



American Heart Association.



Connecting for Change

Health Equity • Inclusion • Advocacy

Roundtable Discussion Summary
March 2020



Health Equity. Inclusion. Advocacy.

CONNECTING FOR CHANGE



Voices for Healthy Kids, an initiative of the American Heart Association with support from the Robert Wood Johnson Foundation, supports campaigns advocating for equitable policies so that kids can live, learn and play healthier. Voices for Healthy Kids hosts equity roundtables with stakeholders from across the country. During these intentional conversations, attendees dive into policy issues, share their experiences, build relationships and provide overall guidance to the work. Findings from these discussions may apply to similar teams and organizations seeking health equity.

Host Organizations and Participants

Lakeshore Foundation's mission is to encourage and provide opportunities for people with disabilities to live a healthy lifestyle through activity, research, advocacy and health promotion. Staff: Karin Korb

The National Center of Health, Physical Activity and Disability (NCHPAD) is a national resource and practice center that empowers communities, organizations and individuals through training, advocacy, thought leadership, health promotion and health communication to create livable places, healthy people and sustainable inclusion. Staff: Amy Rauworth

Voices for Healthy Kids, an initiative of the American Heart Association with support from the Robert Wood Johnson Foundation, works around the country to improve or create equitable policies that make the places kids, live, learn and play healthier. Staff: Marla Hollander, Yui Iwase, Ali Rahimi & April Wallace

The host organizations appreciate the time and effort of all participants and partners in making this roundtable a success. Their insights and perspectives are integral to the growth of our equity journey. Thanks also Clarus Consulting for onsite facilitation and We-Collab for health equity guidance.

Participants

Dara Baldwin, Center for Disability Rights

Chris Kissler, Centers for Disease Control and Prevention

Georgina Peacock Goebel, Centers for Disease Control and Prevention

Reyma McCoy McDeid, Central Iowa Center for Independent Living

Jessica Breslin, ChangeLab Solutions

Nicole Watkins, Disability Rights & Resources

Carol Tyson, Disability Rights Education and Defense Fund

Terra Branson-Thomas, Muscogee (Creek) Nation

Susan Weisman, Public Health Law Center

Krista Scott, Robert Wood Johnson Foundation

Allison Warner, Robert Wood Johnson Foundation

Kasey Dudley, SPAN Advocacy

Liz Mahar, The Arc U.S.

Colleen Crispino, The Viscardi Center

Meg Traci, Univ. of Montana Rural Institute for Inclusive Communities

Keith Jones, Advocate, SoulTouchin' Experiences

Talila Lewis, Advocate and Social Justice Engineer, HEARD and Disability Solidarity

Bob Lujano, Paralympian, Disability Inclusion Advocate

Amelia O'Hare, Advocate, Urban Planner and Designer



American Heart Association®



Executive Summary

In March 2020, Voices for Healthy Kids, Lakeshore Foundation and the National Center of Health, Physical Activity and Disability (NCHPAD) hosted the Connecting for Change: Health Equity – Inclusion – Advocacy roundtable. A diverse group of people joined in the conversation, including people with disabilities and national experts from the Disability Rights and Disability Justice movements. The roundtable sought to better understand participants' policy priorities and ways to engage people with disabilities in advocacy efforts of the Voices for Healthy Kids initiative. The summary and lessons learned from this roundtable encourages readers to explore how ableism negatively shapes policy, to learn about the intersectional systemic oppression of people with disabilities and intentionally include the use of the disability justice framework in their ongoing advocacy.

Ableism, Intersectionality and Disability Justice

The roundtable created a space for shared learning at the intersections of advocacy, equity, disability and inclusion to help all kids live healthier lives. Many participants found the conversation jarring, yet necessary. Roundtable conveners without the lived experience of disability began to shamefully recognize how [ableism](#) is woven into policies, systems and language in our society that explicitly benefits non-disabled people. Participants shared deeply personal insights on the marginalization of people with disabilities with [intersectional](#) identifiers, specifically Black, Brown, Latinx, Native American and/or those who identify as LGBTQ+. Many participants were challenged to move beyond the traditional disability rights narrative to include the [disability justice](#) framework.

Lessons Learned for Disability Inclusion in Advocacy

Together, participants identified six lessons for Voices for Healthy Kids to build a more inclusive and equitable approach. These lessons can be applied by other advocacy organizations.

- 1. Words Matter: Take time to be a knowledgeable and conversant ally**
A deeper understanding of the history of disability justice, current issues faced by disability advocates and biases fueled by ableism are critical to build trust and authentic engagement.
- 2. Nothing About Us, Without Us: People with disabilities should be decision makers and leaders**
There is a clear need across health advocacy efforts to increase representation of people with disabilities in decision-making to ensure that their needs and perspectives are being prioritized and properly resourced.
- 3. Be Intentional: Authentic and candid conversations are critical to dismantle ableism**
Authentic engagement is required to address the historical biases that have led many disability rights and justice advocates to be neutral on issues not specific to disabilities.
- 4. Diversity in Disabilities: Recognize the diversity and unique concerns of people with disabilities**
There is a wide range of disabilities, each with unique realities that must be considered. When seeking to inform policy and advocacy work, efforts should be made to identify a range of partners and perspectives representing this diversity.
- 5. Find Intersections: Listen, learn and then align with disability advocate policy priorities**
Health advocates need to understand the policy needs of people with disabilities in order to identify areas where policy priorities intersect and to remediate for any unintended consequences.
- 6. Be an Ally: Use your power, influence and funding to raise awareness**
Allyship from health advocates is critical and we all can use our influence to raise awareness, educate, engage and advocate for systemic changes with people with disabilities.

Connecting for Change Health Equity Roundtable Summary

Background

In March 2020, Voices for Healthy Kids collaborated with the Lakeshore Foundation and the National Center for Health Physical Activity and Disability (NCHPAD) to hold the Connecting for Change: Health Equity – Inclusion – Advocacy Roundtable. Participants included people with disabilities as well as organizations and advocates with lived experiences. The goal was to have candid conversations to better understand perspectives and life experiences of people with disabilities as they relate to Voices for Healthy Kids policy priorities to advance health equity.

By the Numbers

With **one in four adults** (26%)¹ and about **one in sixteen children** (6%)² in the U.S. living with a disability, it is critical that the places we live, learn and play benefit all potential users. In general, the word disability is used for both visible and invisible disabilities and acknowledge that each person with a disability has different life experiences based both on their disability and a multitude of other factors (e.g. gender, race, income, support systems). For adults with disabilities, Native Americans have the highest rates of disabilities followed by people of other race/multiracial and Black people.³ People with disabilities have higher rates of obesity and tobacco use compared to people without **disabilities**.⁴ This context is important for health advocates working to address the twin epidemics of type 2 diabetes and obesity as well as those addressing the impact of other noncommunicable diseases.

