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What Makes Inclusion Work: an Autoethnography on Coordinating an Inclusive Youth Advocacy Program

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What Makes Inclusion Work: An Autoethnography on Coordinating an Inclusive Youth

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By

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Abstract:

In this autoethnographic thesis, I analyze my observations as the co-coordinator of an inclusive youth advocacy program (YAP) to detail what made inclusion successful, and what was ineffective. I had the unique position of facilitating conversations and workshops around social justice issues and how to advocate using self-expression and art. In this thesis, I will reflect on the Inclusive Education Conference (IEC) in Spring of 2019, and the Summer Summit in the summer of 2019, both in Portland, Oregon. At the IEC some of the observations noted as harmful to inclusion included: people wanting to silence the youth, inclusion being coerced, neurotypical youth segregating due to lack of support, youth creating a hierarchy based on

disabilities, and inability to support youth due to lack of knowledge. The biggest takeaway was the importance of intersectionality. The observations around detrimental practices led to changes for the summer summit. Changes included: having more understanding of workshop, interview the youth to determine their motivation for being involved and their goals, schedule breaks to encourage socialization outside the workshops which led to more inclusive workshops, and being transparent with the youth so they felt comfortable to express themselves and make mistakes. Ultimately, the most damaging elements to the inclusive youth program were 1) When neurotypical youth are neglected due to the focus on inclusion. 2) when the outside world is still modeling ableist behavior. 3) when inclusion isn't a choice. The key finds that made inclusion most successful for this program were 1) the focus on intersectionality. And 2) being transparent and open with the youth. I also strongly encourage inclusive youth programs to not be rooted in disability as it already offsets the power dynamic of the group: rather have the group focus on a common interest.

Disclaimer:

Names were changed to keep individuals and organizations anonymous

Introduction:

I spent the better part of two years organizing and coordinating an inclusive advocacy youth program for young adults with and without disabilities to explore art and social justice. This was a unique transitional-age program designed to create conversations around social change and outlets for self-expression. For this autoethnography, I will be detailing my experience as a youth program coordinator for a disability rights and inclusion activist organization, Pacific North America Disability Support, PNADS, throughout two main events:

an inclusive education conference in April of 2019 in Portland, Oregon and a summer social justice summit in July of 2019 in Portland, Oregon.

Pacific North America Disability Support, PNADS, started as a family support group for parents of children with disabilities. Later it became a support hub for expecting parents and siblings to have access to resources and community, and eventually also a place where the youth with disabilities could go for support themselves. PNADS started hosting huge events and celebrations for people with disabilities and their family, along with doing advocacy and legislative work. In 2006, they started an annual conference dedicated to inclusive education and its best practices called the Inclusive Education Conference (IEC).

As the children of these families grew older and became more involved with the events and conferences, an inclusive youth program was created to give these siblings, youth with disabilities, and peers a group of their own. It was called the Youth Advocacy Program (YAP) and had the goals of bringing young adults, between the ages 16-24, with and without disabilities together to talk about social issues and expression through art. Some of the events that we did included a youth track at the Inclusive Education Conference (IEC), an annual summer summit dedicated to art and social justice workshops, and monthly social gatherings. I volunteered with PNADS for two years before being promoted to a coordinator position. In this new role, my job was to plan, organize, and facilitate conversations and activities around social justice and advocacy at the monthly meetings, the IEC, and the summer summit.

Through an autoethnographic narrative, I will detail my experience co-coordinating the Inclusive Education Conference and the Advocacy Summer Summit to explore my experience of what does and does not make inclusion work for young adults.

<u>Note on language</u>

For this paper when I refer to "youth" and "young adults" I am simply talking about the age range between 16-24 because that is the range that YAP consists of. There is considerable research debating different terms around ages and youth development. They are cultural bound terms, so this is by no means scientific or a societal decision. This paper is talking about young people with and without disabilities between the ages of 16-24. Another quick note, I will discuss specifics around definitions for disabilities, because that is important to understand the history of ableism and inclusion, however when I refer to disabilities in reference to YAP members, I am referring to any conditions— whether physical, mental, or cognitive— that a person believes is interfering with their daily lives. Finally, I occasionally use the term "successful" and "effective." Again, this is not empirical terms, rather based on my own observations, my co-coordinator's observations, and based on conversation with YAP members. I have drawn conclusions that led the YAP members to feel more and less supported as a group.

