



## Webinar #3 Archive of Small Group Discussions

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During the 2018 Autism CARES Virtual Activity Webinar #3, participants were divided into small groups for discussion on how to put together the pieces presented in the Keynotes and Grantee Spotlights, along with their existing knowledge and experience, and apply those concepts to their individual work and the collective work of the network. This resource offers a summary of the discussions within the break out groups first by theme and then by individual discussion.

## Themes across groups

### 1. Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?

- The Social Justice theme
- History: How far we've come but more needs to be done to improve equality and inclusion
  - It's a sensitive issue, change takes time, focus on raising awareness of the issue
  - Ableism across the spectrum of disabilities.
  - Working with an underserved population (not used to having people with autism in the community), there's still much stigma
- "Nothing about us without us!"; listen to the voices of autistic individuals; Respect is key
  - Improved recruitment of trainees and future professionals
  - Don't put the burden of understanding autism on the person.
  - Language Matters: person-first vs identity-first; "fixing"
  - Diverse perspectives among individuals
  - Participation and inclusion takes many forms and should occur in all aspects (including research) and at multiple levels
  - Aligning university priorities that the university with the priorities of people with autism and other PWD
  - Principles of Universal Design for Learning (UDL)—process matters most!

### 2. Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the broader autism community?

- discussions about how to be inquisitive to and responsive to others' identity preferences (including disability identity, gender identity, racial and ethnic identities, etc.) in clinical settings and elsewhere
- Increase self-advocates in leadership roles (e.g. faculty, mentors advisory roles, trainees)
- Change in focus of family advocacy to align with autistic community's priorities
- Convey to trainees and research "nothing about us without us" -- make sure that people who are impacted are also involved in the discussion and model this motto in the work that we do
- Meeting adults who are diagnosed later in life
- Agencies are doing work around increasing access to their programs for those with disabilities, e.g. HRSA
- Opening a dialogue over problematic/ableist language as opposed to just shutting down people who use language that is ableist.
- Network members working on these issues
  - LEND network tries very hard to understand and incorporate these self-advocacy issues -- funding announcement and various workgroup struggle with this concept too
  - State agencies and public health organizations; many are improving awareness of Autism and addressing ableism, but in ways not discussed in the keynote/webinar 2
  - Leadership in UCEDD= training and systems change around ableism; greater need to remind communities about the concept of ableism.
  - Community support groups, centers, all coming together to address these issues; progress being made slowly but surely

### 3. What resources or activities would result in a system of support that prioritizes the voices of autistic individuals? Do these resources exist or do they need to be developed?

- Informing research questions and priorities is a good area to focus on (increase involvement of social scientists)
- Issues to consider in this process:
  - adult voices speaking for children's needs is still an issue
  - balance of voices heard (diverse disabilities and also other aspects of diversity – geographic, socio-economic, racial and ethnic, etc.)
  - how to include autistic voices on didactic topics/ content (e.g. training in evidence based screening, diagnostic, and treatment)
  - how to make sure you include the full spectrum of voices in the discussion? by asking organizations to select their representative, asking them to send different representatives (part of the UCEDD project), several community partners and organizations, statewide information organizations, using community partnerships for LEND self-advocacy trainees to get involved
- In training:
  - Need for resources and activities around neurodiversity --help prioritize voices of autistic individuals
  - Need for more self-advocates on faculty to prioritize autistic voices
  - Need for self-advocates to be involved with developing curricula
- Develop resources for families -- including families who are low-income, of color. Including resources to help them get initial diagnosis.
- For autistic children-- they're children first! Having autism is not a bad thing
- Parents of children with ASD writing a "vision statement" for their child (e.g. have friends, go to college, etc.).

### 4. In what ways could your CARES (and related) work become more inclusive? What are the challenges to implementing these changes? What opportunities would these changes create?