Statistics on children with disabilities are limited and are one area for improvement in public health advocacy. An estimated **5.4% of youth ages 5-15** in the United States report having a disability and **similar to adult statistics**, Native American and Black youth have higher rates of disability than white, Asian or Hispanic youth.⁵ According to the

American Community Survey,⁶ among youth ages 5 to 15, estimates for youth with disabilities by race/ethnicity are as **follows**:

- Native American or Alaska Native – 7.2%
- Black/African American – 6.5%
- White – 5.2%
- Hispanic (all races) – 5.1%
- Asian – 2.5%

Youth with disabilities are at risk of developing serious health conditions like diabetes, obesity and heart **disease**, but they also face greater environmental barriers that impede access to healthy foods and locations for safe physical **activity**.⁷ According to a report published in 2015, children ages 5 to 17 are **35% more likely** to have obesity than youth without disabilities.⁸ All children – from all disability, racial, ethnic and socioeconomic groups, through all grades, and in urban and rural settings – benefit from regular physical activity and good nutrition.

Children with disabilities are among the most discriminated against groups of people – marginalized and excluded from society in nearly every aspect of **life**.⁹ Children with disabilities are often on the receiving end of stares and ridicule or, at best, an awkward invitation to join in activities. This marginalization is often compounded by racism, poverty and lack of both systems of care and cultural norms of caring for those who look, sound or act different from what is considered the norm.



From left to right: Keith Jones, Reyma McCoy McDeid, Alison Hoit Tubbs

Discussion Guide

The host organizations developed the agenda and discussion guide to foster candid conversations and hired professional facilitators with experience working with people with disabilities. A pre-meeting survey gathered information on participant goals and thoughts on successful organization collaboration, organizational assets and policy priorities. An informal gathering the night before helped participants get to know each other.

The meeting started with introductions, establishing rules of engagement and trust. Then participants reflected on a series of questions, including how life might be different for children with disabilities if they had equitable access to health and education resources. These steps were crucial to developing a rapport among participants that lead to an open conversation. To identify concrete steps to increase inclusion and improve health equity for people living with disabilities, roundtable participants discussed the following topics within the context of Voices for Healthy Kids policy priorities:

Coalition Building and Grassroots

- Connecting with disability rights and disability justice advocates in communities
- Pathways for disability rights and disability justice advocates to lead campaigns
- Identification and mitigation of anticipated risks and challenges
- Understanding competing priorities

Technical Assistance

- Campaign technical assistance for youth with disabilities
- Policy changes to better implement inclusivity for youth with disabilities
- Identifying support and training for staff and campaigns

Policy and Advocacy Priorities

- Disability rights and disability justice alignment or discord within Voices for Healthy Kids priorities
- Emerging trends in disability rights and disability justice for consideration to support
- Organizational change vs. policy priority support

¹ Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of disabilities and health care access by disability status and type among adults – United States, 2016. *MMWR Morb Mortal Wkly Rep.* 2018; 67:882-887. doi: 10.15585/mmwr.mm6732a3.

² Erikson W, Lee C, von Schrader S. 2018 Disability Status Report: United States. Published 2020. https://www.disabilitystatistics.org/StatusReports/2018-PDF/2018-StatusReport_US.pdf.

³ Ibid.

⁴ U.S. Centers for Disease Control and Prevention. Disability Impacts All of Us. Updated September 2020. <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#text-version>.

⁵ Erikson W, Lee C, von Schrader S. 2018 Disability Status Report: United States. Published 2020. https://www.disabilitystatistics.org/StatusReports/2018-PDF/2018-StatusReport_US.pdf.

⁶ Erickson, W., Lee, C., von Schrader, S. (2017). Disability Statistics from the American Community Survey (ACS). Ithaca, NY: Cornell University Yang-Tan Institute (YTI). Retrieved from Cornell University Disability Statistics website: www.disabilitystatistics.org.

⁷ Fox MH, Witten MH, Lullo C. Reducing obesity among people with disabilities. *J Disabil Policy Stud.* 2014; 25:175-185. doi: 10.1177/1044207313494236.

⁸ Bandini L, Danielson M, Esposito LE, et al. Obesity in children with developmental and/or physical disabilities. *Disabil Health J.* 2015; 8: 309-316. doi: 10.1016/j.dhjo.2015.04.005.

⁹ UNICEF. Children and Young People with Disabilities Fact Sheet. May 2013. https://www.unicef.org/disabilities/files/Fact_Sheet_Children_and_Young_People_with_Disabilities_-_2013.pdf.

Deep Dive: Lessons Learned for Disability Inclusion in Advocacy

The Connecting for Change roundtable identified six lessons that advocacy organizations can use to be more inclusive of the needs and priorities of people with disabilities in policy efforts. The following summary is intended to help advocates develop their path towards disability inclusion.

1. Words Matter: Take time to be a knowledgeable and conversant ally

In order to be a conversant and trusted ally, advocates may need to re-build their vocabulary and re-learn history of their policy issues. This means clarifying and strengthening language of inclusion—and full immersion in the value of words used to represent the wide array of issues facing people with disabilities.

“What definition of inclusion are we using and who is being included?”

Throughout the roundtable, participants emphasized that word choice matters. Without representation, words are defined incorrectly because the definer’s knowledge does not fully encompass the experiences of the individuals impacted by the word. Participants recommended redefining the following language and terms in collaboration with people with disabilities: community, health, wellness, safety, ableism, disability, mental health and inclusion.

“Definitions of health are often made by able-bodied, white men...exercise means something different to everyone.”

A deeper understanding of the historical and current issues faced by disability advocates and biases fueled by ableism is critical to building trust and authentic engagement. This includes learning about historical racism within the Disability Rights movement.

Disability Justice and Disability Rights are **Not** the Same

The Disability Justice and Disability Rights movements are distinct terms and important for health advocates to understand. Disability rights

focuses on securing equal rights and opportunities for people with disabilities whereas disability justice is a framework that explores disability and ableism as it relates to other forms of oppression and identity.

Disability Justice

The examination of disabilities and ableism in the context of various oppressive forces such as race, class, gender, sexuality, citizenship, criminal record, age and body type.

Disability Rights

Disability rights are human rights. Everyone deserves to be included and live a full life in their community — accessing the same public spaces, housing opportunities, education and work as anyone else.

