

AGING EQUITY ROUNDTABLE DISCUSSION SUMMARY

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Health & Medicine staff working on the Illinois Aging Together campaign held six virtual and in-person roundtable discussions in the summer and fall of 2023 with community groups that represent people often underrepresented in aging-policy-focused discussions. These roundtables were made possible through technical assistance funding from the Center for Health Care Strategies, which has been hosting a national learning collaborative on multi-sector planning for aging efforts around the US. The technical assistance funds were offered to both the nonprofit partner organizations supporting our efforts and to the roundtable participants as stipends to honor their time and for sharing their lived experiences.

HELPING ADVANCE A MULTI-SECTOR PLAN FOR AGING EQUITY IN ILLINOIS:

One of the challenges we face in Illinois, which we've heard is a challenge in other states, is ensuring that the groups engaged in aging-focused policy conversations reflect the population. We have found that Black, Latine, Asian, LGBTQ+, and disabled groups are not very prevalent in many aging conversations and coalitions in Illinois. We are working with partners to conduct specific engagement, hoping to get insight and perspective and, hopefully, form new relationships. These engagements will help shape our advocacy and, if successful, the eventual plan. We know we cannot reach aging equity without having racial, social, and economic justice. This requires engaging a much more diverse group of people than aging conversations often do in order to better match the whole population of our state. By conducting this engagement, gaining perspective, and building new relationships stemming from this activity, we will make it more likely that the multi-sector plan for aging will become a reality in Illinois and, when it does, that it will be a strong, equity-focused plan that reflects the needs of Illinois' population.

OBJECTIVES:

- Collect first-person narratives and information from people in the selected groups.
- Begin to develop lasting relationships and produce collaboration with individuals and organizations made up of people from groups underrepresented in aging conversations.
- Show value for the lived experiences of people from diverse communities that aren't always included in aging work and conversations.
- Develop an understanding and appreciation for the cultural and social values related to aging and the preferred terminology for each group regarding aging.

The organizations that we partnered with were Access Living, Southsiders Organized for Unity and Liberation, Pride Action Tank, Hanul Family Alliance, and Telpochcalli Community Education Project. At each session, participants shared their personal experiences and ideas for what aging equity would look like to them.

THEMES:

The main themes summarized from the roundtable discussions were:

- As they age, more people are experiencing increased feelings of loneliness and have greater needs for social activities in their community.
- Some shared that they or people they know have worsening depression as support systems have gotten smaller because of friends passing away or family moving away.
- Almost all the groups mentioned issues with affordable and accessible housing as their mobility needs change.
- Caregiving support is a major unmet need. In some cases, people who already had some form of caregiving reported either needing more hours and not being able to get it or that their caregivers were not able to fully meet their needs. In other cases, people were concerned because they thought about the future and wondered how they would get the support they needed since they didn't have close family or friends.
- Finances remain a major concern, including not wanting to be a financial burden on their family as they age.

BRIEF REFLECTION:

In some ways, the conversations at these roundtables were expected because many of the same themes, such as housing and accessibility, that we often hear about in other settings were discussed. It was also interesting to see the differences in how people viewed aging depending on their culture, neighborhood, and personal circumstances. This was a valuable experience, and it will serve as a guide for including these issues in the multi-sector plan for the aging equity process.

SUMMARIES:

Below are summaries of our conversations with each group of individuals gathered by the partner organizations. These are reflections of these individuals' views and opinions shared during the roundtable discussions. We have summarized these conversations to the best of our ability and shared them with gratitude for the openness of the roundtable participants about difficult subjects related to challenges and injustices.

ACCESS LIVING:

During the first roundtable with Access Living, the feeling of being made to feel less than capable because of a disability came up throughout the session. Many of the participants reported not feeling respected by family members because they are getting older and have a disability. They wanted to make it clear that just because they are older and have a disability does not mean they are not capable. One participant mentioned how they feel even more free to do what they want and love to do now that they are older. They feel they have more of a voice now because they are not worried about what others think or want from them. Many mentioned still wanting to be involved in things such as politics or disability rights, even if their level of involvement may look different now. There is also a large inequity in caregiving services that many of them need. Many reported that the caregiving hours have been reduced, and even when they are available, restrictions make it impossible for them to get their needs fully met. For example, some of the participants live in communities where there are no full-service grocery stores. The small neighborhood stores only sell junk food and frozen foods. Their caregivers are often restricted from traveling beyond a few blocks, so they are forced to pay someone out of their pocket to help them get groceries and other essentials. This puts a financial and physical strain on them.

