

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

Craig Andrade: Okay so this is Eric Rubenstein and Craig Andrade talking about some of our work, particularly with people, and young adults, adults, and children with spectrums of disability.

How about starting by just saying a little bit about how you got started working in, and in this area with this population? And what brought you to the School of Public Health?

Eric Rubenstein: Sure.

Craig Andrade: So just tell about yourself.

Eric Rubenstein: Yeah so I'm Eric Rubenstein. I am a, I started here as an assistant professor in Epidemiology in August of 2020, so I'm, like, been here all of COVID. So this is exciting to be able to be in-person with Craig, and, sort of, see people face to face.

So I I, kind of, joked that, like, the only job I've ever had has been working with people with intellectual development disabilities. All of my hobbies, it's, like, kind of, just something I'd like to do, and I've never tried anything else.

Like, maybe, I would be a great pilot or something. But this is just, like, the only thing I've ever done. I'm good at it, I like it so I keep doing it. But, sort of, that that story is that when I was in fifth grade, I, like, I grew up in Central New Jersey; and this is, like, when the Yankees were really good.

And I loved baseball, but I was, like, really bad, like, really, really, really bad. And my parents hated having to go, and take me to games, and watch me play. So, like, in fifth grade, they'd finally, like, had enough, they're, like, "Eric, why do you love baseball so much? Why don't you just go help the Special Olympics on the field one over instead of having to have us watch you play?"

And I I started doing that, I really took to it. And, sort of, that led to a job as a, a campus, a recreational, sort of, program. And then in college, I studied public health, and medicine, and and did some work in the lab about childhood development while keeping my job working as a, at a school for kids with autism.

And then that, sort of, led me to public health, and from getting a masters, to a PhD, to a postdoc after – I found that I really enjoyed researching in this area, and recognized the gap where a lot of epidemiology focuses on risk factors for a lot of these conditions. Which, I don't need to get into the debate over whether that's warranted, or helpful, or necessary?

But there was that space for looking at outcomes once people who are born and have these conditions. And we see that there's a lot of poor health, and mental, and physical health for these populations that really is preventable.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

And just in conjunction with my research, I've maintained, sort of, a a real passion to coach Special Olympics throughout all of this. It really, kind of, is is a nice way to pair my work with my, sort of, life.

And it keeps me motivated and energized; get a grant rejection for something that you're really passionate about, you can go out to the football field, and throw the football around. And and these athletes really don't care that your grant didn't get funded, they're they're just happy that you're there, and and helping them play football.

And it, and it, kind of, works the other way, too, where you have a a rough loss on the, on the soccer pitch, and then you get to go, and get a paper accepted. And you're, like, "Okay I I can keep going."

So yeah, that's, kind of, where my my background stands in this. And I've been able to develop a ton of really great friends and personal connections that, really, I I, I couldn't trade for anything.

Craig Andrade:

And it's funny how we, we could be seen as brothers from another mother. There's similar connection, it started with sports. And my first introduction to someone that had an intellectual disability is in street hockey. And I didn't, not a hockey fan, well, hadn't been a hockey fan, but learned in in the neighborhood in Brockton where a bunch of people were always playing street hockey.

And one of their brothers was autistic and spectrum. And the the normalization, the kind of inclusion that was just natural, this is a family member. Everybody's playing, everybody has different abilities. I had never played hockey before until I I started getting in with this group of of, of kids in the neighborhood.

And slowly but surely, I really, just liked being around adolescents. I was an adolescent myself, but slowly but surely going to camp as an adolescent, being a camper, and then being a a counselor. And in all of those camps, YMCA camps, sometimes church camps, there invariably were people in any number of physical or intellectual disabilities.

And more often than not, there was a a a, kind of, joy in that, kind of, more co, more collective, inclusive community just because of the differences. As kids, we we may have made fun of people, but we made a fun of everybody. And so that was a form of love so that we didn't not make fun of someone –

Craig Andrade:

Yeah yeah.