Advocate Tips for Embedding Disability, Not Erasing Inclusion

Roundtable participants shared that challenges exist in the development of policies and definitions of words because they are often created by homogenous groups that do not offer diverse perspectives. Racism within decision makers and even in the Disability Rights movement has historically erased the voices of Black, Latinx and other communities of color. They shared these tips for embedding disability:

- Embed people with disabilities at beginning of policy decision-making process and use inclusive language
- Pay attention to language and redefine keywords in collaboration with people with disabilities
- Build a healthy foundation of knowledge by learning more about the history of Disability Justice and Disability Rights
- Implement high-quality training for staff about the issues faced by people with disabilities led by and developed by people with disabilities
- Create space for people with disabilities in ongoing conversations on equity

2. Nothing About Us, Without Us: People with disabilities should be decision makers and leaders

When people with disabilities are not only included, but leading and guiding, conversations on policy, the result will be more inclusive policy design. Inclusion as leaders and decision makers can ensure policy proposals address their priorities and needs as well as to keep policies from doing harm, even if unintentional. Moving beyond the mantra of 'Nothing About Us, Without Us' to 'Nothing Without Us' will accelerate progress of intersectional inclusion.

"If you really want to know, have people who are disabled at the table. That point cannot be lost on us."

It is vital to have people with disabilities be a part of every conversation, from agenda-setting to advocacy and outreach. Having someone with lived experience or those that have been directly impacted at the forefront of decision-making is essential to the successful execution of policy. Without that inclusion, the alignment on policy simply cannot be reached.

- Hire staff members with disabilities to be in positions of policy and leadership - this demonstrates that the organization values diversity and inclusion
- Ensure people with disabilities are in positions of coalition or organizational leadership before engaging disability advocates, look within your organization at who has lived experiences and may be the right ambassador.

3. Be Intentional: Authentic and candid conversations are critical to dismantle ableism

Disability advocates expressed interest in collaboration to improve inclusivity in policy efforts. However, a lack of authentic engagement and historical bias specifically against people with disabilities in health policies has generally led disability advocates to be neutral on policy issues that are not specific to disabilities. Health advocates and disability advocates need to

have more candid conversations about policy development and implications of specific policies on people with disabilities.



From left to right: Nicole Watkins, Bob Lugano, Marla Hollander, Dara Baldwin, Yui Iwase

A stark realization in the roundtable discussion was the impact of having disability advocates who do not have the lived experience of disability and/or organizations led by people without disabilities advocating on behalf of people with disabilities. Although they may have family and loved ones who have disabilities, they do not share the same life experiences. It helps to acknowledge this fact as part of the candid conversations and intentional relationship building.

Social Prejudices and Disability: Ableism and Racism

Participants expressed deep concern about social prejudices, specifically ableism and racism, rooted in health policies and health care. Public health advocates should acknowledge and learn about the historical biases and the impact of ableism on individuals with disabilities and how it is rooted in our existing systems.

Historical Bias and Prejudice

- People with disabilities are and have been overlooked and not asked for opinions on policy development
- People without disabilities have low expectations of people with disabilities
- Racism and classism exist among disability advocates

Ableism

You do not have to be disabled to experience ableism.

Ableism is a system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in racism, eugenics, colonialism and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel and "behave."

Adapted from a working definition by Talila Lewis, January 2020 at www.talilalewis.com.

Guidance for Health Advocates

- Mutually beneficial relationships, active listening and shared learning are required to build trust and partnership with disability right and justice advocates
- A well-rounded understanding of past experiences is critical to assessing things as they are now
- Include disability rights and justice advocates in the policy development process
- Hire, promote or fund people with disabilities to spearhead campaigns
- Engage in bilateral and authentic collaboration and learning
- Use a thoughtful process to include various disability advocates at all levels
- Evaluate policy impact with people with disabilities
- Practice active listening for true understanding in candid conversations
- Learn about the impact of historical bias on people with disabilities

4. Diversity in Disabilities: Recognize the full diversity and unique concerns of people with disabilities

As with any sub-population, people with disabilities cannot be represented by only one organization or perspective. There are a wide range of disabilities, each with unique realities that must be considered. Intersectionality plays a major role in the experiences of people with disabilities who are Native American, Black and/or Latinx, disproportionality impacting their opportunities for healthy lives. Intersectionality is a framework coined by Kimberlé Crenshaw to describe the dynamics of discrimination between race and gender and the compounding effects of discrimination. Intersectionality has been expanded to describe the compounded discrimination people face due to their multiple personal identifiers like social position, race, ethnicity, gender, religion, sexual identity or disability. When seeking to inform policy and advocacy work, efforts should be made to identify a range of partners and perspectives from the disability advocates.



From left to right: Bob Lujano, Meg Traci, Keith Jones

Intersectionality and Diverse Voices

- However diverse and inclusive, understand that a single organization or network does not fully encompass the perspectives of all people with disabilities.
- While not all lived experiences can be represented, the greater diversity in lived experiences, the better the advocacy work and policy outcomes will be.

5. Find Intersections: Listen, learn and then align with disability advocate policy priorities

Coalitions or collaborating organizations often come together due to shared priorities. It is important to start with listening to and learning about the policy priorities of people with disabilities. Organizations may then find ways to broaden their own goals to encompass disability issues. Alignment may also be found in prioritizing programs designed to address basic needs (e.g., housing, food security) in ways that are more inclusive and augment current research and data gathering by including people with disabilities. Ideally, policy formulation at the onset should include disability advocates. This will also avoid the unintended consequences of ableism that has historically created greater disenfranchisement with people with disabilities. Despite advocates efforts to create opportunities for all children, there can be unintended negative consequences for some groups - including children and adults with disabilities.

Basic Needs vs. Health and Wellness

One way health advocates can build a better relationship with disability advocates is to lend their voices and influence to advocating for basic needs – such as access to health care that serves the needs of those with disabilities, accessible and affordable housing, and transportation and critical community supports (e.g., speech devices, personal assistance) – alongside disability advocates.

However, health advocates cannot simply go to disability groups with their agendas when those with disabilities are often fighting for their basic needs. For example, advocacy organizations often want to partner with the “disability community” on issues like nutrition and physical activity. The feedback from the roundtable was that these issues are important but if basic needs – including safety and housing – are not met, then other essential health needs, such as physical activity and wellness are also difficult to access. Organizations need to lend their platforms to these basic needs if they want support on other issues as well. Finally, it must be noted that current policy statements on nutrition and physical activity

do not meet the full scope of needs of people with disabilities. To create the policy language that meets the needs of people with disabilities, we must follow the other recommendations – listen and engage early and authentically.