Conceptual Framework for Disability, Ableism, and Inclusion

Inclusion is a popular word being thrown around these days, particularly in the world of education and disabilities. According to the Merriam-Webster dictionary, the third definition down for Inclusion is: "3: the act or practice of including students with disabilities with the general student population" (Merriam-Webster Online Dictionary, 2019) To really understand the importance of inclusion, especially within the disability community, understanding the history of disability and ableism is necessary.

According to the Americans with Disabilities Act (ADA, 1990, amended 2008), a person has a disability if they have a significant impairment that interferes with a major life activity,

such as walking, hearing, learning, seeing, breathing, standing, lifting, or caring for oneself. This includes both physical and mental impairments such as visual, speech, hearing, or language impairments, emotional disabilities, learning disabilities, autism, attention deficit disorder, mental illnesses like bipolar and depression, environmental illness, and chronic illnesses like cancer, epilepsy, or HIV/AIDS. The United Nations states this is the largest minority (United Nations, 2019).

Ableism is a term used to describe the oppression that people with disabilities experience. Ableism favors those who are temporarily able-bodied and disadvantages those who are disabled. Ableism happens on an individual and a systemic level. For example, students being segregated in school settings due to their disabilities or a building not being accessible to wheelchairs are two forms of systemic ableism. For those who are able-bodied, it is important to remember this is a temporary condition, and at any point, we can become disabled.

So, what if we, as a society, changed the way we viewed disability? What if we saw it as a social construct as Susan Wendell suggests? She says that disability is created by our environment. One becomes disabled when they get put in an environment that doesn't support the needs of the individual, both physically and socially. Our social world includes the fast-paced society that we live in which is not set up for those with disabilities. If we alter the environment then the needs and supports that are necessary will change, and therefore what constitutes a disability also changes. If disabilities can change depending on the environment, then they are socially constructed concepts (Wendell, pg. 481-485).

<u>Importance of Inclusion</u>

This is what makes inclusion so important. Inclusion is a move towards the society that supports everyone and moves away from blaming those with disabilities for their difficulties.

Inclusion looks to create support systems with everyone in mind, not to make everyone the same, but to celebrate that diversity. Inclusion isn't about everyone just being a part of the group, it's about everyone being fully supported within the group. When people can be in an inclusive environment, they become empowered and able to do things they were restricted from before.

So what does make inclusion work? When talking about inclusion the main focus has traditionally been K-12 education. For example, Moore (2016), an inclusive educator and researcher who specializes in studying inclusion talks about what makes inclusion successful.

1. *Presuming competence*. According to Moore, presuming competence is necessary component of inclusion. For example, she once misunderstood a youth with disabilities with whom she was working because she didn't recognize his communication style. This led her to assume things about him. Despite communication barriers we might experience when working with someone, we must accept that the person is understanding and responding how they choose (Moore, 2016, pp. 33-34).

2. *Putting people first:* Moore isn't referring to a person's first language but simply putting individuals before their other identities, labels, or categories. She notes that we should celebrate identities, but not become so label obsessed that we forget the individual. (Moore, 2016, pp. 35-49).

3. *Inclusion is diversity: a composition:* Essentially, if we look at the classroom as a composition of individuals, we won't see the room split into the youth with abilities and disabilities. And learning how to teach to a diverse classroom makes educators better at teaching (Moore, 2016, pp. 41-43).

4. *Inclusion is critical*: Moore uses the example of bowling. Professional bowlers will aim to the side pins, to collect them all and avoid the dreaded 5-7 split. What if you took those

hard to reach outside pins away? Well there would just be a new set of outside pins. This is the same for the classroom. Moore (2016) says:

Homogeneity is a myth, and diversity is unavoidable. Classrooms have changed— for the better, I think— but our education system hasn't. Why aren't we teaching to the kids who have hoodies over their heads and headphones in their ears, who probably didn't sleep much and may be hungry, or even looking to the child who has autism as our starting point and aim? (p. 51)

She explains that if we teach to the hardest to reach kids, we would inevitably catch the others who educators are taught to teach (Moore, 2016, pp. 48-51).

