may think of it as not being true and they may not actually believe it so this may result in them not even bothering because what they're told may not actually happen. And then lastly another barrier that comes up quite often in the literature is this misunderstanding of culture. The culture of the Indigenous people is such a framework in how they live and if we're not, and very often researchers don't have the time or resources or interest to take on the task of understanding this culture of people they are studying. And if you cannot take the time to understand the culture of the participants you may end up offending them - the language you use may be offensive or may result in them just not participating at all. And also, it's very interesting within the Indigenous population one culture in one Indigenous group may not be the same as someone else but you do need to take the time to work through all the cultures that you are working with, really do the research, get on their level and help try and understand where the barriers are so that you can get their valuable information within your research study.

F: My research was on barriers to family engaged research in recent immigrants, so newcomers to Canada, and what is it that's preventing them from being a part of these studies. And the ideas of trust and language and time all came up. So I will say that there wasn't a ton of research on this it was more about what is preventing them from accessing health care, but if you're not accessing health care then you're not going to access the research studies that are related to it so I had to narrow it down a bit, but one of the primary barriers to recent immigrants being part of research is just a lack of

knowledge and general confusion about how health services systems work in Canada. So some of the things cited were lengthy wait times and shortage of healthcare workers, especially those who speak the languages of the newcomers to Canada. And then also things like medication costs were all contributors to the struggle to be involved in health care in the 1st place, let alone research. Then there are the barriers that are specifically related to challenges with accessing services - even if you do know how the system works, so for instance access and money for transportation, dealing with weather extremes, language again, and then cultural differences are problematic for many newcomers to Canada. There was/is a general distrust of researchers who speak different languages and one of the studies I looked at said that even just speaking to researchers who are of different ethnicities was something that caused some anxiety and distrust in people who were interested in participating, but just they didn't trust the researcher. And so these were all barriers to family participation in research for newcomers to Canada.

J: Right, and the group that I'm focusing on is those who earn a lower income - so that might be people who are living in poverty or people who are receiving social support, groups that just generally are in a lower socioeconomic status. And I think something important to point out at this point is that this is a group that really intersects with all of the groups that we've identified so far. And I think as we continue our discussion on this we'll see the different ways that this kind of weaves into the different groups. But the barriers that I came across in the literature are really relevant to - I think - all of the groups that we've identified so far, but some of them are particularly true for those who do have a lower income. So one of the main barriers to participating in research is access. So families might lack awareness or don't know how to go about participating in research, and I think this is something that's likely even more true for when we talk about partnering in research. And then another barrier is time demands and scheduling conflicts. So meeting times are often in the evenings, but this is something that doesn't always work for low income families; we know that some low income adults combine part time jobs or they might work variable hours within each week, so that can be a big preventative factor for being able to plan beyond a few days and that can make it difficult for them to commit to participation in research. A, another barrier is participation concerns. So some people with low incomes have been found to either lack interest in participating or they don't feel that they need the help that the research study might offer. So that's a big thing in this group identified in the literature is denial of the need for help is one of the most common barriers to participating in research, along with other participation concerns like privacy concerns. And then lastly some demographic barriers - things like language and literacy demands can be a big barrier for participation. So if you have individuals who are unable to read or write or speak English they might be discouraged from engaging in the research. As well as the competing priorities that this group faces- so we know that they may have multiple jobs, different work priorities, they might have family members to take care of, all of these things that make it really difficult to participate or partner in research.

Podcast Part 2: Facilitators and Final Thoughts.

[F: My name is Dr. Fakhri Shafai I and I am the research and evaluation project coordinator for AIDE Canada.

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F: OK so we've been focusing a lot on the barriers but through our research we also looked at what are the facilitators? So how do we get over this issue, what has been done in this area already that has shown success for engaging families more in the research process?