Sample of Potential Policies to Lend Support

- **Housing**—Affordable housing should be explored as a policy priority by any organization looking to increase engagement with the disability advocates. Increasing organizational focus on accessible and affordable housing, including the impact of gentrification and migratory patterns, would prioritize the needs and livelihoods of people with disabilities.
- **Women, Infants and Children (WIC) Nutrition Program**—Focusing on WIC is an area for alignment given that one key opportunity for identifying children with developmental disabilities among low-income families is through this program and early identification of disabilities is a key factor in addressing access to care and needed services.
- **Active Transportation**—Disability advocates have been engaged and many see this as a natural fit. Unfortunately, the reality is that most Complete Streets and Vision Zero projects do not address key disability priorities and have left the disability advocates and communities of color out of decision-making process. The increasing enforcement practices can perpetuate propensity of police violence towards Black people with criminalization of violations.
- **Inclusive Data and Research**—All policy priorities should be based in quality data and research. Increasing research projects that support people with disabilities and, more generally, ensuring inclusion of people with disabilities in ongoing research will provide better rationale for addressing the needs and priorities of the disability advocates at a more local level.

6. Be an Ally: Use your power, influence and funding to raise awareness

Power, influence and funding are all important factors to create systemic change and shift how policies are created and implemented to be inclusive of people with disabilities. An entry point for health advocates to use their influence to support this kind of change is available. But first, organizations must build trust, demonstrate commitment and recognize expertise of people with disabilities. When



From left to right: Kelly Bonner, Amelia O'Hare, Jessica Breslin

harnessing this leverage for good, organizations can shift how policies are designed and implemented. For example, when funders align priorities with communities they are supporting, the communities experience greater impact. Below are ways health advocates can grow to also be true disability and racial justice advocates.

Trust: Building It and Keeping It

- **Build trust** through engagement and education on Disability Rights and Disability Justice
- **Respect and learn deep history** of disability inclusion and racial justice work
- **Recognize expertise** of longstanding intersectional advocates that is critical for future of the movement
- **Acknowledge commitment** to the broader wellness of disability advocates
- **Funding aligned** with population priorities builds and keeps trusts and shifts policy decisions

Conclusion

“It’s okay to not know and ask and have hard conversations.”

Once an organization establishes a relationship with disability advocates, further dialogue must occur to learn more about the issues facing the group. Participants highlighted the importance of authentic listening and learning to successful collaboration and policy development. Participants agreed that asking questions, listening actively, engaging in shared learning and having hard conversations are essential parts of this work.

Beyond the six lessons outlined above, Voices for Healthy Kids identified further opportunities to improve our equity and inclusion efforts, specific to people with disabilities. The Voices for Healthy Kids team, led by Marla Hollander and April Wallace, identified several actions for our team as we look at our policy priorities, strategies and processes based on what was shared at this roundtable. The team at Voices for Healthy Kids looks forward to continued growth and taking next steps to improve capacity and competencies in disability inclusion.

Appendix A

Opportunities for Action for Disability Inclusion within Voices for Healthy Kids

The Connecting for Change roundtable led to two set of outcomes. The six lessons learned are applicable to all advocacy organizations whereas the following opportunities are specific to Voices for Healthy Kids to increase disability inclusion and infuse disability justice throughout the initiative's work. Commitment to this work requires the entire team to be bold and courageous in making long-term commitments to disability inclusion.

Inform Policy Development

- Engage/diversify disability advocates on the Strategic Advisory Committee (SAC) and Policy Research Network (PRN)
- **Action:** Invite disability leaders to engage in policy review process

Support Culturally Appropriate Research

- Ensure relevant research represents needs of disability advocates
- **Action:** Invite researchers with disabilities, including Black and Latinx, to join the PRN

Increase Inclusivity of Advocacy Campaigns

- Review and adjust campaign guidance for inclusive language of people with disabilities
- Train campaigns on increasing opportunities for people with disabilities and creating inclusive spaces that are fully accessible, or Americans with Disabilities Act (ADA) compliant
- **Action:** Work with disability communication experts to develop campaign guidance

Move Beyond Traditional Partnerships

- Explore new collaboration opportunities looking beyond traditional disability rights organizations

- Have conversations with disability justice activists
- **Action:** Grow relationships with roundtable participants and other disability advocates

Make a Long-term Commitment to this Work

- Develop team skills for being more inclusive of people with disabilities in the hiring processes
- **Action:** Intentional hiring and recruitment of people with disabilities

Be Informed and Inform Others

- Invite people with disabilities to train on history, current issues and language of disability justice
- **Action:** Health equity consultant and training specialist consults with disability experts to integrate review and update training plan and overarching equity framework

Create Space for Direct Representation

- Create opportunities for people with disabilities to join conversations and decision-making
- Without representation, key considerations can and will be missed, risking unintended consequences and further disenfranchisement of the disability community
- **Action:** Identify mechanisms for integration of disability leaders into advisory positions

Keep Participants in the Loop

- Establish effective bilateral communication/feedback loops with participants
- Share actions incorporated and continue ongoing communication (email, meetings)
- **Action:** Share draft report with roundtable participants for their review and feedback

Appendix B

Addendum on Lessons Learned for Voices for Healthy Kids

Throughout the roundtable conversations, participants provided candid feedback and thoughts on how Voices for Healthy Kids could specifically address disability inclusion. The following sections match the six lessons learned and should be paired with those learnings for greatest impact.

1. Find Intersections: Listen, Learn and then align with disability advocate policy priorities

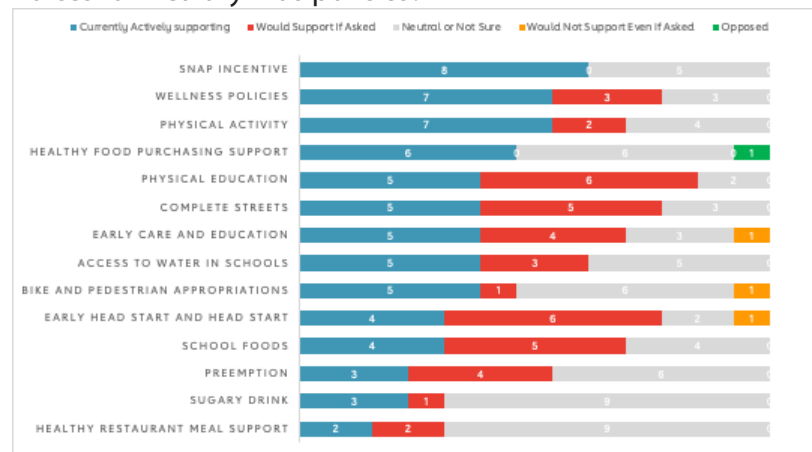
The policy priorities of Voices for Healthy Kids that roundtable participants flagged as the strongest opportunity for collaboration with disability advocates include Supplemental Nutrition Assistance Program (SNAP) incentives, school wellness policies, physical activity and healthy food purchasing support. However, there are potential unintended consequences of policies as noted about active transportation above.