5. *Inclusion is learning from each other:* This is straight forward in that we do all learn from each other. Moore gives the example of a student with a vision impairment who the other students created textured pages for, so that when the teacher read the story he could also engage with the pictures. This expanded the classroom experience for everyone (Moore, 2016, pp. 53-58).

6. *Inclusion is collaborative:* Moore talks about her experience working with a student and creating a great education plan for him, but without communicating effectively with the teacher, which made the plan not content relevant. This reminded Moore of the importance of collaboration with everyone in the team, including the student (Moore, 2016, pp. 59-64).

7. *Inclusion is multiple and diverse perspective:* This is the idea that we take all the stories involved to create a complete picture of the situation. This avoids judgements, assumptions, and attitudes towards parents and students. (Moore, 2016, p. 65-78).

8. *Inclusion is leaving no one behind:* This is Universal Design! And it goes hand in hand with inclusion. Universal Design is a concept in architecture that aims to limit barriers. The best example is wheelchair ramps were created to help people with mobility limitations, but not only people in wheelchair's benefit from them. This framework extends beyond architecture into education, medicine, technology, and other aspects of our lives. In Universal Design, supports may be designed for a few, but they are ultimately helpful to all. According to Moore, Universal Design needs to be more commonly applied in education and throughout the community (Moore, 2016, pp 79-85).

Moore does note that for inclusion to actually work, we do need time for collaboration, funding to support goals, space for teachers and professionals to grow, and materials and resources that help people respond to diverse students (Moore, 2016, p. 46). This isn't easily attainable in most cases, but it is necessary.

As Moore (2016) says:

So why is Inclusion important? It is important because we *need* diversity. We *need* each other. We *need* communities of varying ability, culture, experience, knowledge, and language. This symbiosis is important for inclusion to work and be sustained. It is critical, and not just for students with special needs. It is critical for every one of us. (p. 52)

Inclusion is critical, and because of that it can't just be for K-12 education. Inclusion needs to be researched post-school so that our society can get better at being inclusive in colleges, jobs, public settings, and everywhere. This autoethnography will discuss what I found effective and ineffective in an inclusive youth program for youth in transitional ages with hopes to start to bring the conversation around inclusion farther than just education.

Methodology and Method Design

To explore what makes an inclusive youth program work, and in turn what makes it less effective, I chose the qualitative research method: autoethnography. Autoethnography combines elements of ethnography and autobiography to analyze and write (*graphy*) about one's personal experience (*auto*) for a better understanding of a cultural experience (*ethno*). (Ellis et al, 2010). With ethnography the researchers become participant observers in the culture in order to observe the culture's common values and belief, practices, and shared experiences (Ellis et al, 2010). This gives them a better understanding of the culture for both the culture members and those outside of it (Ellis et al, 2010). With autobiography writing, the author assembles past experiences using hindsight to share these experiences, and these are often epiphany moments (Ellis et al, 2010). Combining elements of both is what makes autoethnography a self-reflective research method.

For this thesis, I combined qualitative research on key aspects of inclusion with narrative storytelling of my own experience— First reflecting on my relationship with disabilities, and next detailing and reflecting on my experience planning and coordinating the Inclusive Education Conference youth sessions and the annual Summer Summit a few months later.

<u>Background and rationale</u>

Autoethnography is a newer qualitative research method that was created due to the need for more reflection on how the researcher interacts with the culture around them. Briefly understanding qualitative research is helpful, and Mariza Méndez describes that journey. She writes (2013):

In the traditional period (the early 1900s), researchers aimed at presenting an objective

account of their field experiences. The modernist period (from the post-war years to the

1970s) was characterised by researchers' concerns about formalising qualitative research

to be as rigorous as quantitative research. The period of blurred genres (1970-1986) was

characterised by the diverse research strategies and formats used by qualitative

researchers. (p. 280)

Méndez explains that, during the 'crisis of representation' period (the mid-1980s), autoethnography emerged to highlight the ethnographer's interaction with the culture being researched, allowing us to draw on our own experience (Méndez, 2013). For these reasons I chose autoethnography as the methodological approach best fitting to narrate my experience coordinating an inclusive youth program, and my observations around what was effective and what wasn't effective.