Another major concern was that people with disabilities often age faster than those without disabilities. There was concern about that and sadness when thinking about how their inner circle of friends became smaller because of premature death. Difficulties dealing with insurance companies to meet basic needs such as therapy and wheelchairs are burdensome and should not be that way. Participants all agreed that there needs to be a better system and that it should not always be up to individuals and their families to get things done.

SOUTHSIDERS ORGANIZED FOR UNITY AND LIBERATION (SOUL):

The next roundtable was held with Southsiders Organized for Unity and Liberation (SOUL). This Chicago-based organization focuses on helping low-income people of color build power. One of the most prominent issues discussed during this session was the financial burden of getting older. Many mentioned having difficulty accepting that they can no longer do everything for themselves and that they don't want to be a burden. Some of the younger participants in the group have concerns about having to work forever to live because the future availability and quality of programs such as Medicare and Social Security are unknown. They shared feeling as though resources that are meant to help older adults are not as accessible in low-income black communities as they are in more affluent areas. Even when they are available, they run into barriers such as long waitlists or a ridiculous number of requirements. One of the participants has a 73-year-old mother and is navigating social services and insurance issues for the first time. They find it frustrating and think insurance premiums for older adults are too high. They are glad that their mother has them to help with all of this but worry for those who have no support and get taken advantage of because everything is so complicated.

PRIDE ACTION TANK:

We hosted two roundtables with Pride Action Tank because there was significant interest and too many participants for only one session. Pride Action Tank works with the LGBTQ+ community in the Chicago region. A major issue for most of the participants was the feeling of not being accepted by the communities they live in, including establishments and their families. They noted that many LGBTQ+ older adults didn't have a family support system and, as a result, relied on close friends and the community they have built with like-minded people who likewise may not be accepted because of who they are. One participant noted that they have added their close friend as an emergency contact and have designated them to make any important medical decisions if it is needed. This same participant also mentioned being on good terms with their family after many years, but they feel closer to the community of friends they have built throughout their lives. Many were upset that most of the resources and organizations that exist to help LGBTQ+ people are on the North side of Chicago, but there is a lack in other areas of the city. One of the participants reported moving to the Northside because they felt more accepted and supported. The reality is that it is not feasible for every LGBTQ+ older adult to move, so those in other areas, especially neighborhoods with large numbers of low-income people of color, are left with little to no support.

There was a moment in the first roundtable where the participants were telling each other about different resources that are available near their neighborhood, and it was great to see them helping one another. The reality is that there are not enough resources, and even

when they do exist, many people do not know about them, or they are not accessible to most. There was also discussion about people who are not part of the LGBTQ+ community trying to come up with solutions and help. The reality is that they are not the indicated people to do so because they don't understand the needs and wants of their community. They mentioned that there was a disconnect between how society views aging people and what the reality is. Many of the participants do not feel frail or helpless. They want to be social and go out, but doing so looks different now compared with when they were in their 20s and 30s. If organizations are going to have events for their community, they would prefer it to be during the day, and there doesn't always have to be alcohol involved. Some participants said that many LGBTQ+ events cater more to the younger crowd, with late start times, alcohol, and rowdy behavior encouraged. They want spaces specifically for older LGBTQ+ people, and there are not many of those.

HANUL FAMILY ALLIANCE:

The first in-person roundtable we held was with Hanul Family Alliance. They work primarily with the Korean American community in Chicago and its suburbs. The Director of Hanul Family Alliance provided translation during the roundtable. Many of the participants' primary concern was feeling lonely as they age and not feeling like they belong in community spaces in predominately white neighborhoods because of the language barrier. They spoke extensively about wanting a space with recreational activities, educational classes, and a social area for older Korean adults. Hanul Family Alliance provides some educational classes and a daily lunch, but because of insufficient funding, they are unable to meet the needs of the growing Korean community. They said they do not feel welcome in senior centers catering primarily to English speakers because they sense no effort from such centers to promote the resources to the Korean community despite there being a large community of them near the centers. They also said that they find it unfair how senior centers in predominately white neighborhoods receive a lot of funding while spaces that are for their communities receive significantly less.

