

FOR CHANGE: LESSONS LEARNED FROM ENGAGING LGBTQ+ OLDER ADULTS FOR ADVOCACY

MAY 2023





ABOUT THE LEAD ORGANIZATIONS



The OUTAging Committee made up of LGBTQ+ older adults and allies and was borne out of Pride Action Tank's OUTAging: Summit on Our Possibilities convening in May 2017.

The goals of OUTAging were to:

- Create a platform that centers the voices and experiences of LGBTQ+ older adults to shed light on the issues they face and gaps in services, resources and opportunities,
- Provide a diverse and inclusive forum for redefining aging and care, and
- Develop an agenda for advocacy, resources, and inclusion with and for LGBTQ+ older adults.



Pride Action Tank (PAT) is a think tank that is focused on action that leads to improved outcomes and opportunities for LGBTQ+ communities in Illinois through a collaborative process of inquiry, advocacy, and action. Launched in October 2015, PAT's work focuses on six overlapping issue areas: aging, financial security, health, housing, safety, and youth.



AIDS Foundation Chicago (AFC) mobilizes communities to create equity and justice for people living with and vulnerable to HIV or chronic conditions.

AFC brings together service providers and funders to develop systems that meet the needs of those living with HIV/AIDS and to maximize the use of scarce resources. By assisting government entities in planning, distributing, and monitoring service contracts, AFC helps develop provider expertise and promotes uniform and high-quality delivery across the region.

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EXECUTIVE SUMMARY

OUTReach: Advocating for Safe & Inclusive Spaces for LGBTQ+ Older Adults (OUTReach) is a project to improve culturally competent care for LGBTQ+ older adults who experience long-term care facilities and other aging services in the Chicago area. OUTReach raises awareness around issues facing this community through storytelling and advocacy trainings for LGBTQ+ older adults, dissemination of educational materials and conversations with policy makers, providers of aging services, caregivers and other decision makers.

OUTReach itself was born from the work and committee that was created from the OUTAging: Summit on Our Possibilities (the Summit) in May 2017. The Summit brought together people from the LGBTQ+ community, particularly LGBTQ+ older adults, with service providers and stakeholders to discuss issues facing the LGBTQ+ aging community. It sought to bring forth the voices of our elders, calling on a history of oral tradition, well known to the LGBTQ+ community, to shed light on those who may feel forgotten or cast aside. To read the full Summit Report, <u>please visit this link</u>.

To continue the work of the Summit, OUTReach includes two annual workshop series, the *Storytelling for Change Workshop* and the *Advocating for Change* workshop (For Change workshop series). It's important to note the social and political context in which the For Change workshop series took place. When the OUTAging Committee pivoted to developing the For Change workshop series for the OUTReach initiative, it had only been a few months into the experience of a global lockdown due to the COVID-19 pandemic. In addition to the fear of health complications, the pandemic forced an intense period of isolation and distancing that impacted social health. This was particularly true for older adults who, like everyone else, were watching the early news stories about how COVID-19 and our poor health infrastructure were disproportionately killing older adults. That fear and prolonged isolation was the backdrop of the first set of the For Change workshop series and guided the direction and structure toward virtual sessions.

In 2022, the OUTAging committee sought to conduct focus groups to gather feedback on the workshops to gain further insights on what was working and what needed improvement. In total, there were four, 2-hour focus group sessions (one for those who attended only the Storytelling for Change Series, one for those who attended both training series, and another for facilitators of each workshop). Each focus group averaged 3-4 participants (except for the facilitator's focus group, which included 6 participants).

Once focus groups were completed, transcripts were developed to conduct analysis with a reflexive thematic analysis approach. Due to the overlap in participants' reflections of both the Storytelling and Advocating for Change workshops, the Research Subcommittee decided to analyze the transcripts together instead of as separate programs.