Autoethnographies inherently both reflect on the process while going through the process and creating something. I was already doing the work, and it felt like the right time to write down those thoughts and really consider what I was finding successful about coordinating an inclusive transitional young adult program and where the downfalls were. So often youth with disabilities are only talked about in terms of inclusion in education and its core subjects of math, science, English, and history. I am not a teacher, and I am not coming at this from an educator's point of view, but rather, from a social work point of view. My job is also to build different conversations than the ones that tend to happen at schools. YAP is focused on conversations around ableism, sexism, racism, immigration, environmentalism, and other social issues, along with how we can combat these social issues through art and advocacy. YAP is also focused on the age group 16-24. This is a more transitional age group than is typically discussed, as much of the existing

literature focuses exclusively on K-12 education with limited discussion of college-level inclusion. My research sought to address a gap in the research on what makes these groups, and similar groups, successful.

<u>Limitations</u>

There are limitations to autoethnographic research. First, the question of ethics comes up, and the concern of the participants not being aware they are being researched. According to Méndez, Ellis emphasizes that autoethnography should be inherently ethical because the writer should be honest about the experience and events (Méndez, 2013). While some might think that is a bit hopeful, I will add that for me, I considered ethics a lot with this project. I reminded myself often that I did not change how I acted as a coordinator due to working on an autoethnography. I also approached this project as one primarily involved self-reflection about what I noticed was helpful and hurtful.

Other criticisms of autoethnography include its focus on the self which has been called self-indulgent and too individualized. Others say it simply is not scientific enough and is too artful. Finally, some critics suggest autoethnographies are inherently biased. (Ellis et al, 2010). I am not going to disagree or agree with any of these points, simply because I am not making an argument for autoethnography across the board. In this autoethnography, I sought to make my narrative attainable rather than scientific. It *is* individualized for a reason, and yes, it has biases because it is my story. My hope is that I told a story, based on years of time, energy, self-reflection, and research, that will help social workers and others create more inclusive youth programs.

My Autoethnography:

Self-reflection is a key component of autoethnography and was a central part of being effective in my role as the youth coordinator. When I got that role, and even as a volunteer, I explored deeply how ability and disability connect to my life, I feel I should start there. First and foremost, I recognize that being able-bodied is a temporary condition that I am lucky to have. Second, I consider a question I was asked at an ableism training I attended: "What is your first experience with disabilities?" I thought of all those early moments of my life in which I intersected with disabilities. I remembered my first friend and the hours we spent playing in her basement, who years later I would find out had a developmental disability. I thought of my best friend at 11 years old, who had a deaf uncle, and in turn, she was also going deaf. I remember fearing him and not knowing why. I wouldn't understand until years later that it was my lack of ability to communicate with him that scared me. I remember the "special ed" classes at school and the kids who were in them, how the other kids treated them, how the teachers treated them. I thought of friends throughout my life who have been on and off medications. I thought of elderly folks in my life who once did not have a disability and now use a wheelchair or walker. Then I thought even more, how I was always one step away from some of those situations.

I thought of the time in first grade when I was taken out of class and brought to one of those "special classrooms" because I had trouble reading out loud. I remember my mom coming to the school and arguing with them until I was put back in with the other students. My first experience with disabilities was the conflict over whether my impairments required extra help, and that my mom didn't want that. I thought of my glasses and how I could not drive without them, or the challenges I would face in school without them. Yet, I am not considered disabled despite either of these conditions. I thought of mental health, how it has impacted my life and

people I know, but even more, I considered its invisibility. We pass people every single day who experience disabilities through birth, war, and everyday life, whether we are aware or not. We ourselves have them or could easily have a life change that brings about a disability any day. A more inclusive world is a better and safer world for those around us and ourselves yet it's a demographic so often ignored. As I moved towards social work as a degree, I started working with this population more. First with adults in residential care and later volunteering with PNADS, until my promotion to the Youth Advocacy Program Coordinator through PNADS.

I knew I wanted to detail my experience co-coordinating the Inclusive Education Conference because in previous years this event has been really impactful to me, so I started to document in the spring of 2019 as we prepared for IEC. IEC is a two-day event when parents, teachers, students, government officials, and community members come together to talk about and advocate for inclusion. I had attended two years before becoming a coordinator and each year I noticed feeling so comfortable and content. As someone who has a long history of social anxiety, being comfortable around hundreds of people was not a normal feeling. When I got promoted to coordinator of the youth program, I was so excited to be part of that group that created that safe space and inherent judgment-free zone at this event.