Craig Andrade:

– Who, because they had an intellectual or a physical disability, it was something that we would hit it, and quit it, and go back to playing in the pool –

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

Craig Andrade: Yeah yeah.

Craig Andrade: – Or and all those kinds of things. And and there's a, there's a nice start there to seeing that you, in a, in any kind of game, you can all, see more of people of who they are in all kinds of different ways than you can, kind of, sitting in an office. So and so there's a nice, kind of, synergy, and the close proximity helps you see all of people.

Eric Rubenstein: Right, and then, I think, sort of, to touch on what you just mentioned about, sort of, joking, and teasing, is that, like, too often this population is too often this community is infatalized ____ [00:05:43].

Craig Andrade: Right.

Eric Rubenstein: And, like, I know it; like, we want to be respectful to people, but, like, little jokes that are funny, that aren't really offensive that one would make about a silly shirt or something. Sometimes that becomes exclusionary, when you're, like, "This person is disabled, we can't really include them."

And this, sort of, stuff where, like, that's kind of a, I find, personally, that a lot of my friends, sort of, really miss that part of the –

Craig Andrade: ____ [00:06:11].

Eric Rubenstein: – Especially, not to to gender too much but, sort of, the male butting heads kind of stuff where they just don't get that in a world where they're, there is adults treated like children.

Craig Andrade: Right.

Eric Rubenstein: And and to give them that respect, to to be like, "Hey, man, why are you doing that?" Like, is it really –? It's it's something that I think is important.

Craig Andrade: Yeah so so can you say a little bit more about how –? You you said that you, you were encouraged to go, because of your love of baseball, to go do that with Special Olympics, and it could begin in that. But what what, what helped you stay connected to that population, and then make it a part of your academic career?

Eric Rubenstein: Yeah so so I think that, kind of, an important motivator has been, sort of, a a driving push from my mom. So I'm the epidemiologist, and my sister is an occupational therapist, and my brother is a physical therapist. So it's, sort of, this, and we we joked, it's like, "This is a family business." We all work with with this population. I I am, like, I'm a little wonky as an academic, I can't, like, join the clinic that my brother, and sister might start one day.

But it's, sort of, always pushed that way. I I think that there's something that you see the need. I I think it's very clear when you spend time with this

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

community, especially in areas that aren't, well, well, even in areas that are high income, there are still these obstacles that are really evident just from spending a few minutes.

Where there, they're obviously more evident, and more, more needy communities. But it's very clear, even when I was a kid that for a lot of these children that I was working with, and young adults, that a lot of, a lot was needed for their community.

Which, I know, I don't have these conditions but at this point I consider myself a part of the community. I have so many friends but that was always, sort of, a driving factor.

And my research really started, mostly in the autism world, which at the time, and including now, had, sort of, there are just so many unknowns. That as someone that, like, really likes puzzles, and solving problems, it's an area where there's just a lot of really good scientific questions that need to be answered, and, sort of, from a, from an intellectual point of view.

It's a topic that, at the time and it, kind of, still is, it is really intriguing. Not to, sort of, talk of, not not to, like, put that on a community but to say that, like, the the, what we don't know is so glaring. And being that, really, the the rise, and identification of autism is a 21st century thing. That it's not like a condition that we've been studying for hundreds of years, there's still so much we need to know, and understand.

That there's, I felt like I could make a difference, whereas in some other, sort of, public health topics, the the ground is a little more trod. And, sort of, from the academic, intellectual side of things, there's there's really a lot of ground to cover in this area, which which is exciting.

Craig Andrade: Yeah it's it's something that you said in the the, kind of, so that we've only really leaned into autism, for example. And in recent times, we recognized previously, there was, there was a a dearth of information. And therefore people filled in the blanks with all kinds of levels of pathologic pathologically, kind of, framing them in ways that just undid their capacity.

We we, for the most part, side lined a whole community across multiple ways of identifying intellectually and physically to the side margins of our, of our community. And in, that includes to a degree, a public health community, a medical community –

Eric Rubenstein: Yeah.