- Include people with autism in many levels and forms
  - in advisory activities or staffing
  - in curricula development
  - in research on evidence based practices
  - Be proactive in getting autistic representation
  - include self-advocacy trainees in the self-advocacy discipline rather than a professional with a disability
  - infuse family and SA across campus strategic planning
  - Integrate disability throughout curriculum in pre-service training.
  - Make college and graduate programs more inclusive to autistic students
- Having clear conversations regarding the SA's role based on a discussion that involves both the program and the individual
  - Consider how autistic students contribute to the program and highlight those skills, characteristics, etc.
  - have a strong orientation to the LEND program for projects, what the seminars look like, etc., whether they can or cannot have certain roles and why (e.g. going to clinic visits)

## 2018 CARES Virtual Activity/Activities

Webinar #3 – October 29, 2018, 2pm ET (1pm CT, 12am MT, 11am PT)

### Breakout Discussion Notes

- What's next for self-advocacy trainees after they finish LEND
- Rate of transgender folx with ASD is higher than neurotypical population -- how to use intersection to heighten their sense of belonging?
- Consistently pay individuals with disabilities for their contributions
- Resources shared through these webinars can serve as a guide for future conversation within programs
- Utilize UDL
  - In teaching
  - Making modules/materials/assignments/readings accessible for everyone. Have
  - role models and mentors for SAs aligned with their individualized leadership plan
  - Recognizing the scaffolding to see what kind of supports SA trainees may need -- start everyone at the same level early on (recognizing that any trainee may need to start from the beginning)
- Challenges
  - In pediatric grants, autistic adults are interested in screening for autism which is a key focus
  - Grant funding being temporary is a challenge to consistently paying self-advocates
  - Institutional rules also are a challenge to paying self-advocates
  - Attitudinal barriers to recruiting people with disabilities into health professions that continues to persist, even though we have shortages in health care professionals.
  - Some disciplines more progressive than others.
  - Issues around income and benefits, with regard to paid employment for self-advocates.

### 5. How can your CARES (and related) work add to the knowledge base on addressing ableism?

- PCORI is helpful within health research context, because funding focuses on including voices of individuals impacted by the research. This reinforced and added new ideas to directions we were going, will use these ideas in future grant applications.
- Theme from Trainees: be an ally"--following autistic individuals shared stories/experience-- consider how one can best support or be best ally through interactions and work
- Purposefully include autistic participants; interested in being a self-advocate
- Educate others about the word "ableism" and how it relates intersectionality to other marginalized communities (i.e. people of color, LGBTQ+, religion, etc.)
  - Ex) Queer folx considered "disabled" by outside folks, which LGBTQ+ then reject in an abelist way
  - defining Ableism to trainees
  - LEND Programs have an opportunity since it touches programs across the institutions, can distill knowledge across departments and universities.
  - Consider research on culture and health disparities as they relate to ableism (i.e. the intersectionality between racism and ableism, access to care/quality care mediated by disability, race, and gender)
- Be mindful and embed disability competence into the framework of your actions/work
  - Cause vs. Cure ... Intervention vs. Care ... Medical Model vs. Social Model
  - Be careful about "prevention" - abelist (eugenicist)
  - Viewing different diagnoses with different levels of stigma.

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### Breakout Discussion Notes

- Principles to abide by:
  - allow autistic individuals space to communicate
  - don't speak for the experiences of another
  - recognize and acknowledge what you don't know
  - recognize that perspectives differ across spectrum
- Being purposeful with funding
- Potential to learn from the lessons of the family discipline. (Families on advisory boards, as trainees, as panelists, etc.)
- Have to focus on the social experience of disability, not just focus on the medical model, in order to effectively address autism.

### 6. In what ways will you commit to taking action to address ableism at the individual, program, organizational or systems level?