My colleague, Annie, and I had been running YAP together for over a year by this point. We had already had a successful IEC summit last year, completed the advocacy summit, and we knew the group well. By this point, YAP was a consistent group of between 8-16 young adults aged 16-24 years old. Some of them were children of parents who ran the organization, some were friends of those families, and a few were from outside of the organization. Annie and I were doing our best to expand the community, but it was difficult due to different factors such as office location and time restrictions everyone had.

To prepare for the conference Annie and I spent a lot of time researching which topics were going to be helpful to this set of young adults and talking with the group about what they would find useful. After collaborating, we decided on sessions dedicated to self-care, transitioning out of college, resume building, goal building and other transitional topics. We had meetings with different presenters, had workshops created, and for the most part, we knew what the layout of the weekend would look like.

The weekend of the conference arrived, but not without complications. Several sessions had been changed on us due to logistics with those running the conference. This was difficult, but we were able to adapt and manage. The first day went well overall, the youth got along and were mostly engaging with each other.

The second day was a different story. At the start of the day while setting up, our boss came up to us and asked us to stop one of the youth from speaking on stage at the end of the conference. They said that this particular youth focused too much on relationships when they spoke the night before, and not enough on education. Annie and I were devastated. We knew this particular youth was very passionate about marriage rights for folks with disabilities because if you get married you lose a portion of your benefits. We knew this is such a valid social issue, and she was just being a strong advocate. We were so heartbroken that we were being told to silence her. Annie and I talked between ourselves and agreed that we would not follow through with stopping this youth from speaking, took a lot of deep breaths, and got back to work. But the whole day was thrown off and we both felt very uncomfortable with our values now being misaligned with the organization.

In the first couple of sessions, we started to notice a few concerns right away. One table of "neurotypical" youth were not sitting with the youth with disabilities. All of these particular

youth had been in YAP for many years and we had a great relationship with them. Annie and I pointed out that the tables were looking segregated with the hopes that they would switch things up. They ignored us and continued to sit with the same group. This was not typical of them in the past, and we were already frustrated with the sessions changing and with the conversation from that morning. Finally, we just told them to move seats. They were very upset with us, again, not typical of what we had seen in the past.

Another thing we started to notice at this time was a very distinct divide in the youth with differing disabilities. Frequently in these inclusive environments youth with and without disabilities partner up at points to help each other complete projects. This time, we noticed a lot of youth with disabilities choosing to work with each other. We quickly noticed the youth participants who were verbal and have autism, were taking a "caregiving" role of youth who were either non-verbal or had Down syndrome. We would notice interactions that would have been considered very condescending, such as patting another youth on the head, or saying "No, bad!" Sometimes, we witnessed one youth physically moving another youth around. It was very difficult to watch and Annie, myself, and the lead volunteers were doing our best to interrupt the behavior when we saw it. At one point we had to stop a session to talk about how everyone is equal despite any type of disability.

Another issue we ran into throughout the day was that there were some youth we did not have the capacity to support yet or did not know what supports that they needed to be fully included. For example, to support youth who yell or become aggressive. We need to know their triggers and their coping skills. We ask for this information, but often do not get enough details. This causes disruptions for other youth. Along the same lines, we had a youth who just simply did not want to be there, but their parents made them. During our check-in we asked what people

were excited about and they said, "I hate this and wish I could leave." This felt damaging to the community as a whole. For an event to be inclusive, it cannot be coercive. The youth need to want to be part of it, inclusion cannot come solely from the parents.

The day continued, and overall, Annie and I felt pretty defeated with how the day was turning out. There was a huge lack of the type of inclusion we had seen in previous years. The youth were clearly frustrated and upset and we did not understand why. We were clearly upset, and they didn't understand why. There was a tension that was unbearable the entire day. The conference finally came to an end, and overall, I really felt like we failed. I felt like we let the youth down and we were certainly let down.

Later that night I got a text from one of the youth that I had mentioned earlier wasn't being inclusive. She wrote that they felt singled out and attacked when we made them move seats. She explained they were all having a really hard time that day based on different reasons and that she herself was having a lot of anxiety that day. I felt guilty for not checking in and frustrated for being called out for not being a good leader at that moment. As I thought about it, I realized she was right. I should have considered why they were acting differently, as opposed to just being frustrated with them. I was so focused on "inclusion," that I was ignoring the "neurotypical" youth, who also needed support. Their support just looked different, but I didn't bother to ask what they needed.