Our analysis yielded seven themes. Some of these themes centered on the impacts and outcomes of participating in the Storytelling for Change and Advocating for Change workshops, whereas others are better described as process themes. In all cases, we provide practical recommendations related to each theme. The seven themes are:

THEMES

1. THE JOYS OF BEING IN COMMUNITY WITH LGBTQ+ ELDERS

The workshops were not just important for skill-building, but for building community, too. Lack of community contributes to the invisibility that older adults experience, and the workshops became a vital way for individuals to tap into their community. As one respondent claimed, "This workshop has been my lifeline."

2. BEING SEEN AND HEARD AS LGBTQ+ ELDERS AT ALL INTERSECTIONS

We often heard from our participants about how older adults are invisible to society and to each other, which is compounded by social isolation and the lack of resources and services. The project re-emphasized the need to take on an intersectional lens to understand LGBTQ+ aging. Participants often brought up their many identities (whether based on race, disability status, or religious background) which provides much needed nuance to LGBTQ+ aging.

Storytelling and advocacy became platforms for members of the LGBTQ+ older adult community to be visible on personal and public levels. Additionally, hearing others was also just as important as being heard.

3. GAINING A (RE)NEW(ED) SENSE OF PURPOSE IN AND THROUGH ADVOCACY

Participants shared their experiences "transitioning" into older adulthood and expressed the uncertainty of aging. The trainings often assisted participants to reconceptualize their life (past and future) and sparked a feeling of a "new lease on life" or a second "coming of age." Relatedly, participants shared how their engagement with the programs led to new opportunities. One participant said, "It opened up a bigger world for me."

4. LEARNING TO TELL "A DIFFERENT KIND OF STORY"

The participants enjoyed the unique challenge of learning how to adapt their stories so that they would have optimal impact among policymakers. It provided them a different lens through which to filter their lived experiences. Through the workshops, the participants were able to see the difference between a story they might tell friends versus a story that they might tell in an advocacy setting.

5. LEARNING ABOUT ONESELF THROUGH LEARNING TO HELP OTHERS

We saw a pattern among participants that these workshops were a turning point and empowered them to make a difference or leave something behind. Participants expressed being able to see themselves as storytellers or advocates, and that these roles are not confined to specific people. One participant said, "You have to activate it," which showed us how much determination and will power are needed on the participant's end to incorporate the learnings from the trainings into their daily lives.

6. THE COST OF THE STORY: CREATING SPACE FOR VULNERABILITY

We recognize that these trainings take work, both on the facilitator and participant sides of the spectrum, and so there is a cost to continuing programs like these. For participants, it costs them vulnerability around cognitive ability and the risks associated with bringing up past trauma. For facilitators and organizers, the costs are our ethical responsibility to storytellers and other training participants. Through this analysis, we began to question what our obligations are to support participants beyond training and education (i.e., connection to professional opportunities, linkage to behavioral health resources and services, and linkage to housing services).

7. CULTIVATING A COMMUNITY OF SUPPORT

Because of the costs associated with telling stories and engaging in advocacy work, it is essential to cultivate a community of support in the workshops. Well-being is the responsibility of both facilitators and all participants alike. Investing in cultivating a community of support from the start allows participants to give themselves permission to take risks and participate more fully and openly. A participant spoke to this collective responsibility when he said: "We're here to lift each other up, we're here to support each other, we're here to help each other get the word out and make things change. We can't do that if we're shutting people down for whatever the reason is."

Through the focus group sessions, we have gained deep insight into the importance and need of programs like the For Change workshop series. We learned the many ways OUTReach programming can be improved to create safer and more inclusive spaces for LGBTQ+ older adults, such as providing emotional supports for participants or ensuring clarity of purpose. Additionally, we found that focus groups themselves were not only a useful tool for evaluative purposes, but for providing yet another opportunity for LGBTQ+ older adults to reconnect and reflect on their experiences together.