- Infuse concept of "ableism" into talks, into conversations about multiculturalism
- Feel emboldened to push programs to be mindful about tokenism and remind colleagues about ableism
- Designing research with a disability perspective/lens
- Ensure that all aspects of work are informed by autistic individuals, as partners AND as drivers
- True engagement with self-advocates
- Continue to teach principles beyond LEND curriculum --including medical students, psych residents, fellows, etc.
- Pay self-advocates for their time and expertise
- If the grant is focused on ableism or adults or transition, include autistic adults as contractors.
- Joining the family and PWD workgroups via AUCD
- Ask trainees to look on social media to see how often ableist terms are used and see how they view people with disabilities in the media (art, culture, movies, news, etc.) -- moving away from the mindset of "suffering from" "overcoming this" "we will beat this" , book called "no pity" from Joseph Shapiro gives a historical perspective
- Added the topic (ableism) to LEND faculty meeting, once a month have a "coffee chat" to redeliver information and participate in discussion
- Coffee chat - meet over coffee to participate in a 45 min discussion on various topics and/or watch a TED talk before the meeting and chat about it
- Including this topic in a lecture in the spring.
- Including in lecture materials, take information and work to improve experience for LEND programs, and bring to advocacy networks.
- Tuesdays with Liz - makes policy more accessible for all
- Continue to speak up individually on ableism and be open to dialogues on an organizational level.
- creating safe and inclusive opportunities for discussion about language (e.g. disability- identity versus person first; gender identity);
- Inclusion & ensuring autistic adults and other stakeholders are on research and practice teams;
- ensuring (because participants have come and gone) that autistic individuals are included in several different project advisory groups;

- ensuring that communication is inclusive (e.g. opportunities to speak, or text, or reflect later after given time to process);
- and work with a group of individuals to ensure that diverse voices are heard instead of relying on one or two representative perspectives.

## Detailed notes by breakout group

### Breakout 1:

1. *Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?*

I liked the push Ari gave us to focus on more community participation in autism research and make the research relevant to them

2. *Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the broader autism community?*

we've had very interesting and fruitful discussions about being inquisitive about and responsive to how everyone wants to be identified -- this includes disability, as well as other identities like gender identify It's been very individualistic, based on conversations, because different individuals in "group" identify differently and have different preferences

In the WI LEND we have addressed these issues in our leadership development workshops for trainees, helping them to think through how to be inquisitive to and responsive to others' identity preferences. The conversations in this case are health care visits, but they also acknowledge that follow-up can occur "virtually " through the EMR, but another tool that has been used is a tablet used for youth to respond to questions in the visit, pre and post visit.

Also, in our work with Youth HEALTH transitions, we work with a group called PATCH which helps clinicians and youth have these types of conversations to get to know each other

3. *What resources or activities would result in a system of support that prioritizes the voices of autistic individuals? Do these resources exist or do they need to be developed?*

One thought I have is that informing research questions and priorities is a good area to focus on - through whatever methods. Part of what CARES probably needs to do is increase involvement of social scientists in setting research priorities. But I think the issue of adult voices speaking for children's needs is still an issue - this is a well-recognized limit in childhood studies, so we need to be careful and thoughtful about this issue

In terms of LEND, it's also important to maintain the balance of voices heard from people with other disabilities - we focus on a wide range of developmental disabilities and then also including diversity by race, ethnicity, SES, region, gender identity, etc.

4. *In what ways could your CARES (and related) work become more inclusive? What are the*

*challenges to implementing these changes? What opportunities would these changes create?*

We remain interested in considering more ways to include people with autism in advisory activities or staffing but it is interesting to explore this with pediatric grants, because some adults with autism have mentioned they aren't interested in screening for autism, which is a key focus in our state autism grant

We need to identify ways to consistently pay individuals with disabilities for their contributions. Grant funding being temporary makes this a challenge; institutional rules also makes this a challenge repeatedly.

5. *How can your CARES (and related) work add to the knowledge base on addressing ableism?*

PCORI is helpful within health research context, because funding focuses on including voices of individuals impacted by the research. This reinforced and added new ideas to directions we were going, will use these ideas in future grant applications.