Voices for Healthy Kids fosters a culture of belonging: every voice adds value; every contribution enables

change. That said, the initiative realizes that singular voices cannot and should not be representative of an entire community. In light of this, a number of participants expressed that some of the Voices for Healthy Kids policy priorities seem to compete with one another. “[Some policies are] missing the ‘margins of the margins’ issues or even doing harm by ignoring them,” one representative said. The policy priorities could be bolder and more inclusive to truly meet needs of people with disabilities.

The following chart contains participants’ responses from prior to the roundtable about their potential support for the current policy priorities of Voices for Healthy Kids. Staff and facilitators were surprised that so many participants were ‘neutral’ on many of the policies, given the known impact on many people with disabilities. The roundtable conversation was enlightening to staff that unless policies were specifically designed to support people with disabilities, they tend to be neutral or, at least, have real concerns for ableism bias they have endured throughout their experiences with health policies.

How likely are roundtable participants to support Voices for Healthy Kids policies?



2. Be Intentional: Authentic and candid conversations are critical to dismantle ableism

Participants highlighted a few national organizations such as the Centers for Disease Control and Prevention for data and the Centers for Independent Living which have chapters across the country as being helpful resources and connectors. Most importantly, connecting with local disability advocates will help campaigns better understand

how policies impact people with disabilities in their respective communities. In addition, campaigns need training to build pathways for disability advocates to lead campaigns. Collaboration accessible to all and characterized by trust and transparency, community leadership, courage, clarity and sustainability, continuous learning and flexibility, commitment and principled struggle, inclusive approach, and language and shared

resources are all keys to success.

The extensiveness of discrimination and oppression against people with disabilities cannot be overstated for public health advocates. Mutually beneficial relationships, active listening and shared learning are required to build trust and partnership with the disability advocates. This includes learning about historical bias and prejudice and the impact of ableism – either systemic or personal.

3. Be an Ally: Use your power, influence and funding to raise awareness

As with other health organizations, there is an opportunity for Voices for Healthy Kids to use its influence to raise awareness of the need for cross-sectional collaboration of health advocacy, disability inclusion and racial justice. However, it will take significant education and trust-building to be informed enough to play the role of influencer with disability justice.

Voices for Healthy Kids can join in disability work and influence other funders by raising awareness of the need for intersectional collaboration with disability advocates. If the initiative intends to step into a strong leadership role, it will require significant time, commitment and understanding. Practicing active involvement and engagement to achieve successful collaboration and policy development needs to include engaging people who have been disenfranchised at all levels and phases of policy development.

Diving into being an ally on disability rights and disability justice cannot be forced and will take dedication. The element of time is crucial in this process, and attendees were keen to reinforce the understanding that change will not and cannot be forced overnight. “[Disability inclusion] is not a quick fix and will require dedication and commitment,” one participant said. Participants also stressed that a well-rounded understanding of the community’s past experiences is critical to assessing things as they are now. One participant urged Voices for Healthy Kids to “commit to learning the history and making more local connections.”

4. Nothing About Us, Without Us: People with disabilities should be decision makers and leaders

While participants did not have in-depth knowledge of the Voices for Healthy Kids initiative or staff,

they were keen to know whether the organization employed people with disabilities. One participant posed the following question, “How is Voices for Healthy Kids tapping into the understanding, perspectives and lived experiences that come with being disabled?” Increasing engagement of people with disabilities and understanding their capabilities as a resource and an asset will improve organizational impact on the communities served.

5. Diversity in Disabilities: Recognize the diversity and unique concerns of people with disabilities

Participants noted that when Voices for Healthy Kids decides to partner with outside organizations and advocates, team members cannot assume that certain groups represent all people with disabilities. In addition to the disabilities themselves, the socioeconomic, demographic and racial variances within the community are endless. Lastly, some people live a lifetime with disability while others become disabled later in life. Anyone can become disabled at any time. This is one of the reasons why it is nearly impossible to replicate this same variance in a small conference room collaboration. Even when trying to create diversity by including people with disabilities, organizations need to be cognizant that those efforts do not represent all members/ experiences of the disability community.

“Voices for Healthy Kids has an opportunity to collaborate differently.”

Once it is time to lay the foundation for new policy measures, organizations should embed community members in the process from the start. Having people with disabilities lead, guide and influence Voices for Healthy Kids policy is critical to help shape policy so that it is truly beneficial for people of all abilities. Participants emphasized the importance of engaging populations that have been disenfranchised before and during policy development, in addition to reviewing policy after it is developed. They also emphasized the importance of letting them lead. The key to successful policy creation lies in the feedback provided by community members along the way.

Appendix C

Roundtable Meeting Agenda

Connecting for Change:

Health Equity • Inclusion • Advocacy

March 12, 2020

Agenda

Thursday, March 12

9:00 – 11:00 am	Welcome	Lakeshore Foundation NCHPAD & Voices for Healthy Kids teams
	Rules of Engagement	April Wallace
	Arc of the Day	Taylor Cooper & Kay Kornmeier
	Participant Introductions	
	Ice Breaker Activity	April Wallace & Marla Hollander
	Setting the Stage: Intersection of Youth, Disability and Health Equity	April Wallace, Marla Hollander, Amy Rauworth & Karin Korb
11:00 – 11:15am	Break	
11:15 – 12:15pm	Facilitated Discussion # 1 How and where does our policy and advocacy work align?	Taylor Cooper & Kay Kornmeier
12:15 – 12:45pm	Lunch	
12:45 – 1:30pm	Facilitated Discussion # 2 What opportunities exist to collaborate on state and local campaigns?	Taylor Cooper & Kay Kornmeier
	Facilitated Discussion # 3 What pathways exist to inform the Voices for Healthy Kids model?	Taylor Cooper & Kay Kornmeier
2:30 – 3:00pm	Re-cap, Next Steps & Evaluation	Taylor Cooper & Kay Kornmeier
3:00pm	Meeting Adjourns	Lakeshore Foundation NCHPAD & Voices for Healthy Kids teams

Success Factors for Partnerships and Collaboration

Participants shared the following factors that contribute to successful collaboration based on their experiences.

