

Youth with Intellectual and Developmental Disabilities

Dr. Kineka Hull:

[00:03](#)

Welcome to Elevate Youth Programming, a podcast for adolescent pregnancy prevention programs and other youth-serving agencies. In each episode, we will discuss best practices, tips, and strategies to strengthen your programming. Each episode will cover a specific topic discussed with experts from the field. Listen along as our guests join me to discuss these relevant topics. I'm your host, Dr. Kineka Hall. [00:00:30] Equity in sexual and reproductive health education and services includes access to comprehensive, high-quality information about sex and sexuality, knowledge about risk and adverse consequences of unprotected sexual activity, access to care, and living in an environment that affirms and promotes sexual health. Youth with mild to moderate intellectual and developmental disabilities or IDD are just as likely to be sexually [00:01:00] active as their peers who do not have disabilities. However, they are less likely to receive comprehensive sexual education and less likely to report using condoms or prescription contraception at their last sexual encounter. Youth with IDD are often at increased risk of high rates of sexual activity at younger ages, teen pregnancy, and subsequent early pregnancies, HIV and other sexually transmitted infections, sexual abuse, victimization [00:01:30] or exploitation, and receiving misinformation.

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In this episode, we speak with April Kayser from the Multnomah County Health Department who coordinates the sexual health equity for individuals with intellectual developmental disabilities or SHEIDD and Nadia Lockheart to elevate a voice of lived experience and learn tips and strategies to advance sexual health equity. In working with youth with IDD. April Kayser is a member of the Multnomah County Health [00:02:00] Department Health Education team where she helps promote health equity by facilitating inclusive comprehensive sexuality education opportunities for young people and by supporting school and community partners to strengthen capacity to provide culturally responsible and accessible youth sexual health education. Since 2016, she has coordinated the community and adolescent health programs community capacity building project, SHEIDD, where she works along community [00:02:30] advisory group members to advance efforts to support relationship sexual and reproductive rights.

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Nadia Lockheart is a community advisory group member with lived experience for the Multnomah County Health Department's SHEIDD project where she assists with co-facilitation for their organizational capacity building program, co-facilitates Team Works trainings, and serves as a public speaker in numerous community outreach efforts.

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- [02:59](#) Welcome [00:03:00] to the Elevate Youth Programming Podcast, April and Nadia. I'm excited to have you on the episode today. How are you?
- April Kayser: [03:09](#) Doing so good. Thank you, Kineka for inviting us. It is sunny in Portland Oregon, so nothing to complain about.
- Dr. Kineka Hull: [03:14](#) Nadia, how are you?
- Nadia Lockheart: [03:15](#) Oh, I'm feeling pretty peachy keen. I like to take this moment to thank you for inviting me to the podcast along with my amazing colleague, April. Really grateful to be a part of this.
- Dr. Kineka Hull: [03:25](#) Thank you. So let's jump right into our conversation. So doing some research [00:03:30] on working with youth with intellectual and developmental disabilities. I stumbled across the sexual health equity for individuals with Intellectual and Developmental Disabilities website or SHEIDD. And so I would like to just have you give us an overview of your organization so that our listeners would know about the wonderful things that you have to offer.
- April Kayser: [03:53](#) Yeah, thank you. I'm so excited to hear that you came across SHEIDD and what SHEIDD is. [00:04:00] I work for the Multnomah County Health Department and Multnomah County Health Department's Community and Adolescent Health Program coordinates the SHEIDD project. And the SHEIDD project started in 2016 and it was really meant to be a collaborative effort to promote comprehensive sexuality education for youth experiencing intellectual and developmental disabilities between ages 14 and 21. And the way that we sort of designed this project and envisioned this project was that it would be [00:04:30] a countywide effort to strengthen the capacity of both support people and support organizations. So those folks who have a relationship of any sort with a young person experiencing disability, or organizations that specifically provide support services to young people experiencing disabilities. We want to help them learn how to provide sexual health education and support so that we have more robust systems and environments for young people to experience sexual health and rights.
- Dr. Kineka Hull: [04:58](#) As I looked through your website, I saw [00:05:00] a lot of tools and resources and best practices for facilitators and agencies who want to make sure that we are doing our best to support young people. Can you tell us about some of the resources that you have on your website?