Craig Andrade: – Our our psychiatric community. There's, there clearly, always been advocates, and champions, and and allies. And it's it's only in in relatively modern times that we've, we've been more deliberate about including a population of different communities in education, and healthcare.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

And in, and and, and employment, and and, and in relative, broad terms in terms of, kind of, accessibility across all kinds of spectrums. That that's, that's part of what, what brought me into this work. The, kind of, that the equity is relatively new word that we're using; but the exclusion and the, and the marginalization was familiar for me as a Black man.

But also, it it just, when I watched friends be ignored; when you talk to the parent and not talk to the –

Eric Rubenstein: Right.

Craig Andrade: – The the person that is experiencing whatever is in line for some kind of service, or or just understanding who they are. They would not even look at the person. Those kinds of things are so glaring, and I find them so so, so so frustrating, angering, all kinds of things.

Can you say anything about how that is is, kind of – ? Has that been part of your research and how you've, kind of, done any kind of focus on particular populations?

Eric Rubenstein: Yeah so so on that, I I, kind of, recognize the same struggle of, sort of, getting these voices into the the public health arena. And I think that there are a lot of educational barriers, that we talk a lot about a lot of other minoritized, and marginalized populations, and having them seat, how to seat at the research table.

And it's a lot easier to find people in those communities that can keep up with the speed of a research team without needing any, sort of, time investment in their training.

Craig Andrade: Yeah.

Eric Rubenstein: A lot of, whether it's a high school having a high school GED, or a a college degree, you can, kind of, keep up in a community advisory board setting, or even as a community researcher. Whereas this population, especially with intellectual disabilities, it could be a little harder to be given that chance to to be able to, kind of, be included in a research team of academics, and community members.

So with the help of the the, the the, with BUSPH and the the Activist Lab where we have a a funding to do a researcher training with Special Olympic athletes. We're actually having our first session tomorrow. So it's led by a master's practicum student named Anna Maria Carova, who has been excellent. She's also a social worker.

And we're not reinventing the wheel, we're borrowing from other programs that have done similar things. But, sort of, both delivering the message that,

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

yeah, you you can be a researcher, you do belong. And also, these are, kind of, the ins and outs of what you need to know, both the hard skills, and the soft skills, with the goal of eventually being able to to have the skill that I can hire them to to be on my research team.

I mean, there are some hurdles in that; like, we're conducting this in Marlboro because that's where Special Olympics is. And like, well, I'm in Boston. So it's, kind of, more of a pilot training at this point to, sort of, build a team and a base.

There are also, kind of, a lot of structural limitations for, that that prevent equity; so a lot of this population is on Medicaid. And there, there's a means-tested program. So if I can't give them full-time work, if I want to hire them part-time for a few hours a week, if that pushes them above an income threshold, they may lose their benefits.

Craig Andrade: Yeah.

Eric Rubenstein: So it actually hurts them to work, which is really, really a terrible thing, that hopefully, policy wise, we can change. But it does, kind of, tie your hands as someone that really wants to hire, and bring people to the School of Public Health with these conditions, that it may, actually, be, not the beneficial to them to to get paid because of this really archaic structure.

So those are, sort of, the loopholes that I still need to figure out, and iron out, and talk to HR about how can we make this work? Which is not usually the case for hiring other employees, and and it's something that, hopefully, in the the current administration, they get this ironed out soon.

But it definitely, there are some some structural barriers to really. inclusivity that, that really align with equity, and getting people to be paid for their input.

Craig Andrade: Yeah and that, and that happens in other communities as well. Or right, some of the community members that we've partnered with for years here at the School of Public Health, including those that live in housing projects –

Eric Rubenstein: Yeah.

Craig Andrade: – Locally and elsewhere, we've had those similar kinds of challenges. And so, yeah, I I welcome an opportunity sometime later, following this, this conversation to, kind of, think together: How we might partner with some other organizations that have had the same concern?