L: Thanks Fakhri, I think some of the facilitators that were shown - and I should say, I didn't say earlier but I meant to say that when I talk about fathers I'm talking not just about hetero fathers or cisgender fathers, I'm talking about anyone who identifies as male who is involved in child care shall we say. So because 20% of same sex couples are involved or have children and I expect that number to grow. So I also tried to look - a little bit - what some of the barriers and facilitators were for those group. But facilitators, we're back on facilitators. So basically as other people have indicated, it should be broken down into you know who you're really after and specified so that you have specific strategies to encourage their participation. So broken down by race or ethnicity, fathers tend to self segregate, they like to go out with the guys - I think that's kind of a universal thing (I'm making sweeping assumptions of the kind one should never make) but some facilitators that were mentioned in the literature were finding opportunities for pediatric research in social services, in Barber shops, playgrounds, on public transportation, sporting events, father support groups on the Internet or in person when COVID is over. The brevity of the study was of great importance to fathers because they didn't want to be involved with something that was going to continuously interrupt their life. And so the credibility of the organization was also very important. And I think you know some of these things hit all of our groups but some of them, like the sporting events - I hadn't thought about that, Barber shops - I hadn't thought about that, father support groups - that seems to be a very good place. And I think sometimes you know we go to a quote unquote parent support group and sort of hope that that's going to have everybody but it doesn't necessarily.

N: Yeah thank you Laurel. Looking at the facilitators for engaging the Indigenous population in research, there were definitely quite a few. One of the main facilitators for

engagement was go to them, do not expect them to come to you. Because many people who identify as Indigenous live in remote areas and it's very difficult to access research opportunities when you live so far away and you may not have access to really good Wi-Fi and it may be very difficult to look up these research opportunities. So if you're doing research on Indigenous population it's always best to go to them and give them that opportunity, instead of waiting for them to come to you. Another facilitator was, and I mentioned this before as a bit as a barrier, one way to get around this issue of not knowing the language and the culture is to familiarize yourself with the language and the culture and make sure that any people you are working with feel welcome and respected in their role in the research. Thirdly, many forms of literature use a skill-based approach when defining the roles between the researchers and the participants, especially in a family engaged research. So you use a skill-based approach which means you take what the people are good at and you use them in the most appropriate way possible. So yes researchers may have more skills at say writing the manuscript, but your participants may be very interested and very, very quick readers so this is always a very, that that would be a very good opportunity for them to maybe support the completion of a literature review at the beginning of the article. Lastly one of the facilitators for engagement is to offer diverse opportunities for engagement. So very often there will be some form of compensation to increase the engagement with the population you are working with. But sometimes it doesn't always have to be a form of like a monetary value, it can always be you can offer these participants the option to present at a conference with the researchers, or go back to their community and present their findings say at their local community centre or at a church or something like that. And then of course the other one was to offer authorship to let everyone know and that they did the work and to help advertise that they were just as big, they played just as big the role as everyone else did.

F: Yes, through my research a lot of the themes that both Laurel and Nick have touched on so far are true also for recent immigrants to Canada. One study I read suggested that the number one motivator for immigrants to be part of studies is because they want to learn more about the topic itself, they want that information in a way that they can digest it, so in their language. And this was something that really surprised me that this wasn't taken into account. So for instance, one of the studies I looked at said "we wanted to engage older women where English is a second language and so we reached out and we found out that one of the barriers was that we had everything in English and our speakers only spoke English so once we brought in an interpreter then our recruiting got better." But it's a little surprising that that wasn't the consideration right from the beginning. Other studies did point out that simply advertising via posters even if they are in different languages in areas where they tend to congregate was not very successful for some of these studies. So even if you put a poster in a particular language in community centres or churches where people of that language tend to congregate, that wasn't as successful as word of mouth. So by word of mouth we mean individuals in the community saying, "hey you should be a part of this" and so that's where you really need to engage the community leaders. And I think Nick already touched on that with regards to the Indigenous population. So one group really advocated for what's called the 'snowball method' and so that's the method where you

connect with a key community leader and ask them for help. They'll usually identify some people they think would be interested in participating and the fact that it's a key community leader - for instance let's say a priest - really goes a long way to fostering trust. And once people participate and they find the involvement valuable and they know that oh I am actually getting paid, they followed through on their promise, then they're going to often share that study with their friends and your participant recruitment numbers will go up. Another facilitator that was brought up in the research was conducting the research either in the participants home or in a familiar setting like a community centre. So that really goes back to the point of go where they are that both Laurel and Nick brought up. Like you need to know where they are and you need to have facilitated trust and just like all of us, we are more comfortable in settings we've been to before. So if there's any way to adjust your research so they don't have to come to the lab, so they don't have to come to a new place, that's an effort that needs to be made and again one of the biggest facilitators was use of language interpreters right from the beginning - it really helps people feel more comfortable.