Summary: Inclusion & ensuring autistic adults and other stakeholders are on research and practice teams; creating safe and inclusive opportunities for discussion about language (e.g. disability- identity versus person first; gender identity); ensuring (because participants have come and gone) that autistic individuals are included in several different project advisory groups; ensuring that communication is inclusive (e.g. opportunities to speak, or text, or reflect later after given time to process); and work with a group of individuals to ensure that diverse voices are heard instead of relying on one or two representative perspectives.

## Breakout 2

1. *Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?*

Issues of Ableism resonate with the social Justice theme incorporated in LEND curriculum at Nisonger -- Intrigued with principles of UDL—particularly the notion that process matters most!

History: How far we've come but still work that needs to be done to improve equality and inclusion  
Challenge for inclusion is in the details

The history of disability and ableism was a good reminder of how far we have come, but also of how much we still need to continue working toward equality and inclusion

2. *Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the broader autism community?*

Increase visibility of self-advocates assuming leadership roles: for employment options and supports, post-secondary and vocational options, etc.

Families--changes in advocacy; refocus on community living, employment, and other transitions to adult life.

Leadership amongst various employers

3. *What resources or activities would result in a system of support that prioritizes the voices of*

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### Breakout Discussion Notes

*autistic individuals? Do these resources exist or do they need to be developed?*

Need for resources and activities around neurodiversity --help prioritize voices of autistic individuals

Need for more self-advocates on faculty to prioritize autistic voices

Question to consider: how to include autistic voices on topics/ content that are didactic --e.g. training in evidence based screening, diagnostic, and treatment – need for self-advocates to be involved with developing curricula

4. *In what ways could your CARES (and related) work become more inclusive? What are the challenges to implementing these changes? What opportunities would these changes create?*

Self-advocates to be directly involved in curricula development

Self-advocates being involved in research on evidence based practices

5. *How can your CARES (and related) work add to the knowledge base on addressing ableism?*

Theme from Trainees: be an ally"--following autistic individuals shared stories/experience--consider how one can best support or be best ally through interactions and work

Principles to abide by:

- allow autistic individuals space to communicate
- don't speak for the experiences of another
- recognize and acknowledge what you don't know
- recognize that perspectives differ across spectrum

6. *In what ways will you commit to taking action to address ableism at the individual, program, organizational or systems level?*

Ensure that all aspects of work are informed by autistic individuals, not only as partners but also as drivers

True engagement with self-advocates

Continue to teach principles beyond LEND curriculum --including medical students, psych residents, fellows, etc.

Pay self-advocates for their time and expertise

### Breakout 3

1. *Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?*

- "Nothing about us without us!"

- Be mindful of the voices of autistic individuals

- Do your homework! Don't put the burden of understanding autism on the person. Make it your job!

There are several resources out there.

- Get autistic individuals' perspectives... listen to them

2. *Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the*

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### Breakout Discussion Notes

*broader autism community?*

- Programs using self-advocates

3. *What resources or activities would result in a system of support that prioritizes the voices of autistic individuals? Do these resources exist or do they need to be developed?*

- Develop resources for families -- including families who are low-income, of color. Including resources to help them get initial diagnosis.

- For autistic children-- they're children first! Having autism is not a bad thing

- Parents of children with ASD writing a "vision statement" for their child (e.g. have friends, go to college, etc.).

4. *In what ways could your CARES (and related) work become more inclusive? What are the challenges to implementing these changes? What opportunities would these changes create?*

- How to make college and graduate programs more inclusive to autistic students

- Rate of transgender folk with ASD is higher than neurotypical population -- how to use intersection to heighten their sense of belonging?

- Consider how autistic students contribute to the program and highlight those skills, characteristics, etc.

- Be proactive in getting autistic representation

5. *How can your CARES (and related) work add to the knowledge base on addressing ableism?*

- Purposefully include autistic participants; interested in being a self-advocate

- Educate others about the word "ableism" and how it relates intersectionality to other marginalized communities (i.e. people of color, LGBTQ+, religion, etc.)