For example, how do we, recognizing that there is a spectrum of people on the spectrum for autism that really can contribute in all kinds of ways? And then, in addition, beyond the kind of, basics of of, of qualitative of quantitative research, making sure that we're using voices in in research that that allows more of our community members to be seen, including those

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

around intellectual, and and physical disabilities.

To, kind of, bring the qualitative of stories, in part, next to the quantitative considerations so that more and more decision makers, policymakers, others can see, and feel. They understanding why, for example, we need to get rid of these policies that make it hard for someone that's on public assistance to get advance in a certain way? And be able to, kind of, add to the research, add to better understanding of what needs are there in real contexts, and color. That's just one thing.

Eric Rubenstein: Yeah.

Craig Andrade: I I, we also know that more, because we've done better in education, and development, and finding ways to serve communities better, particularly in this area of of cognitive intellectual physical disabilities, more, and more people are able to go to school, college, and elsewhere. And therefore, there may be better representation in academia as as that's happening.

How do we, how do we find ways here at the School of Public Health, and in other institutions to acknowledge that inclusion as writ large, is critical, and have a a way to be sure we're deliberate about making sure we are sending the message as clear as possible?

That all are welcome and then that the the capacity, and and ways to do – ways to accommodate. and and the balance of of possibilities include this population as well.

Eric Rubenstein: Yeah, well, I, just just to put a pin on that for a second, and and going back. I always used to talk about, sort of, like the inclusivity, and research team, and incorporating people. And and that this is, is _____ [00:18:28], like, it's really hard for trainees to be able to do that with their own work.

So as someone that's been on faculty for a year that now has some research funding to do it, I'm really excited. But, like, I was a graduate student that could not involve community participants because I couldn't pay them.

Craig Andrade: Yeah.

Eric Rubenstein: Because I didn't have research funding. So that's, sort of, an area where not just in the disability field, but in in so many social topics where, if we want to incorporate the community in your student; either you're exploiting people's experience and not paying them. Or you're not including it because you can't pay them.

So that's, sort of, another, maybe, university level thing that we can work to figure out. Is how can we get money for participants for student projects that otherwise that they don't have that opportunity?

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

Craig Andrade: Look, just to, just to say I I, I'm so glad you raised that, and and, and, kind of, brought that up before we move forward. Because that that is so critical. Again, it has to be somewhat of a, not somewhat, an inside out approach.

Eric Rubenstein: Right.

Craig Andrade: So the the Activist Lab is trying to find ways to have conversations with our RWJ, Robert Wood Johnson Foundation, Boston foundation, locally. How do we, in this moment of equity that is writ large, or how do we make sure that we are bringing those voices in a way that treats them with the respect, and acknowledgement of the value that they bring?

The idea that that's one way, that we would find ways to make sure we can make, we can bring a more inclusive, open opportunity for all spectrums of people to to be able to do that. Part of it is what, we have the conversations we have at the School of Public Health. But part of it is also, kind of, helping to continue to educate decision makers, funders, foundations in ways that really, kind of, kind of, open that up.

Now, we have this window open given what we've been through over the last year, and the exposure of inequities across different communities in this. This, people's ears are a little bit more open than they have been. So it's a, that's a consideration that we should, we should, kind of, take advantage of.

Eric Rubenstein: Yeah and and it's a really a valuable training opportunity for students. So in epidemiology, in my training, I knew so many people that didn't know anyone with the conditions that they were researching. Which, like, always boggled my mind.

And not everyone is going to want to be a community-based participatory researcher. I I don't know if I consider myself that. But just the exposure to it –

Craig Andrade: Yeah.

Eric Rubenstein: – It might influence a few people greatly. And I I think it is something that should really be considered for, sort of, everyone to to have a foot in the population that they're researching on.

Craig Andrade: I I, I say more than a few times in in public audiences, and and, and conferences, this, they're, kind of, white-led institutions have excluded a subset of populations across the globe. We can also speak in terms of able-bodied –

Eric Rubenstein: Right.

Craig Andrade: – Kind of, leadership that has excluded otherwise able in all kinds of ways, physical. and cognitive. That, bringing that into the conversation in that

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

larger sphere means that we can make sure that those that are able can bring that spectrum so that we can, kind of, open the, this, the possibilities in much broader terms.