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- April Kayser: [05:16](#) And we can kind of speak in general to the SHEIDD approach because we kind of have four different components to our approach. And you likely saw the SHEIDD online resource hub, which is one piece of that, but we have some [00:05:30] other aspects that we would like to share too. So our goal really, like I said before, is to help create systems and environments that ensure that young people experiencing disability can access their relationships, sexual and reproductive rights. And so, we do that by focusing in four different areas for these policy systems and environmental changes. The first is we collaborate alongside community members and organizations. The second element of our approach is focused on capacity building [00:06:00] opportunities for support people, the third on capacity building opportunities for organizations. And then the fourth is maintaining that SHEIDD online resource hub that has a number of resources. So we thought we would share a little bit about what each of those approaches tries to do in this area.
- Nadia Lockheart: [06:18](#) Touching on collaboration for a moment, what we mean by that is that is since our inception, we've been a group of community members and organizations that basically come together once a month [00:06:30] in a form of a community advisory group. And what we do in the community advisory group is we're always promoting comprehensive sexual education, and that's for young people, primarily ages 14 to 21, that have intellectual and developmental disabilities. And the community advisory group, it's not just made of IDD youth in particular, it's also made up of community members who are allied to the cause and support people from all walks of life. So we all just kind of band together once a month and the heart of our project and [00:07:00] our vision is to help us promote sexual health for all, essentially.
- Dr. Kineka Hull: [07:05](#) So Nadia, if I could turn this to you for a second, can you tell us a little bit more about your role and your experience with SHEIDD, how you found out about it, and just your overall involvement?
- Nadia Lockheart: [07:17](#) Yeah, absolutely. Prior to my immersion in SHEIDD, I had actually already had a bit of a background with primarily working with sex positive organizations here in greater Portland, Oregon area. I [00:07:30] started off in 2009, actually, I had just graduated from college. My headspace was in a very emaciated exasperated state at the time. I was feeling very dislocated and I really needed some community in my life. So I started doing all these one off volunteer opportunities across the greater Portland area. And then, ultimately I came across one for this festival called ErosFest Northwest. And I was intrigued by it and I just assumed that I would go into it treating

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it [00:08:00] just like any other volunteer opportunity. Little did I know that it would fundamentally change me inside out, and it exposed me to a lot of ideas and concepts and knowledge that I had previously had been completely oblivious to.

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And I continue to push myself to going to other workshops and doing other educational opportunities in the community. And then, ultimately, when I was really confused, especially with my long time struggles with relationship, I was wondering, do [00:08:30] people that are neurodivergent like me, do we really have it worse off than most others in this particular front among others? And so, I remember in 2014, for example, I tried to see how many compiled texts that are were surrounding the two. And to my shock when it came to autism and sexuality, there were only three that I came across at the time. And that alarmed me. It really opened my eyes to a lot, but also it hit way too close to home and I just felt so emotionally drained. And so [00:09:00] I kind of put it on the back burner for a couple of years and I just wasn't really feeling like getting engaged in the community because I felt kind of alone in some respects.

[09:10](#)

So September of 2017, I tend attended the summer festival, it was called Group Therapy. I was kind of opening up to a lot of colleagues there about what I do exactly, and I was really moved by how many were saying they could relate to what I had to share. I was getting very vulnerable. And [00:09:30] then when I got back about six weeks after the festival in November of 2017 through vocational rehabilitation at the time, I got this referral from a case manager about this internship. And basically it was the first internship they had ever done, but essentially it was kind of a way of further building the community advisory group and also helping get some of their project plan vision further into focus. And so, I followed through on the application [00:10:00] and then I went to the interview and that was 2018. It was just such a moving experience. And so, that's kind of the series of events that kind of led me to where I continue to be now today.

Dr. Kineka Hull:

[10:12](#)

Thank you for sharing your story and your experience and being vulnerable. I think that is absolutely what we all need to hear. We are in this profession because we're passionate about it and we really want to make sure that we are providing the best support and education. As a person who is [00:10:30] coming to the advisory board with lived experience, how can we as health educators do a better job in making sure that we are very collaborative in including all the right voices?