J: Right, and facilitators for lower income groups really overlap with many of the other groups that we've already mentioned. So one of the big themes for facilitators for this group is around making participation easier. So like everyone has said already, about providing transportation or avoiding the need for transportation entirely. Doing things like providing childcare, reducing the effort and costs on the participant's part. Also ensuring flexibility to account for the differences and fluctuations in ability to participate. And then another facilitator that I hadn't thought of is providing training and ongoing mentorship for new participants who might be uncomfortable or unfamiliar with the process. So we know that one of the biggest barriers for this group is a lack of awareness or engagement in the research, so they might not know how to go about partnering with researchers or even participating in research, so providing training and mentorship or even a go between so that they are more comfortable in that role. And then lastly similar to what Nick said around the role of incentives. So one of the big things is incentives. And for this group, financial incentives are particularly important but not the only kind. So there are also social incentives - so things like being part of a group or doing something for their community can be a social incentive. And then personal incentives like learning new information. And really you see the best results when you layer all of these incentives - so you might have a financial incentive, but also layer on the importance of the social benefits that they might get out of participation or the personal benefits.

F: It's interesting how much overlap there really is between these various groups and the best way to approach them.

J: My biggest takeaways from all of this is how many similarities there are between the barriers and facilitators for engaging the different groups that we identified. Which makes sense because the groups aren't mutually exclusive, right. People's identities intersect at many of these groups. And because many of the barriers and facilitators are connected or they do overlap, makes me wonder about the potential for some sort of like universal design that uses these facilitators to cater to all of those populations as

well as, they would also capture the populations that we traditionally recruit for participation. And then also adding on layers that are needed to, or having more of a concerted effort to, reach specific populations within that universal design as well.

L: One thing you know we've talked about some of the those, but one thing that is missing, and I would say is a general barrier is funding to lay the groundwork for doing this kind of relationship building, research into how a specific group might be better approached. And I think until institutions and funders start to recognize that - I mean they're recognizing 'Oh yes we want a wide swath of the Canadian population' but you know how do we do that without the funds, and the people, and the time to do these things.

F: I think You're absolutely right about that Laurel. I mean when you have a limited window of a grant when you can conduct a study and they're expecting you to produce a certain amount of research and data within a certain time point, if they're not building into that grant both the time and the money it will take to lay that groundwork, then we're always going to stop short of actually having an inclusive study that's represented/representative of the Canadian population as a whole.

N: Yeah, and I think Fakhri you bring up a really good point about, they may not build in that amount of time and resources that you need and the time and resources that a researcher may need to conduct efficacious family engaged research will be very long if we don't take courses like this family engaged research course. You know, before I joined this course I would have no idea what to do and I would be spending an enormous amount of time and probably resources as well, doing a trial and error session and you know when you have that limited window you mentioned, you don't have the availability to do a trial and error. So learning how to do family engaged research before you attempt to do family needs research and maybe remediate that issue of - make that window, the window size may not change but you can be able to fit through it a little bit easier.

F: And if you know what you need to do because you've taken a course like this, you've just been able to argue why you need that time in your grant proposal. So having this information ahead of time really can help say, "Actually I do need more than 2 years for this, I need 3 because the first year is going to be building these relationships with the community leaders" or something along those lines.

F: [Throughout our research and discussion, we also wanted to reflect on the question of] What does diversity mean to you? So in my mind, when I think about diversity, sometimes it's the absence of the WEIRD acronym - so anybody who is not white, educated from an industrialized nation or industrialized rich nation, with the Democratic society - so if you don't fall under any one of those terms then therefore you are diverse. But I think it's probably a little bit more nuanced than that. When we think about diversity often what we mean is marginalized. So who is it that's marginalized in our society, who is it that's under represented?

J: Yeah I think Nick and Laurel - well everyone really hit the nail on the head. So acknowledging that having diverse representation in research takes time I think is one of the key things that we're saying here. It might not always be feasible within the limited windows, say grants might give you. So having an acknowledgement of how much time it does take to lay the groundwork for those relationships before even getting into actually doing the research, right. And then I think we also brought up the importance of diversity in our research. So we know that some of the worst health outcomes are seen in some of the groups that we're talking about today, and that might be because of their under representation in research. So I think in order to best serve the whole population, we need to really move away from only that WEIRD group and have a more diverse population in our research studies.

F: I really appreciate the amount of intersectionality that we witnessed between all of these groups. So I hope that those that are listening are able to learn something from this and plan accordingly. Thank you for your time.

L: Stay classy San Francisco or San Diego! 😊

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