Ex) Queer folk considered "disabled" by outside folks, which LGBTQ+ then reject in an ableist way

- Cause vs. Cure ... Intervention vs. Care ... Medical Model vs. Social Model

- Be careful about "prevention" - ableist (eugenicist)

- Be mindful and embed disability competence into the framework of your actions/work

- Being purposeful with funding

6. *In what ways will you commit to taking action to address ableism at the individual, program, organizational or systems level?*

- Infuse concept of "ableism" into talks, into conversations about multiculturalism

- Feel emboldened to push programs to be mindful about tokenism and remind colleagues about ableism

- Designing research with a disability perspective/lens

## Breakout 4

1. *Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?*

Avoid language that takes away the importance of person-first vs identity-first

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### Breakout Discussion Notes

Avoid language regarding "fixing" your child and find a balance

Have an open conversation with self-advocacy trainees to make sure both sides are able to contribute to solution

People have differing perspectives, even within the self-advocacy community -- even with faculty and trainees

Respect is key -- if an individual has a preference, then we have to respect their preference

We don't assume what is important, but give them an opportunity to identify what the priorities are

This is a sensitive issue, it's not going to be solved but we can raise awareness and increase understanding of the differing perspectives

Participation and inclusion takes many forms and should occur at multiple levels

2. *Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the broader autism community?*

Convey to trainees and research "nothing about us without us" -- make sure that people who are impacted are also involved in the discussion and model this motto in the work that we do

LEND program (OK) has core self-advocacy faculty, and advisory committee

Meeting adults who are diagnosed later in life and how to include them in research, and how to do it successfully

LEND network tries very hard to understand and incorporate these self-advocacy issues -- funding announcement and various workgroup struggle with this concept too

Agencies are doing work around increasing access to their programs for those with disabilities, e.g. HRSA

Developing a plan for the self-advocacy faculty member to be a mentor, thinking about how participation can take many forms doing things WITH individuals

3. *What resources or activities would result in a system of support that prioritizes the voices of autistic individuals? Do these resources exist or do they need to be developed?*

Consumer advisory committee (CAC) - OK - how to make sure you include the full spectrum of voices in the discussion? by asking organizations to select their representative, asking them to send different representatives (part of the UCEDD project), several community partners and organizations, statewide information organizations, using community partnerships for LEND self-advocacy trainees to get involved

it needs to be a priority upfront and revisited throughout the process

4. *In what ways could your CARES (and related) work become more inclusive? What are the challenges to implementing these changes? What opportunities would these changes create?*

Participation taking many levels and forms

Some LEND programs are more limited in the roles for self-advocacy trainees and families while others totally include them in clinic visits and such -- programs are working hard to make materials and experiences more accessible

Staff and faculty are having clear conversations regarding the SA's role -- when both parties are involved in the discussion, bigger progress

Clear-cut roles are key, sometimes the expectations of the trainees are not met

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### Breakout Discussion Notes

Expectations of what the trainee will get out of the training are not clear - it becomes disappointment. Important for self-advocacy trainees to have a strong orientation to the LEND program for projects, what the seminars look like, etc., making things more explicit -- especially around what's next for self-advocacy trainees after they finish LENDs?

- This includes the role that self-advocacy trainees can and cannot play in certain programs (e.g. going to clinic visits)
- Some may think they will have a job at the end of the traineeship, so just have to be clear and have information for them that is accessible and that everyone at the table has the information

It can be a mindset shift for some people -- takes time

Trying to intentionally include self-advocacy trainees in the self-advocacy discipline rather than a professional with a disability

Inviting self-advocacy trainees to presentations

Important to have role models and mentors for SAs, because they all can have different pathways to leadership and make individualized leadership plan -- this helps the SA trainee figure out their leadership trajectory and see what comes next

Recognizing the scaffolding to see what kind of supports SA trainees may need -- start everyone at the same level early on (recognizing that any trainee may need to start from the beginning)

Figuring out how to do this respectfully

More impact on the entire campus, infuse family and SA across campus strategic planning (recruiting using existing SA core faculty, family mentors, community partnerships like OK People First)

#### 5. *How can your CARES (and related) work add to the knowledge base on addressing ableism?*

Yes, we have family members on advisory boards, invite them to participate in panel discussions for class, family mentor experience, etc. However, struggle with recruiting family members as trainees due to time commitment (LTT=300 hours). We are a fairly new LEND too. Next year thinking about families as MTT.