Annie and I met up soon after to talk about everything and think about where things went wrong. We thought about how the session changed on us at the last second. We thought about the disappointment in trying to silence a youth. We thought about the internal ableism we saw in the youth. We thought about how a good chunk of the youth didn't want to be there but were forced by their parents, and how that created its own issues. We thought about our lack of

support for some of the youth. Then we decided to think of the good things. We talked about the two Chinese youth who both experience a disability and how they connected by speaking Chinese together. We talked about a youth of color with a disability, who told us how meaningful it was for him to see an adult of color who has a disability present to them. Other youth spoke Spanish with each other and bonded over that. We thought about the session where they worked with a disability rights activist and created "Who Am I" poems exploring their identities. We talked about the end of the conference when they chose to read these poems in front of a full audience of over 600 people. And how the youth felt comfortable enough to confront me about issues they had with how I was leading, which means we now know and can work on it. We had advocated hard for intersectionality to be a key part of the curriculum, and this was the proof and confirmation that we needed.

When I say intersectionality, I'm referring to the term coined by legal scholar Kimberlé Crenshaw in 1989 to explain the unique interlocking oppression of race, gender, and class that black women face which separates their discrimination from that of white women or black men (Warde, 2017). Other intersections can include religion, disability, ethnicity, immigration status, ethnicity, and sexual orientation/identity (Warde, 2017). Essentially our different identities overlap to shape how we experience the world and how the world treats or impacts us. I'll also point back to that dictionary definition of inclusion, "4: the act or practice of including and accommodating people who have historically been excluded (because of their race, gender, sexuality, or ability)." (Merriam-Webster Online Dictionary, 2019). The topics of intersectionality and inclusion are inherently tied together, and yet society continues to pull them apart. We did not want to be part of that continuous cycle.

We had two choices to be defeated or try again with the new understanding we had of what worked and didn't work when creating an inclusive environment. We knew we had another upcoming chance during our summer summit to make a great inclusive and intersectional experience, and we wanted to make sure we got it right. We first knew we needed a break because we were jaded, and the youth were drained too. So, we took time away to reflect and then came back together. In that time away I took a step back from leadership roles and became a participant in conferences myself to observe what made me feel comfortable in the role of a participant.

When we came back together, we took all the issues we had with the conference and fixed them. First, our lack of control over the session topics became an issue during the IEC. This time, we set boundaries around outsiders making changes to our schedule and made sure we were a bigger part of the progress so if anything changed, we would still be able to keep with schedule and run the session. We met with workshop presenters at coffee shops and bars and over zoom meetings to ensure we were using universal designed to create workshops using our expertise on the youth and inclusion, and combining this with the presenters' expertise on the topics. I researched lesson plans around different topics like sexism, racism, the queer community, art, and created ones that were accessible for the whole group despite ability levels. We designed a specific structure over the three days so the youth would have enough time to bond and explore different parts of their identities and work together.

Another huge issue we faced at the inclusive education conference was the youth who did not want to be there, and youth we were unable to support. This time, we interviewed each person who applied to see what made them want to come to the summit. We asked each participant what they hoped to gain from it, so that we could make sure the topics we picked for

the summit interested the youth. We also wanted to make sure that the individuals would be a good fit together. We knew we wanted the focus to be on each individual so they felt empowered to bring themselves into the community.

The Summer Summit arrived, and we felt a lot more confident about the direction. The first evening of the summit was dedicated to community building, and Annie and I made sure to be included in that. We built rules and goals together as a group. We did some icebreakers and made sure to have fun. We noticed at the conference and previous summits that the youth with disabilities wouldn't sit with their peers unless asked. We took away this pressure from the first dinner, by having a huge table that everyone sat at together. Then the next day by choice, they sat together.

The second and third days were structured the same around sessions and long breaks and social hours. The second day mostly focused on intersectionality and understanding our identities, while the third day was about how those identities intersect with the world. We had topics on sexism, sexual orientation, and gender identity, transitioning into adulthood, white supremacy, and mental health and the brain to name a few. All the sessions were very interactive, and we, as facilitators, tried to make sure to be present with them too so that we were all going through the journey together. This appeared to make the youth feel more and more comfortable with us, and it helped us create a completely judgement-free environment. This was a game-changer and led to deeper conversations. For example, more than one youth asked me if their parents would see how they identified their sexual orientation. When they heard their parents would not know they changed their answers. It seemed clear that sexuality and sexual identity were things participants have wanted to explore and discuss but lacked a safe place to do so.