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- Nadia Lockheart: [10:45](#) There's no straight answer for that, necessarily. I think ultimately it just comes down to consistency, making sure that we have this kind of space available for anyone and everyone who is genuinely [00:11:00] allied to our cause and our vision and really wants to advocate for these long disenfranchised vulnerable populations. And also, I think it's about sort of our bonding and resilience as a community that it's kind of a testament in itself, the longevity and the overall health of any sort of group of passionate like-hearted individuals who want to instill change in awareness and want to advocate for the vulnerable and marginalized. And so, I think [00:11:30] there's no real easy answer to that question necessarily, but that's kind of my perspective. And I think April could share some additional insight as well here.
- April Kayser: [11:38](#) I think that is the key. I think our role as a health department was to recognize both what we knew and what we didn't know, what we had skills in and what we didn't have skills in. So one thing we knew is that we had some experience providing relationship and sexuality education. What we also knew was that there were significant disparities among young people experiencing disability [00:12:00] in terms of relationship and sexual and reproductive rights related issues and health disparities. We also knew that we did not have a lot of experience or skill specifically supporting youth experiencing disability. So we knew that we of course, needed a collaborative approach that centered the folks who were closest to those issues, who had experienced some of those disparities themselves, who maybe didn't receive comprehensive sexuality education before, [00:12:30] or who worked with people experiencing disability and knew that there were opportunities to do better when it came to supporting their sexual health. So we brought our combined expertise or combined experience together in the community advisory group to accomplish what we have accomplished so far.
- Dr. Kineka Hull: [12:48](#) So a lot of our listeners are required to have some type of collaborative board for their projects or desire to have a collaborative board. Can you tell us about the other partners that you have? [00:13:00] I know when people are putting together their boards or some type of referral systems, sometimes they have questions about who really might be the best people to bring to the table. And so, can you tell us about any other considerations or any other partners that you think they should definitely consider?
- April Kayser: [13:16](#) Absolutely, yes. Of course we want to make sure that the people with lived experience are part of a community advisory

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group. So in this case, young people experiencing intellectual and developmental disabilities, community [00:13:30] members in general, including adults that experience intellectual and developmental disabilities, who can speak to their experience as young people. And then, we've talked a little bit about support people in organizations, so friends and family members, but also professionals who might be providing, for example, service coordination or case management support, or maybe they work in school as an educator or a support staff member, behavior support. Those are kind of more general examples. But what I would also say in terms of thinking [00:14:00] about the composition of a community advisory group is to think about having both local representation as well as state representation. So we are based in Multnomah County and we focus on Multnomah County, but we also have some statewide advocacy organizations that are part of our community advisory group that can help us amplify our approach, help us reach more people throughout the state.

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One partner in particular that I wanted to make sure that folks know about throughout the United [00:14:30] States are the university centers on disabilities. There's one in every state. The one that we are closely partnered with is Oregon Health and Sciences University, University Center for Excellence and Developmental Disabilities. They're the ones who host our SHEIDD online resource hub. So that takes it from a Multnomah, County-specific website to a statewide website, and is a great example of how we can fit those quality of life and health promotion efforts at a local level and a state level and weave them [00:15:00] together to reach more people. And then, the government programs would be something to think about. So how either for us it would be a county or a state is administering intellectual and developmental disability services. And then, if any youth sexual health or reproductive health government programs could also potentially be a part of that.

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And then we've also mentioned education in particular, but that could be teachers, that could be support staff, but also we have found that community transition programs are a really important [00:15:30] space to reach out to. And in Oregon, those are programs that support young people experiencing disability between the ages of 18 and 21 who are building career skills, building additional higher education skills, and also still getting to participate in comprehensive sexuality education as a part of that. So those programs in particular have been ones that are important to reach out to and folks can really speak to their experience in high school, but then also have the

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opportunity to participate in sex [00:16:00] ed in their transition programs.

Dr. Kineka Hull:

[16:02](#)

As a former college professor, I know that this is very needed and a shout out to all of the teachers. My mom is a 30 year retired teacher who worked with, I'm in North Carolina, it's called the Exceptional Children. And so I have a passion for this as I have watched her love her profession and all the things that she have done. And so I really want to shout out you and your partner because that's how I found you on the website. So it's not just [00:16:30] a state reach, it's a national reach. With that, I want to talk about that second piece that you mentioned, April, that talked about capacity. And so we've talked about the need. We've heard from Nadia's wonderful experience about how we still need to do more. What are some recommendations that you have for youth serving agencies and professionals as they work to build their capacity to provide support?