We still have physical access and a cognitive access challenges in all kinds of different ways. And it's in part because of their, the leadership that is more able-body minded, more cognitively centered in a certain way, as well as, kind of, the the broad spectrum of otherizing people in all kinds of ways.

We we center in the, in the center, and forget the margins, and therefore, lose out on a whole spectrum of perspectives, and and insights.

Eric Rubenstein: Right, and then just, I'm a straight, cis, het white guy talking about the disabled population. And I don't have – I'm able-body, I don't have a disability. And that, in a way, is part of the problem.

I try my best, I try to stay grounded, I try to do the best work I can do for a community that I've really taken the time, and and feel a part of. But I I mean, as what we were, the question you originally asked, like, to move forward? More disabled faculty, whether they're researching disability or not.

I think, sort of, the the ability to be open about disability, too. There is some stigma surrounding it, especially for, sort of, more hidden disabilities. That is an area to to think about, and as we move forward.

And I think that there are – I I'd, I I can just try to use my voice to advocate for others. And I, it's my my, my view of what I am advocating for, it may not always be the most.... Rewind that, but, like, my, I I am in the ivory tower. I, my boots are not always on the ground, so I am trying to to advocate the best I see fit.

But real people that are living these experiences, 24/7, are the ones whose voices should should be leading. As to, sort of, what we can do to make it a more inclusive environment? I think the technology of this last two years has been a huge advancement, just, sort of, like, the closed captioning on PowerPoints now, and and Google.

Like, any any talk you give with zero cost or zero, really, effort can be transcribed automatically which is, is really amazing for, maybe some some deaf students, or or hard of hearing, the audience members. I I think that the approach to online learning is a, is a really big area to improve access.

I I don't want to get into this, sort of, the politics of being on campus; or it's not on campus. and a lot of stuff, that's above my pay grade. But it is an area to consider going forward because it does improve access for a lot of people that might otherwise struggle. But then and again, sort of, thinking of inclusion, having people on campus in a room together, it still has that value.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

I I, I think that there are, sort of, the the school is definitely becoming more accessible, and a lot of these, sort of, policies. Like, I think that just the the attendance _____ [00:24:57], that there was a a note about attendance, and and giving credit attendance. And why that may not be the best approach?

It is really thoughtful and moving in the right direction. Whereas if someone has, what is it, ME/CFS [PH], or some, sort of, physical condition that really makes it hard to get into class, and they can't make it that day, they really shouldn't be penalized.

Craig Andrade: Yeah.

Eric Rubenstein: And, sort of, keeping our eyes open for those types of issues, and and being willing to adapt in favor of inclusivity is is really the way to go.

Craig Andrade: Can you say a little bit about your choice of, kind of, what would be one of your favorite research projects that worked with Special Olympics participants or others that would help students here, and others, researchers here?

Kind of, the approach that you take, the the focus that you leaned into, and the, kind of, method of doing the work, and what you found? What your findings drew to, kind of, give a little, broad, a, kind of, thumbnail understanding of how all that works for you, and how it is, made a difference in any particular way?

Eric Rubenstein: Yeah so I I think that a good project that, sort of, encapsulates my experience is that I was – I moved to a new town. This was for my postdoc; I moved to Madison, Wisconsin. The only social life I had was Special Olympics, and there was a Friday night fitness club. So it was probably around 20 to 30, mostly adults, some, some young adults.

We would go to the high school gym, and we would, like, do a yoga class, play some basketball or whatever. And it was my Friday night activity, I did not go to the bars. I'm not, I don't, I'm not going on dates. I'm just just go to the gym and playing basketball with my friends.

And maybe it was the next year, I started doing some, some data work for Special Olympics, and I was evaluating this program. That was the task I was given because I needed to see if this is effective in, sort of, did the athletes like it? And then there's weight loss.