Another thing we had noticed about the conference was that we had many sessions back to back, with very few breaks. This burned us out, it burned the volunteers out, and made it impossible for the youth to retain the information they were receiving. For the summit, we knew we wanted to give the participants more free time. This was something I found to be extremely helpful when I was a participant of conferences. These breaks became important time to breathe and time to bond for me, and I wanted the youth to have that freedom too. In between sessions, the youth had long breaks to get some space or spend time with other youth. These breaks were so important because this is when they worked on TikTok dances, got pulled into love triangles and drama, and did all the things that teenagers and young adults should be allowed to experience together. This is when a huge part of the community building happened, and that community building was so needed for the workshops to be engaging.

This weekend didn't go without problems, but overall the problems were nothing like at IEC. The biggest difference was we confronted issues head-on this time. At the conference when we saw segregation, we moved seats. At the Summit, we started off by having a really open conversation about the expectation of wanting people to engage with new people early on. The youth agreed and we didn't have an issue with it again. The incentive needed to be mutual and they needed to be interested in and understand why we were putting these intentions in place. At the conference, we forced this too early, without talking about it— which led to discomfort and anxiety. For the summit, we talked about it and were transparent about the intentions. Having these open conversations made everyone feel safer to ask for what they needed while still pushing themselves out of their comfort zones.

When rules were broken or bent, we were able to take the individuals aside and have honest, frank conversations about why the rules were important and what the consequences were.

Creating a group dynamic where people felt respected and trusted to be themselves— and to make mistakes— is what made inclusion successful. Our leadership and individual support led to them being comfortable in the group environment. This, in turn, led to successful conversations around tough topics like race and sexism, completing huge group projects like creating a map of the brain as a group, and completing scavenger hunts through a farmer's market. The way the group members interacted with each other, with the session leaders, and with us absolutely made us feel that these changes made the group much more inclusive. By the last night of the summit, the focus on intersectionality helped everyone feel more like individuals, the whole group certainly had a strong bond, and everyone's supports looked different, but no one was looking at each other negatively for those differences. In fact, everyone was doing what they could to accommodate each other. By the end, each youth left with personal and community goals.

The Summit ended with a bittersweet feel, as Annie and I knew we were not going back to PNADS. We knew that we were limited there for a number of reasons, and a truly inclusive program wouldn't be possible in that environment. A key part of Pacific North America Disability Support, that people forget because they do so much advocacy work, is that they started as a parent support group. We were trying to run an inclusive youth program through a disability service and a family service. This structural and historical reality introduces two biases: 1) That we serve a certain population and 2) Parents have more power in the organization. These types of organizations and support groups are awesome and so needed, but this is a youth activism and advocacy program, so inherently it can't be run by the majority of the kids' parents deciding what they're passionate about and dictating their projects and statements.

Along with that, we are currently bringing people to the wrong table in a couple of ways. First, we have a table of youth with disabilities, and we are asking them to come to us when

that's not how our society works. The dominant groups need to look around and notice who isn't at the table, and then open that table and listen. Second, PNADS is also bringing the wrong people to the table and not looking around at who needs to be included. For example, the youth who attended the summit were all white and predominantly middle class so they experience privilege despite the other identities they hold. Without the right mix of people, we can't have the conversations that we're ready for and that are needed. Because of this, we decided to change a workshop to be a panel about the impact of racism to the prominence of white supremacy in our society. Ongoing we can't just keep changing workshops, we need to attract different and new people to expand the conversation. Annie and I don't believe that is going to happen at PNADS. We left the organization with the goal and intention for them to create a young ambassador program or something similar. The youth can continue the work that they're doing in that organization, but with actual power and choice. This will help the youth who want leadership roles and the youth about to age out stay engaged and mentor the next group of youth.

Implications

Overall the main take-aways between the Inclusion Education Conference and The Summer Summit together were:

What was damaging to the inclusive youth program?