April Kayser:

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So in terms of how support people in organizations [00:17:00] can build their capacity, there are just so many opportunities. One thing that we were so fortunate to be able to do early on in our project was to conduct a community needs and resources assessment. And we were able to share that with the world on our web page. And so, you're definitely invited to take a look at that, and we would highly encourage you to do that because we use the results from those surveys and focus groups to create a report called In Their Own Words, [00:17:30] guidelines for supporting the sexual health of young people experiencing Intellectual and Developmental Disabilities. In it, you will find 13 guidelines both for providing sexual health education to young people experiencing IDD, as well as helping support people build their skills to be able to do that. So in terms of building capacity, we definitely encourage you to take a look at that, but also I think it is important for us to be aware of who is already doing this type of work in our communities and where the partnerships [00:18:00] and alliances can be built.

[18:02](#)

So I would encourage folks to try to find out who might be already working at this intersection of sexuality and disability in some way in your communities as you look at how to build your capacity in this area. Because like I said, for Multnomah County Health Department, we had that expertise in relationship and sexual health education, but we didn't have it in working with young people experiencing IDD. So we had to find those areas where we could work together. And there are [00:18:30] some spaces where we could find some common goals. Of course, I would invite folks to take a look at the SHEIDD online resource

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Hub as well and really become familiar with relationship, sexual, and reproductive rights, and especially think about how are youth experiencing disability able to access those rights or not able to access those rights in your communities, and what can you do to facilitate that access.

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It's one thing for it to be on paper. We all have these rights. It's another thing for us to actually be able to [00:19:00] exercise those rights. We often need a lot of support. And then building capacity can also look at being familiar with policy. So because we're talking about young people, often we're talking about education policies. So policies around human sexuality education in your states can be really helpful to know. In Oregon comprehensive sexuality education is required kindergarten through 12th grade. And so that is a policy that we work with a lot as we're [00:19:30] working to promote comprehensive sexuality education for everyone. But it's helpful to know that, helpful to know the health education standards that relate to our relationship, sexual, and reproductive rights.

[19:41](#)

And then, specific to working with folks experiencing disability. It's also important for us to know that some folks will have guardians and not just as minors, but possibly also once they become legal adults. And it's important for us to know about guardianship rights in our states so [00:20:00] that we know what sorts of decisions a guardian might be helping somebody with. And also so we can be aware of what decisions they aren't helping with because that goal of guardianship should be to support as much self-determination as possible. And there's a lot of misunderstanding about what rights people who have guardians.

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And then, I'll just mention one more thing, which is often people may shy away from comprehensive sexuality education, especially with this particular group of young folks because [00:20:30] people are not sure how to approach it. But many folks are much more comfortable offering sexual abuse prevention education. So I would encourage folks to be looking for programs or education happening in that sexual abuse prevention area and encourage folks to also explore opportunities to expand that to more holistic, more comprehensive sexuality education that goes beyond the typical messaging of no, go, tell, which is often what [00:21:00] sexual abuse prevention is, and those can be important messages, but holistic sexuality education is so much more than that. And includes helping folks have opportunities to build their skills around communication and communication about what they both want and what they don't want in addition to things like

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learning about their bodies and learning about their relationship, sexual, and reproductive rights. So that is another area I think, where folks can look to build their capacity and also work with people who are already doing the work [00:21:30] to find out if they can combine their efforts.

Dr. Kineka Hull:

[21:33](#)

Thank you for sharing. You've given us a lot of tips, and on your website, a lot of examples of how to actually do this fact-finding do this internal reflection of what your capabilities are and what your capabilities are not. And I think that's a huge thing. We are sexual and reproductive health researchers or facilitators or health educators, but there is [00:22:00] going to be some gaps whenever we are working with diverse populations. And so, Nadia, to piggyback about what you said earlier that as you look back and reflect on what you were taught or were not taught, you felt betrayed. I think that's a very powerful and impactful word for our listeners to hear about realizing what it was that you did not receive that you actually needed. And so, if you don't mind just elaborating a little bit more on that, [00:22:30] what can youth serving agencies and professionals do to make sure that we are really being of service and supporting and being impactful to the young people that we work with?