And for someone that was, would have been foreign to this program, I was, like, "Well, what are they doing? What's the active intervention?" Dah-dah-dah, it's like, _____ [00:27:25], no, I know this. I've done this. Like, this, I was there, like, not that I was going through the data, and finding the people I knew but, like, yeah, I was part of this.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

And I wasn't, it wasn't from the onset, it wasn't, sort of, like, "I'm only doing this because of research." It was just, like, this great opportunity to to take this program that I really enjoyed, that I got value out of, and, sort of, show how it could – how it's either benefiting, or how we can improve it.

It's it's, sort of, the, it's it's also, like, a good problem of, like, as a researcher, not every, not, the world doesn't revolve around your research. Where this program was not originally intended to collect data, and it, there's no randomized control arm, and all of those things that make research hard were were in place.

So, like, we're talking about the impacts, maybe they're not so great. We saw some some effect. We just, the athletes liked it. We saw a little bit of weight loss but, like, nothing to put in the New England Journal of Medicine, or anything.

But it's, sort of, kind of, sets the stage for showing an organization like Special Olympics the value of this type of research, the value of this type of program while being able to take part in it. And and, and I I don't know if, like, there's some, sort of, ethical or conflict of interest in that I participated if I was there on the Friday nights?

But I think that, sort of, it sets the stage for, sort of, maybe, more rigorous trialed, and stuff like that going forward. Where they can invest more in this program because it shows these great results. And being, having a seat at the table to, sort of, advocate for fitness in some of these programs as, sort of, a health outcome, is really important.

And, sort of, every part of that was, it was fun, both doing the yoga, and then collecting the data, and then seeing it published, and, hopefully, experience Special Olympics to do more of that type of programming.

Craig Andrade: What would you say to to students that are interested in this population and interested in working on behalf – whether it's around advocacy or activism, in the midst of also wanting to find ways to to continue to push the field in this area in ways that continue to make more, better difference, more, better outcomes, and all that?

What would you say to people that are interested in, kind of, starting from the beginning, and getting in the field? What are some of the things that they should be considering?

Eric Rubenstein: So not everyone has the luxury of time. But, like the, the number one advice, maybe, is to volunteer for an organization that you like, you enjoy doing, and you're passionate about. So many opportunities come about that way, especially in a city like Boston.

Craig Andrade: Yeah.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

Eric Rubenstein: That, kind of, any cause you're about under the sun, there's the opportunity here. And your skills that you're developing at a School of Public Health are very valuable to a lot of these smaller nonprofits. So you go in, you're, show, you show your consistent.

You show you're pleasant to be around, and you say, "Hey, I'm working on my MPH, I'm doing data analysis, quantitative, qualitative." They will definitely be thrilled to talk to you, depending on the organization, whether there's a job to come out of it afterwards, or whatever?

Who knows, but getting your foot in the door through that type of volunteer work where you can enjoy yourself while doing, this is not an unpaid internship while you're grabbing coffee for the boss. Like, do something you like to do in the avenue that you like without, sort of, having to be too Machiavellian about, like, the end result of the job.

Again, that's a luxury if you have the time to do it, but not everyone does. But I I think that's, sort of, in a world where everyone is in the building has a Public Health degree, or has studied Public Health degree, or has a PhD in some Public Health field. Like, you may forget in the real world how valuable your your skills are, and your tools.

And getting outside of the bubble even as I I do some cooking at the Haley House down the street, and just, like, that's three blocks. Like, even one block, you you can see how valuable your tools are. And it's just, sort of, taking the time to do that, and understanding the value in in that.

It's, sort of, like, it is a worthwhile experience even if you have to, maybe, wake up early on a Saturday or forego something else. It's, it really is beneficial both, like, spiritually; and I think that if it's something that you want to have a career in, definitely making those connections, and showing that you're, you're willing to to put the legwork in for this cause, is is really something that nonprofits value.

Craig Andrade: Yeah yeah, I I, I resonated with that word, "spiritually," the the, kind of, connection that getting proximal to people, and whatever challenges they may face, and understanding them. Getting involved, starting by volunteering, and and being just getting closer to the population, working in in the same space with people.