1. When neurotypical youth and youth with disabilities aren't treated the same. We all have dynamic aspects of our lives interacting and we all need support. My lack of noticing that some of the "neurotypical" youth needed some 1:1 leadership led to the whole

community having issues the second day of the conference. When we were able to provide 1:1 mentoring, even briefly, those relationships and trust grew demonstrably.

2. When in the outside world, we were still being ableist and modeling that behavior. This is why some of the youth felt the need to over-help other youth with disabilities. The youth who were engaging in that behavior all attended a school that had a reading level requirement to get into their college program. These students who were able to get into this restrictive program, were being ableist towards youth who they seemed to view as "more disabled" than themselves, as these youth wouldn't have been able to pass those same required tests.

3. When it was forced. It needs to be a choice; you have to want to be included. You have that right. You also have to work on skills to do it. You can't just throw someone in because it might unsuccessful without the correct support, and in turn damaging for future inclusivity. You can choose to be as included or NOT as you want. Oftentimes inclusion is forced and leads to discomfort.

What was effective for the inclusive youth program?

1. When incorporating and celebrating intersectionality and making sure you're bringing everyone to the table and getting everyone's voices. If the youth can feel confident as individuals, they bring that to the community. Both at the conference and summit, youth seemed to gain more when they were exploring how their identities overlapped.

2. By being open and honest with the youth. Talking to all of them like the people and individuals that they are was huge. This is something people forget when working with youth in general, but it's so, so important for them to know they have agency and their

opinion has value. The damage that happened at the conference wasn't solved until I had that uncomfortable texting conversation with a youth about how they felt unsupported. At the summit, making sure to be transparent and have open conversations led to the community feeling open and able to ask questions and engage in tough conversations.

Shelley Moore might call some of these aspects part of "Inclusion 2.0" or "teaching to diversity." We can no longer assume we are teaching to a "majority." Classrooms are so diverse now that students are different and need different supports, and this diversity needs to be seen as a strength to the classrooms and communities as opposed to a burden (Moore, 2019). We received a lot of validation when we decided to follow our own curricula during the summit and decided to leave afterward.

For Annie and I specifically, we now have a lot of skills and understanding in how to run a program through an inclusive lens, we can take that approach and run a youth program that does not have connections to a disability resource. I feel that a properly done inclusive program should be rooted in something that isn't disability focused. It can be video games, it can be social justice, it can be education or art, it can be literally anything else. But when we make the target group the group's focus, we're already offsetting power and inputting a dynamic. Inclusive groups can't get rid of power imbalances that their larger society has created but they can acknowledge them and work to counteract their effects within the group. An inclusive group can be healing if done right, but more damaging if it creates a system of dependence, learned helplessness, and damages self-esteem

We feel programs being run in this format are more likely to be truly inclusive. This will normalize that young activists with disabilities are young activists who deserve to be in all conversations around social justice in whatever way they communicate, and not just

conversations about disability. With YAP we were constantly reminded that this group is for social connection for young adults, specifically with disabilities. And that's nice. We can create safe spaces for friendships, but that won't necessarily make a change or provide their kids with the leadership opportunities or long-lasting, goal-setting skills, or evolving friendships they need. It won't help get youth with disabilities ideas out there, and a lot of the youth are aging out or will be soon and will lose the social connection anyway unless they learn to branch out and find other places for socialization. It just creates a bubble where this person is empowered in one small place but gets crushed by the weight of the world as soon as they leave that bubble. We created one of those bubbles and it is amazing in that bubble. Now we need to use those skills and the framework to work on making outside the bubble safe also. We need to take these young adults outside of the same circle they've been in, so they're sharing their ideas with new groups. It's time for us to give the power to the youth at this specific agency and let them run the program.

A better format for running an Inclusive Advocacy Youth Program: 1) Take the three-day summit to different locations, programs, and organizations to spread that inclusion is possible, awesome, and to create better conversations around it. The focus and theme would be social justice and advocacy, or 2) A year-long youth engagement program dedicated to teaching young people about grassroots community organizing. A cohort will get together to learn about intersectionality, identity, and creative expression and activism. They'll create teams and work on a civic engagement project throughout the year. The program will end with a retreat where cohorts talk about their projects. Regardless, it is obvious that continuing to move towards a more inclusive community with an intersectionality lens is necessary for the growth and development of society, and this is the work we will continue to do.

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