Success Factor or Characteristic	Description
Trust and Transparency	Trust Two-way collaboration Honest collaboration Respectful awareness
Community Leadership	Valuing members of the community Community-led
Courage	Taking a risk Daring, solidarity Be brave enough to go deeper than diversity
Clarity and Sustainability	Clear and well-defined goals Shared goals and deal-breakers Planning for implementation and sustainability
Continuous Learning and Flexibility	Set aside preconceived ideas Change directions if needed Know where to lead and where to support Learn from what others are already doing
Commitment and Principled Struggle	Be part of it for the long haul Center the marginalized Admit to harm and mistakes Commit to do justice
Inclusive Approach and Language	Use inclusive language Make spaces welcoming for all Act on the talk Intersectional connections
Shared Resources	Commit resources Share the pie in a real way

Appendix F

Participant Survey

Prior to the Connecting for Change Roundtable, participants received a survey to help facilitators prepare for the meeting. The following is the summary of the 15 responses received from participants.

Participant Goals and Interests

Survey respondents identified **goals for the roundtable** including building relationships and networks; increasing knowledge of policies, issues and organizations participating; understanding intersections across sectors and interests; and understanding how to contribute and take action.

Respondents also identified **specific areas of interest** they would like to explore including education, schools, race and equity, gender, disability identity, legal context, rural areas, physical activity and healthcare access. Survey respondents indicated they planned to contribute to the discussion with personal experience, professional experience and skillsets, as well as resources, funded programs and existing networks.

Attending so I can...

- **Collaborate:** Network, build new alliances, break down silos
- **Engage in Dialogue:** Participate in high-level discussion, structured conversation
- **Learn:** Hear new perspectives, listen to what others are working on
- **Share:** Share our work, add an intersectional vantage point
- **Improve:** Enhance ability to be effective, strengthen our work and outcomes
- **Highlight Personal Experiences:** Lived experience, serving as a peer advocate
- **“You asked!”** Colleague or mentor invitation to participate

My goals for partnership are...

- **Leadership:** Increase leadership for persons with disabilities
- **Relationships:** Building trust and buy-in among partners, understanding of interests and needs as a foundation
- **Shared Goals:** Recognizing one another’s priorities and goals, identifying shared goals
- **Process:** Using a collaborative, representative process with community engagement; communicate, coordinate and collaborate
- **Outcomes:** Build capacity among partners, remove barriers to inclusion, funding for an advocacy system in which individuals are paid for their time

Survey respondents thoughtfully provided **challenges and obstacles** as well as **success factors, resources and supports** to building successful partnerships.

Partnership challenges...

- Lack of awareness
- Lack of communication, trust and listening
- Lack of training
- Lack of resources and funding
- Competing priorities
- History and past harms
- Subconscious bias
- Language
- Resistance to shifts in resources and power

Partnership success factors...

- **Relationships:** Trust, openness and willingness to try new things
- **People:** Trained staff, capacity
- **Shared Goals:** Shared goals, plan and roadmap
- **Funding:** Funding to support shared initiatives

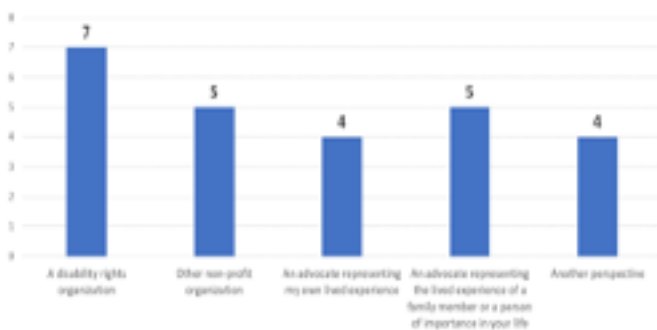
Organizational Structure and Asset Inventory

Organizational Characteristics

- Respondent organizations range in size:
 - 1 – 25 employees (3)
 - 26 – 100 employees (6)
 - 251 – 1,000 employees (2)
- All respondent organizations are either very inclusive (4) or working to be more inclusive (7).
- Most respondent organizations (9) have state/local chapters or work through affiliated networks. Of those organizations, 5 work in all 50 states.
- Most respondent organizations (9) have a national network and connect to individuals

Participant Overview

Which perspectives will you be representing at the Roundtable?



Another perspective write in answers: Federal Government (2), Tribal Government (1), A Black Women Activist for Equity (1)

Federal Policy and Advocacy Efforts

All respondent organizations (11) support Federal policy and advocacy efforts.

- How does your organization **decide which Federal policy** to support?
 - **Internal:** Organizational governance, in-house experts, case-by-case analysis, policy and position statements, collaborative process based on organizational values and surveys of membership
 - **External:** Local advocacy leadership, other national organizations
- Who is involved in the **decision-making**?
 - Leadership (Board, management, CEO) (5)
 - Leadership and staff (3)
 - Policy team / director of policy (2)

State, Regional, Tribal or Local Advocacy and Policy

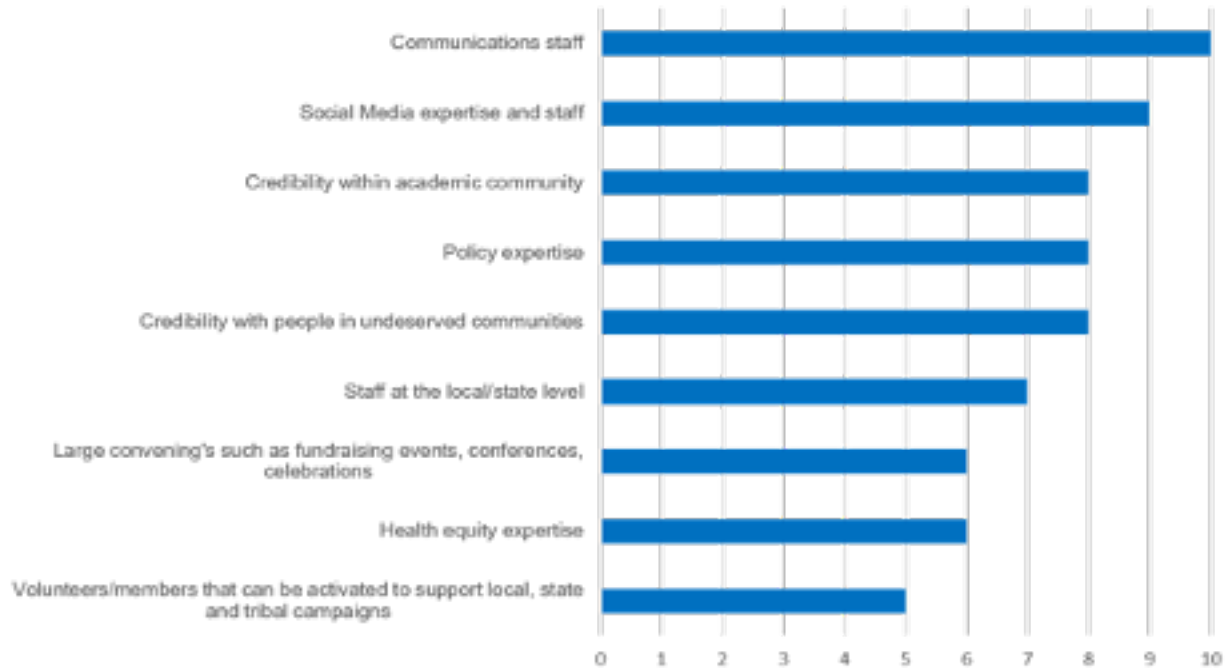
All respondent organizations (11) support state, regional, tribal or local policy and advocacy efforts.