Some participants talked about their personal circumstances and why they felt so lonely. Some said they came to the US from Korea, leaving behind their families and support systems. Many of their children are grown and have moved away. They talked about their children, not wanting to be involved in their lives or help them. Still, although feeling alone and unsupported, they try to have a positive outlook on life. They all want spaces where they can socialize because they do not like staying at home to get more depressed. They like to keep themselves active and exercise their mind. They noted that a place that they regularly use as a meeting place to socialize is McDonald's because they can get an inexpensive cup of coffee and talk to their friends. They mentioned that if Hanul Family Alliance could offer more classes, they would rather go there.

TELPOCHCALLI COMMUNITY EDUCATION PROJECT:

Our last roundtable, which was in-person, was with Telpochcalli Community Education Project (Tcep). Tcep focuses on creating social change in Little Village and nearby communities. The participants had a lengthy conversation about how many in their community, including themselves, don't feel like they fully belong to the U.S. or Mexico. They used the common Spanish phrase, "ni de aquí, ni de allá," which means "not from here or there." Most of those in the discussion immigrated from Mexico and have established a life for themselves here. They explained that their reality is that with their undocumented status, there is very little in terms of services for them to look forward to as they age. They are all aware of services that help older adults, but they won't qualify for most of them. They mentioned that most of the Latine community in Little Village thinks about going back to their home country for retirement once their children are grown and their children no longer need them.

A conversation also started about how much better it is for older adults in Mexico, with warmer weather and more social activities, to keep active and happy. The reality for some was that because of the low wages their children make, they feel they must care for their grandchildren for free, which leaves them with little to no time for themselves. One of the participants mentioned that it would be great if the government could pay grandparents to care for their grandchildren just as a non-family caregiver would. They mentioned it would help with mental health because the grandparents would not only feel useful but also happy to be compensated for their contribution to society and have income to afford living expenses better or save for the future. Living in Little Village, all of the participants reported safety being a major concern and one of the primary reasons they have stopped walking in their community. One participant stated they used to enjoy daily walks around the park but that with increasing violence, it is impossible. A major issue they all agreed on was that the neighborhood is changing; it is being gentrified, and they are being forced out of their community because of increasing rents. They all love their community but wish they had more of the resources that more affluent and white neighborhoods have.

CLOSING:

Health & Medicine is grateful to these five organizations – Access Living, Southsiders Organized for Unity and Liberation, Pride Action Tank, Hanul Family Alliance, and Telpochcalli Community Education Project – and the dozens of individual roundtable participants for supporting these rich conversations. As we sought to do, we believe these roundtables enriched our understanding of aging-related issues from demographic groups who are often underrepresented in aging-focused policy discussions. We've connected with new potential partners and have grown our support. We share these notes above with gratitude for the openness and hope for a more just, equitable society.

ABOUT ILLINOIS AGING TOGETHER:

Illinois Aging Together is a statewide movement for aging equity. It includes a campaign for a strategic action plan for aging equity. We also seek to reframe aging in positive terms of value, meaning, and purpose, and to link aging equity to other justice-focused movements. You can learn more and support the campaign at www.IllinoisAgingTogether.org.

ABOUT HEALTH & MEDICINE:

Health & Medicine is a Chicago-based non-profit working to improve the health of all people in Illinois by promoting health equity. Founded in 1981, it was formed as an action-oriented policy center—nimble, independent, and focused on regional health issues. Health & Medicine's mission is to promote social justice and challenge inequities in health and health care. It conducts research, educates, and collaborates with other groups to advocate for policies and health systems that improve the health of all people. Health & Medicine has successfully developed health policy recommendations and implementation strategies for different public and private entities to become the region's "honest broker" on healthcare policy matters.