Nadia Lockheart:

[22:41](#)

Absolutely. I could go on and on numerous different aisles and alleyways regarding this, but I'd say the first and foremost thing that burns in the back of my mind is don't avoid these conversations around sexuality and disability. And what I mean by that is one of my favorite resources, for example, that we [00:23:00] actually implemented into our online resource hub is called Real Talk, and it's a Canadian-based resource and they have pizza parties as they call them. And essentially what the pizza parties entail is you have a mixed group of youth as well as adults who they have these nuanced discussions surrounding all kinds of topics regarding puberty and gender identity, all these other kind of nuanced topics as well. And [00:23:30] it's done in a way where it feels very natural, it feels like an actual authentic conversation. It doesn't feel stilted. There's something about the way that Real Talk tailors creates these conversations that feel very wholesome and you can really get behind because it's very relatable and very authentic. But that's just one way in which you could start having these conversations surrounding disability, sexuality, reproductive rights.

[23:56](#)

Another thing that I've been spending a lot of emphasis [00:24:00] towards since 2018 is reproductive justice. For those of you who are unfamiliar with reproductive justice or RJ, the short version of it is in 1994, the Clinton administration was talking about healthcare reform and some of the proposals or

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ideas that they were proposing at the time, a group of BIPOC women they've added together in 1994 because they felt like there were some aspects that were not accurately represented in the healthcare reform, [00:24:30] including things like being able to safely raise your kids in your communities and also other nuances like access to STI testing, stuff like that, and numerous other nuanced things that were not being adequately represented at the time. And that kind of set the stage for what we know now as reproductive justice with Sister Song and other coalitions banding together to kind of really put the momentum into focus.

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But essentially, reproductive justice is also [00:25:00] disability justice. And we've been having this ongoing effort to further educate ourselves about disability justice. It's a constant work in progress, I have to say. So none of us are by any means, any seasoned experts, but essentially it's like we are making a concerted effort to be aware of history and how it's deprived us of our rights and how we reaffirm and reengage with them. Again, part of why I felt betrayed previously and being kind of withheld from all this really critical knowledge [00:25:30] was realizing that so much of what I had been exposed to was myths and how myths deprive us of our sense of agency and also our dignity to a wide degree. And with that, it also infringes upon our fundamental birthrights. And so, I'll give you an example. One of the major myths that we're often faced in the neurodivergent community is that people with disabilities are not sexual beings, and they don't experience sexual desire to have sexual relationships alone.

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[00:26:00] I'm just one example that just is a testament to that's not true whatsoever, and many others can attest to that as well. It's not to say that there aren't some people who identify as asexual in the community, but the point is it's important to realize that we are just as diverse a community as any other. And even so, it's acknowledging the importance of advocating for all of us. Another myth is that people with disabilities are hypersexual and unable to control their sexuality. So it's [00:26:30] trying to have it both ways where it's like you're trying to insist we don't have any sexual capacities or circuitry, but then it's in the same breath it's like when someone does express it, it's like suddenly it's abnormal or something that needs to be controlled or tempered. And then, also that we're childlike and dependent. And also that you often hear that people with disabilities only have abusive sexual relationships if we even have them at all, [00:27:00] and that we're only capable of forming them if we're victims or perpetrators, which again is just very demoralizing, very dehumanizing I would add.

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[27:09](#)

And part of our work is addressing these myths head on and just acknowledging the importance of sharing and learning from others experiences and growing all the more wiser and resilient in turn. Part of how we do this is we embrace popular education in a lot of our education materials. The essence of popular education is [00:27:30] realizing that we're all teachers and we're all learners, and that also that we're always enriched by other people's experiences, that we all have something to give. And then that in turn, it also makes our communities a better place and we're imperfect. We're still learning every step of the way. We're still becoming knowledgeable about things like some of the aspects of disability justice, for example, trying to be more inclusive to other marginalized communities from an intersectional lens and being able to [00:28:00] do better in that regard, further making the uncomfortable, comfortable and continuing to have courageous conversations. That's kind of in a nutshell, a large part of what we do as an organization among many other things.