- How does your organization decide which policy to support?
 - Data, evidence, research and strategic planning
 - Collaboration with coalitions and community partners
 - State and local chapters
 - Survey of membership
- Who is involved in the **decision-making**?
 - Community stakeholders
 - Organizational leadership, management and staff
 - State and local chapters
 - Advocacy staff
- What is the **process for a campaign or stakeholders to engage your organization** at the state, regional, tribal or local level?
 - Contact individuals directly (executive director, program director, staff)
 - Connect to state or local chapter
 - Participatory approach, collaborative partnership
 - Use guidelines developed by the organization
- In response to the question, “What **partners** do you consult with or reach out to for collaboration on disability and inclusion initiatives?” survey respondents identified a mix of national, state and local organizations. Some examples (in no particular order) are included below.
 - **National organizations**, such as American Association on Intellectual Developmental Disabilities, American Red Cross, Autism Society, national Association of Councils on Developmental Disabilities and NCHPAD
 - **State and local organizations**, such as independent living centers, state departments of transportation, state developmental disabilities councils, state disability rights organizations and state hospital associations,

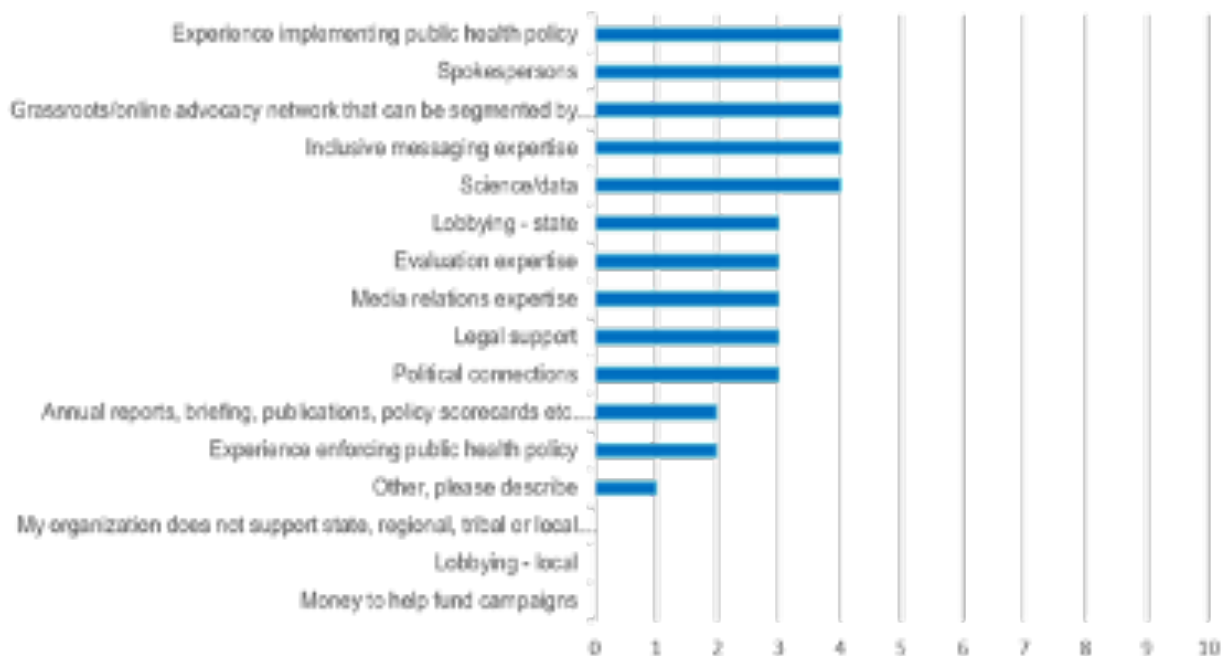
- Community stakeholders and partners, such as city councils, community partners, parents, students, school districts

- Assets for State, Regional, Tribal or Local Policy and advocacy efforts. Respondent organizations have a wide variety of policy and advocacy efforts at their disposal, ranked highest to lowest below.

What assets does your organization currently have?



What assets does your organization currently have? (pg2)



Appendix G

Policy Alignment Survey Results

This appendix summarizes the priority areas as it relates to Voices for Healthy Kids policy levers based on a survey conducted of all participants prior to participation at the roundtable.

Shared General Priorities

The Disability & Inclusion community has policy priorities unique to their needs, however, the survey showed there are also shared overarching priorities with Voices for Healthy Kids.