Whatever you're interested about, and this population in particular, I, I resonate with that in a way. My second week of being the Bureau Director of Bureau of Family Health & Nutrition and going to the Federation for Children & Youth with Special Health Needs, their annual convention that brings family, and children, and all people together with researchers, and funders, and policymakers, and on.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

I I've said this over and over again, now years of going to this conference, and I'm working with the Federation. To be in that community, to be with children, youth, adolescents, young adults that have been part of that community, and, kind of, had their own journey in that.

And just listen to their stories, be in them for lunch, and dinner, and all kinds of other things. The, there is a, there is a kinship, a a, a, a connection that just – you can't put into –

Eric Rubenstein: Yeah.

Craig Andrade: – A word. It it, it's, it's better than... We all need resources, we need to pay our bills, we need to, kind of, make a living, and connecting with population, like you said, in volunteer ways when you have the time. The the idea that we get as much as we give is is, is a consistent theme in my life.

And it has been one of the things that, kind of, helped me be. Why I became a public health practitioner, why I think services is is critical. And the the surprises that come from that, though, that, kind of, network, the connections, the learning, the the growth that happens is just phenomenal.

Eric Rubenstein: Yeah yeah and just, just especially for students moving to Boston; I have found that, sort of, every place I moved, having moved a whole bunch of times to follow this career path, that I had a built-in community. Right when I landed, I say, "I'm the Special Olympics coach, where is the program? Alright, see you Tuesday, Thursday," and you're in.

Where where it was, it was amazing to be able to, sort of, have a home instantly. Again, I I'm sure, people probably – religion is something that does the same thing where you find a church or a synagogue, and your _____ [00:35:32].

But someone that doesn't have that, and it was really, kind of, great to be able to get in right away, and find a, find a a group, which I think that is volunteering. And finding a cause like that, whether it's politics, or be religion, or something like that, is really meant, a mentally, a mental health wise, really important for a a graduate student to to, sort of, stay grounded.

Craig Andrade: Yeah.

Eric Rubenstein: And have friends that are not just, also going through the same public health, grad school grind. Someone that can say, "I don't have a test tomorrow, I can talk to you," and....

Craig Andrade: So as you know, the Activist Lab, it has a a significant focus on activism and advocacy. How would you frame your brand of advocacy in in, in the work that you do? What what does that look like for you?

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

I I, I have a clear sense, and from this conversation, that this is just natural. This is, kind of, your – you've you've grown up in a sense, connected with _____ [00:36:41] community that became your friends. And you've been, you became part of that community.

And I imagine in, on both sides, just being with your friends, and being within community, and also being a researcher, and academic, you see things that, maybe, others don't see as clearly, and the, in terms of the inequities, in terms of the, kind of, to a degree, in justices in all kinds of ways. What, what does that mean for you?

Eric Rubenstein: Yeah so so when it comes to advocacy, I, there are a lot of political issues in this area, especially around autism. Sort of, the the community itself is, sort of, working through some growing pains of what's, what should be advocated for? Or what's needed, what areas of research to pursue?

What policies are fine versus eugenics, versus, sort of, all of these these areas that are are really contentious? And I just don't have the capacity to to do enough of the research into it to, like, take a stance. Nor do I necessarily want to put my neck out there at this point; maybe in the future, I will. So I I, in my research and my advocacy, I try to find things that everyone agrees on.

Sort of, use my platform to promote things that, across the board we know work. So a a big area is, sort of, Medicaid. And it is a a social safety net program that really helps this population. And restricting access to it is really harmful, and the states should expand so more people on the border get in.

And so that's an area, including community, and home and community-based services where people with disabilities can receive these extra supports that they need to live in their communities rather than be, say, institutionalized or put in a nursing facility. So that's an area where there's high community support.

My research can move the needle in strong ways. BU has a a great corps of Medicaid researchers, the the Medicaid Policy Lab that has just started this past year. So it's somewhere, I know, I can make a difference, that helps a lot of people, and that I won't be getting a million tweets about.