Dr. Kineka Hull:

[28:12](#)

I like that you highlighted reproductive justice and disability justice. I think sometimes the word justice makes people uncomfortable and it does lead to the need for some crucial conversations. There is a clear difference between equality and equity. And so [00:28:30] we know that there are some nuances where you have to meet individuals where they are and make a concerted effort to understand what is needed to be a good ally, to realize that all of those rights that you mentioned do not look the same for everyone regardless of the community and the intersectionalities from which they come, regardless of what we consider an ability [00:29:00] or a disability, it does not look the same for everyone. And it is our job to make sure that we are very mindful and conscientious of taking how you said the popular education and tailoring that to the community that we are within, and that we are all learning and teaching at the same time.

[29:22](#)

And so, I know as a teacher, I feel like I learned just as much if not more than talking with young people [00:29:30] and making sure that you are listening and being receptive to what you're hearing and are truly changing with fidelity, what you are doing to make sure that you're working with young people. Because a lot of times, especially with the reproductive health climate that we are in, trying to make sure that you have community buy-in and you have community support. Some of that comes with really listening to the community and being in tune and having [00:30:00] the right voices at the table to make sure that you are being an ally, a teacher, a learner, and a support. And so, with that, as we are starting to wrap up our podcast, I'll ask that

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you each in turn add any final thoughts of how we can be a better service to the young people that we would like to impact.

Nadia Lockheart:

[30:21](#)

For me, it's like I would double down on starting the conversation, having these courageous conversations every opportunity you get. I think often . [00:30:30] There's this kind of underestimating the curiosity and the interest of our youth to a large extent. And I think that the longer that we delay these opportunities for conversation, the more counterintuitive or counterproductive it truly is. So never underestimate youth. So that was the first thing I would impart. And then the second thing is there's five areas where we feel like we've identified where policies and practice should be more explicit about supporting [00:31:00] rights, which is communication where you talk about sexuality in respectful and affirming ways because tonality really is important in dialogue. So really it's like has a conversation, but also be respectful and affirming and how you have these conversations, making sure that they're safe where everyone feels included and their rights are affirmed.

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That choice is a huge aspect of it, where you're acknowledging rights and responsibilities in tandem with decision-making. You're supporting people [00:31:30] and learning about caring for and enjoying their bodies. And then arguably one of the most important ones to me is always having a commitment to growth. It's like again, getting in your growth zone. It's like you're kind of gently guiding them along the way, and in turn you become more capable and you become more confident and you become more resilient. So committing to a growth mindset is really important. And also, I just say organizational change, capacity strengthening and building is something that we really [00:32:00] take to heart and we've been doing for quite some time now. And what we mean by that is changing systems from the inside in a way where we're cultivating environments that better support the people that we advocate for. And also, again, implementing ideas like disability justice and making sure that we combat against things that hold us back from our highest ideals.

April Kayser:

[32:24](#)

Thanks, Nadia. I think Nadia is the perfect example of how important it is for us [00:32:30] to be working alongside each other towards our shared visions and our shared goals around sexual health for all. So I would just encourage everybody to realize that they have a role in supporting the sexual health of young people experiencing disability. We all have a role and to ask ourselves, what can I do in my position with the power that I have, with the resources that I have access to? How can I

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increase access for young people experiencing disability? And I would say, to build [00:33:00] on what Nadia was saying, disability justice is a really powerful framework, and it's one that includes a principle that is called leadership of those most impacted. And so I would also encourage us to remember and to continue to follow the leadership of those most impacted by these systems of oppression or systems that may be curbing or limiting access to rights for folks to really be following the lead of those who know the systems best through experience [00:33:30] so that we can create healthier and more just communities for everyone.

Dr. Kineka Hull:

[33:35](#)

Thank you so much. April and Nadia, this has been valuable information. I know I have learned a lot. I'm sure our listeners will as well. We have tons of resources in the resource list attached to the podcast. I hope that this conversation will be as helpful to others as it has been to me. Thank you so much April and Nadia for joining us.

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[00:34:00] If you enjoyed today's conversation, be sure to like and follow Elevate Youth Programming on your podcast platform of choice. For information on today's topic and resources and adolescent pregnancy prevention visit, the exchange at teenpregnancy.acf.hhs.gov. The Elevate Youth Programming Podcast is funded by the Family and Youth Services Bureau. The content in each episode is not the opinion of FYSB, [00:34:30] nor its training and technical assistance contractors. I'm Kineka Hall, and this has been another episode of Elevate Youth Programming.