Equity (Health and Access)

- Healthy equity through inclusion of people with disabilities
- Promote and maximize health for people with disabilities
- Increase the quality of life among people with disabilities
- Resources and support that families need to ensure that their children become fully participating and contributing members of our community- foremost commitment is to those with the greatest need
- Issues that affect communities of color or multi-marginalized communities

- The study of life-span human development and family relations, and the impact of biological, environmental, and socio-cultural factors on both (Social Determinants of Health)

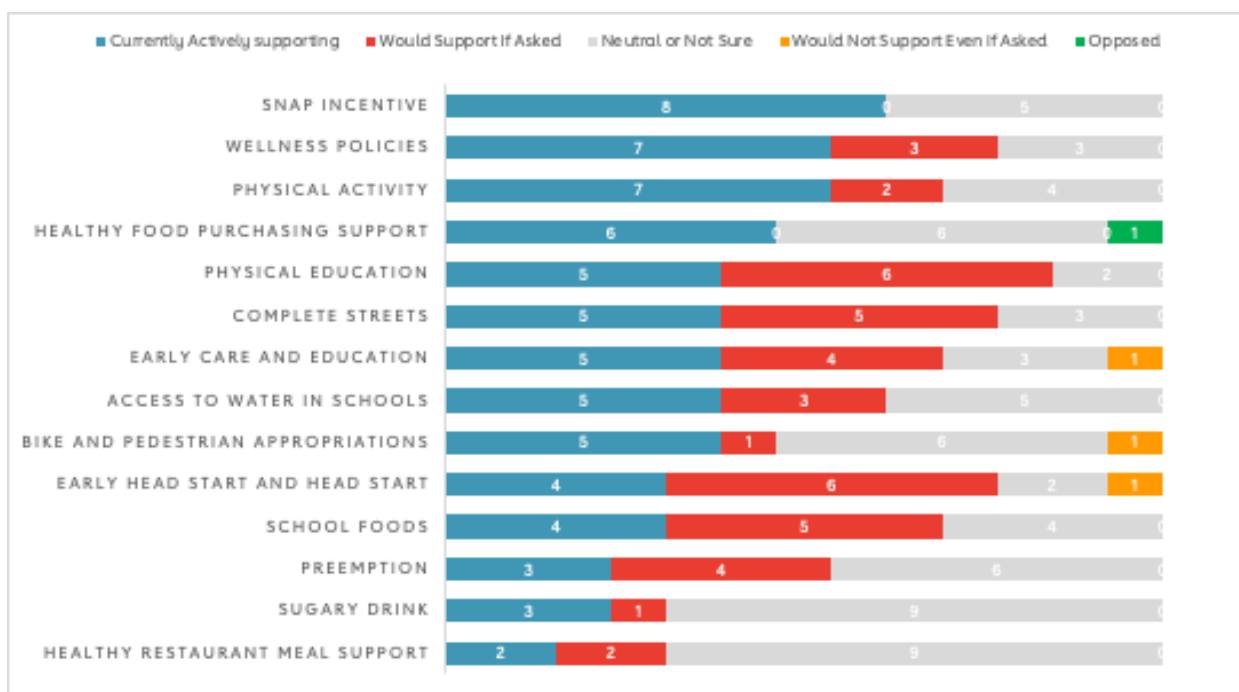
Inclusion

- Champion inclusion of people with disabilities in our own institutions and within all of philanthropy
- Ensure people with disabilities participate in all stages of the development and implementation of research projects
- Work related to including people with disabilities in public health programs

Individual and Systems Advocacy

- Protecting and promoting the rights of people with intellectual and developmental disabilities (I/DD) and their families through policy & advocacy
- For national, state, and local systemic change to advance the rights of people with disabilities by supporting direct action, coalition building, community organizing, policy analysis, litigation, training for advocates, and community education.

How likely are roundtable participants to support Voices for Healthy Kids policies?



Shared Policy Priorities

Some of the priorities specifically mentioned by roundtable participants directly or indirectly align with Voices for Healthy Kids' policies.

Active, Equitable Communities

Policies: Complete Streets, Bike & Pedestrian Appropriations

Support state and local policies and funding and influence the use of federal dollars in states that make communities and neighborhoods more livable by ensuring all people can safely get where they need to go – work, school, the library, grocery stores or parks – starting where the needs are greatest.

D&I Round Table Participant Priorities:

- Integration of disability into autonomous vehicle design and policy, ride hailing, rail systems
- Transportation policies that strive to ensure funding for and access to multi-modal transportation options (Complete Streets; Safe Routes to School; comprehensive planning; state guidance on school siting, construction, and major remodels)

Healthy Equitable Schools

Policies: School foods, Physical education, Physical activity, Wellness policies, Water access

Promote the Whole School, Whole Community, Whole Child (WSCSS) model to support and build broad and inclusive healthy, school environments, particularly in marginalized or under-resourced communities. Work to support and build healthy schools for all children regardless of where they live or go to school.

D&I Round Table Participant Priorities:

- Including inclusionary school discipline practices and school environments (both physical and psycho-social)
- Addressing inclusive physical education and physical activity focusing on internal/external partnerships, data collection systems, developing resources, and supporting programmatic efforts.

Healthy, Accessible Food and Beverage:

Policies: SNAP incentives, Healthy food purchasing, Healthy restaurant meals, Sugary drink taxes

Support state and local policy that increases access to healthy food and beverage, decrease access to unhealthy food and beverages, makes it easier to eat healthy and drives industry innovation to improve the food and drinks we all need.

D&I Round Table Participant Priorities:

- Healthy eating/healthy food access

Early Childhood

Policies: Early care and education, Early Head Start and Head Start

Supporting early childhood development opportunities at the state and local level with a focus on children most in need, that increase healthy outcomes, set children on a path to life-long health and support families.

D&I Round Table Participant Priorities:

- School for children with physical/medical disabilities age 4-21

Preemption

Policies: Preemption repeal, Preemption defense
Preventing states from blocking local actions that promote health, well-being and equity.

D&I Round Table Participant Priorities:

- None

Top three policy priorities noted by respondents prior to the roundtable discussion

Policy 1	Policy 2	Policy 3
Community Living Supports – Disability Integration Act; Olmstead and related CMS HCBS programs; HUD and Fair Housing and H.R.4064 – Eleanor Smith Inclusive Home Design Act of 2019	Employment – Workforce Innovation & Opportunity Act	Accessible health care – Medicaid expansion and ACA
Community integration and living (LTSS/HCBS; housing; transportation)	Reducing barriers to health and healthcare including social determinants	Preserving and improving access to primary and secondary education; reducing school to prison pipeline
Healthy eating/healthy food access/land use planning to promote HEAL/health equity	Physical activity	Commercial tobacco control and prevention
Family and Medical Leave	Medicaid	Long term services and supports
Employment – To improve inclusive employment for individuals with disabilities	Quality of Life-To remove barriers to care to improve health and well-being	Medicaid/Long-Term Supports – Protecting Medicaid to ensure individuals with disabilities have services they rely upon
Health Equity	Structural Drivers of Inequity	Healthy Communities
Economic Development	Human Services and Support	Education
Access to and parity of services	Stabilization and growing of field for direct care workers	Building a comprehensive universal health care system on a continuum with home and community-based services as the default
Medicaid	Education	Community-based living
Physical Education and Physical Activity	School Nutrition Environment and Services	School Health Services for Managing Chronic Health Conditions
Health care	Living wage for people with disabilities	Safe, affordable housing