It's just, sort of, personally I feel like I really love, sort of, advocating for my individual friends, and athletes. There are so many opportunities in the community and, sort of, supporting people to find jobs, and all of those things where that, kind of, is the more immediate personal feeling of satisfaction, and accomplishment.

Where I I can go visit someone at work, and give them a pep talk, and buy them a soda, or a healthy, a healthy drink. And that's like the highlight is when I had athletes that work at CVS or Walgreens; and like, I'm I'm, like, struggling at work, I can just go over there, and just, like, check in, and make

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

sure everyone is doing okay.

And like, say, "How are you?" and that's the stuff that, kind of, gets me the day to day as as I try to to advocate for these more large-scale, societal changes which are, as you know, are very hard. And it can get very frustrating.

And then, obviously, sort of, like, taking a step back, and listening to to those that are leaders in the the advocacy space. And, sort of, following their lead, and, if they say, "Call your representative," and I trust them, and their input, is, "Alright, I'll call my representative."

And it's, sort of, knowing who the leaders are, and and what they're saying. And, sort of, being a a, being a soldier rather than being the general sometimes. And it's, sort of, having my voice in the chorus rather than, sort of, being the the solo singer. It's, like, a whole bunch of analogies going at once, so.

Craig Andrade: Eric, this has been a really great conversation. I feel like we could keep on going, and I, and I know, I want to be respectful of your time. And I, this makes me clearly understand that there is an opportunity for some potential collaboration –

Eric Rubenstein: Awesome, yeah.

Craig Andrade: – In all kinds of different ways.

Eric Rubenstein: Yes.

Craig Andrade: Is there anything from, if you were speaking to your your academic colleagues, if you were speaking to your student colleagues, if you were speaking to the community that you're advocating, that in this conversation you want to say out loud so people know something more than they might know before this conversation? That you want to say about the work that you do, the people that you serve, the the value that you take in the work that you do?

Eric Rubenstein: Yeah yeah, so so I, wearing my epidemiologist hat, this, the disabled population, sort of, using a broad definition, is large. I, estimates can say upwards, like, around 15 to 20%, so this is, this is a a group that is worth studying. And if you're doing large-scale epidemiological studies, you have a good sub-sample of people with disabilities.

And it's worthwhile to pursue research in that area to help this population. And it's not, it's not an area that you'll run up against biostatistical issues and limitations, always. And then, sort of, that this is just a area of public health. I think that oftentimes, you think of big domains of public health, and there are really high initiatives in chronic disease, and infectious disease.

Less Seen/Less Heard: Stories from the Margins
Full Episode with Eric Rubenstein

And I think disability is really its own category with its own, sort of, moral philosophies. And I think it's worthwhile to, sort of, consider that as a domain, and an area of public health, especially as, with long COVID, and increase of dementia.

And as people age, more age-related disability, it really will be a huge proportion of public health services and costs. That it's, I think, it's the the next big wave in terms of where our focus is going to have to go, conditional on us getting through COVID in one piece.

But yeah. I think that, sort of, classes on disability; it, sort of, focuses on it. And I think that that's where the future is heading.

Craig Andrade: Well, again we, I'm sorry, we have to wrap up but I'm, I really have appreciated –

Eric Rubenstein: Yeah great.

Craig Andrade: – This conversation. One, to get to know you a little bit better.

Eric Rubenstein: Yeah.

Craig Andrade: One, to speak about something that I think we share an interest and passion for, this population, and the community that is broad, and and, and diverse in all kinds of ways. And the value, and and, kind of, fun, and joy that they bring, and and, and _____ [00:43:40] all kinds of ways. As well as the the, the room for our society to to serve them better, and in all kinds of ways.

And, yeah, I think you've highlighted a whole bunch of things that will give both faculty, staff, and students good food for thought. I really appreciate your time.

Eric Rubenstein: Yeah thanks, this is great, Craig.

Craig Andrade: Thank you.

[END OF TAPE]