Potential to learn from the lessons of the family discipline.

#### 6. *In what ways will you commit to taking action to address ableism at the individual, program, organizational or systems level?*

Joining the family and PWD workgroups via AUCD, and they meet during the AUCD Conference

Ask trainees to look on social media to see how often ableist terms are used and see how they view people with disabilities in the media (art, culture, movies, news, etc.) -- moving away from the mindset of "suffering from" "overcoming this" "we will beat this", book called "no pity" from Joseph Shapiro gives a historical perspective

Added the topic (ableism) to LEND faculty meeting, once a month have a "coffee chat" to redeliver information and participate in discussion

Coffee chat - meet over coffee to participate in a 45 min discussion on various topics and/or watch a TED talk before the meeting and chat about it

### Breakout 5

1. *Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?*

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### Breakout Discussion Notes

As a person with disability, excited to see our name in it.

Keynote points were important, resonated and really made sense when we think about ableism across the spectrum of disabilities.

2. *Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the broader autism community?*

Example: In LEND program, as the first self-advocate with disability in a LEND program, you'd experience people who would inadvertently make comments that were demeaning towards self-advocates/people with disabilities. There were challenges integrating with the person with a disability on the inclusion front. Issues with language (e.g. "So inspired you're here"). Subconscious biases / unintentional, but problematic / not overt.

Opening a dialogue over problematic/ableist language as opposed to just shutting down people who use language that is ableist.

3. *What resources or activities would result in a system of support that prioritizes the voices of autistic individuals? Do these resources exist or do they need to be developed?*

Including self-advocates, and increased participation of self-advocates in LEND programs.

Need in medical community to have this type of training and communication.

Student directed IEPs, need more authentic participation.

Pre/post-service training for educators and professionals who work with students to better support the ability for students to advocate for themselves and ensure they're heard.

Affect matching / cultural considerations in doctor - physician interactions. Considerations of being neurotypical versus neurodiverse and differences in views of world and how they interact with the world. Doctors who are able to 'culturally match' or affect match with patients with disability could potentially lead to more positive health outcomes.

4. *In what ways could your CARES (and related) work become more inclusive? What are the challenges to implementing these changes? What opportunities would these changes create?*

Universal design considerations for class as far as teaching. Making modules/materials/assignments/readings accessible for everyone.

One size doesn't fit all for making materials/modules/assignments/readings accessible

Woman who was in charge of testing at one university didn't understand why there needed to be accommodations for students with disability, since they wouldn't be able to practice in the healthcare field anyways. Attitudinal barriers to recruiting people with disabilities into health professions that continues to persist, even though we have shortages in health care professionals.

Had problems getting published in social work journals on disability and adversity. Heard that disability 'isn't really a social work thing.' Instead sent to medical journal and had a much easier time getting published.

Integrate disability throughout curriculum in pre-service training.

5. *How can your CARES (and related) work add to the knowledge base on addressing ableism?*

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### Breakout Discussion Notes

LEND program really has an opportunity. Faculty engaged with multiple different programs within their universities, so you can have the faculty share lessons learned and distill knowledge across departments and universities. Real opportunity to do cross-fertilization of ideas and concepts.

Faculty member who has done a lot of research on culture and health disparities, and was excited to hear the discussion around ableism, as he believes it to be a significant underlying factor of why we see health disparities and the intersectionality between racism and ableism, e.g. African American students typically identified with conditions viewed as being more serious, whereas the white students in special education often have diagnoses that are more stigmatizing. More likely to be identified with ID, whereas white students more likely to be identified with a language disorder.

African American women more likely to have pain taken less seriously. For psychiatric diagnoses, when it might be a trauma related disorder, they instead get diagnosed with ADHD or similar disorders.

Parity of access to care/quality care mediated by disability, race, and gender.

Historically, African American more likely to be diagnosed with schizophrenia and a white patient more likely to be diagnosed with depression.

We view different diagnoses with different levels of stigma.

There is discrimination around disability that lead to poorer outcomes later in life e.g. children with autism are more likely to experience childhood adversity, which affects their physical health and leads to disparities in treatment.

Have to focus on the social experience of disability, not just focus on the medical model, in order to effectively address autism.

#### 6. *In what ways will you commit to taking action to address ableism at the individual, program, organizational or systems level?*

David Deere - We will be including this in a lecture in the spring.

Sarah - Including in lecture materials, take information and work to improve experience for LEND programs, and bring to advocacy networks.

Tuesdays with Liz - makes policy more accessible for all

Continue to speak up individually on ableism and be open to dialogues on an organizational level.

### Breakout 6 – did not meet

#### Breakout 7

##### 1. *Which aspects of the keynote on ableism and the promising practices on inclusion resonated with you? Which aspects didn't resonate? Why?*

Aspects that resonated:

- Despite expertise, it's important to include PWD in all aspects, including research.
- Priorities that the university sets should align with the priorities of people with autism and other PWD
- Highlighting that research meaningfully includes PWD, including the interpretation of research results
- History of ableism was helpful
- Working with an underserved population (not used to having people with autism in the community), there's still much stigma
- the importance of asking a person on the spectrum how they prefer to be addressed: either "person first language" (i.e.: adult with autism) or identity first language (i.e. autistic adult)
- Improved recruitment of trainees and future professionals

2018 CARES Virtual Activity/Activities

Webinar #3 – October 29, 2018, 2pm ET (1pm CT, 12am MT, 11am PT)

Breakout Discussion Notes

Aspects that did not resonate:

- Content that wasn't directly related to programs I represent (or projects we work on directly)

2. *Where have you seen leadership in addressing ableism in autism research, training or systems change initiatives? Where have you seen leadership on these issues outside the CARES network, in the broader autism community?*

- Leadership across state agencies/organizations; many were addressing ableism, but maybe not in the way discussed in the keynote/webinar 2

- Leadership in UCEDD= training and systems change around ableism; greater need to remind communities about the concept of ableism.

- Community support groups, centers, all coming together to address these issues; progress being made slowly but surely

- Partnership with state public health organizations; improving awareness of Autism in populations

3. *What resources or activities would result in a system of support that prioritizes the voices of autistic individuals? Do these resources exist or do they need to be developed?*

- Gatherings (conferences, panels, etc.) to share experiences and resources; something intentionally designed to be inclusive

- if the grant is focused on ableism or adults or transition, then autistic adults should be included as contractors

- family participation in training programs (LEND, UCEDDs, etc.); participation and payment beyond the community advisory group/board

4. *In what ways could your CARES (and related) work become more inclusive? What are the challenges to implementing these changes? What opportunities would these changes create?*

- Paid employment opportunities (aside from trainees)

- focus on universal design; addressing ableism in training program curriculum

- Resources shared thru these webinars can serve as a guide for future conversation within programs

Challenges:

-Issues around income and benefits, with regard to paid employment for self-advocates. Helpful to talk with others who've navigated this challenge.

5. *How can your CARES (and related) work add to the knowledge base on addressing ableism?*

- LEND training program sets example of inclusive practices; can do a better job of defining Ableism to trainees

6. *In what ways will you commit to taking action to address ableism at the individual, program, organizational or systems level?*

If the grant is focused on ableism or adults or transition, then autistic adults should be included as contractors.