RECOMMENDATIONS

Based on focus group discussions, we gleaned the following recommendations for future workshops and for organizations or agencies hoping to develop programs for and with LGBT older adults:

1. Include LGBTQ+ older adults in the planning process

- 2. Create spaces for ongoing interactions between workshop participants, such as alumni events or new engagement opportunities
- 3. Share new advocacy or storytelling opportunities with alumni to maximize visibility of LGBTQ+ older adults
- 4. Prioritize in-person/hybrid events and convenings when possible and to the extent that public health advisories allow
- 5. Commit to connecting alumni to future advocacy work and advanced workshops to continue building their skills and experiences in advocacy or storytelling
- 6. Ensure clarity of the purpose and objectives of workshops at the beginning to diffuse any confusion around participation
- 7. Develop strategies to manage differing levels of experience and knowledge in advocacy/storytelling
- 8. Ensure transparency around how and when participants' stories may be used in the future and monitor privacy/confidentiality
- 9. Provide support and resources to participants in the event that they disclose unmet needs (such as access to housing or healthcare).
- 10. Include a peer support person among the facilitator team to minimize anxiety associated with the process of writing their stories, as well as incorporate one-on-one feedback sessions with facilitators as an added feature of the storytelling workshops
- 11. Open programming with a transparent discussion about the potential risks and vulnerabilities associated with the difficult work of storytelling/advocacy, followed by a facilitated discussion of what a community of support can look like in spirit and in practice

OVERVIEW OF THE FOR CHANGE WORKSHOPS

SUMMARY OF STORYTELLING AND ADVOCACY FOR CHANGE

OUTReach: Advocating for Safe & Inclusive Spaces for LGBTQ+ Older Adults (OUTReach) is a project to improve culturally competent care for LGBTQ+ older adults who experience long-term care facilities and other aging services in the Chicago area. OUTReach raises awareness around issues facing this community through storytelling and advocacy trainings for LGBTQ+ older adults, dissemination of educational materials and conversations with policy makers, providers of aging services, caregivers and other decision makers.

OUTReach itself was born from the work and committee that was created from the OUTAging: Summit On Our Possibilities (the Summit) in May 2017. The Summit brought together people from the LGBTQ+ community, particularly LGBTQ+ older adults, with service providers and stakeholders to discuss issues facing the LGBTQ+ aging community. It sought to bring forth the voices of our elders, calling on a history of oral tradition, well known to the LGBTQ+ community, to shed light on those who may feel forgotten or cast aside. The Summit produced three major themes:

- 1. Lack of knowledge or appropriate access to resources which support the LGBTQ+ and aging communities
- 2. Desire to have strong social support networks and communities, and
- 3. The need to update and transform existing systems and institutions (health, legal, justice among others)

To read the full Summit Report, please visit this link.

To continue the work of the Summit, OUTReach includes two annual workshop series, the *Storytelling for Change* workshop and the *Advocating for Change* workshop (For Change Workshop Series). It's important to note the social and political context in which the For Change workshop series took place. When the OUTAging Committee pivoted to developing the For Change workshop series, it had only been a few months into the experience of a global lockdown due to the COVID-19 pandemic. In addition to the fear of health complications, the pandemic forced an intense period of isolation and distancing that impacted social health. This was particularly true for older adults who, like everyone else, were watching the early news stories about how COVID-19 and our poor health infrastructure were disproportionately killing older adults. That fear and prolonged isolation was the backdrop of the first set of the For Change workshop series and guided the direction and structure toward virtual sessions. Storytelling for Change is a workshop that builds upon LGBTQ+ older adults' storytelling skills in a longer form (6–8-minute stories). Participants must complete all six sessions of the Storytelling for Change training. The workshop engages LGBTQ+ older adult community members in a six-week workshop series to

- 1. Empower LGBTQ+ older adults to share their stories on multiple platforms;
- 2. Strengthen skills around crafting and telling a story to discuss issues that older LGBTQ+ adults face as members of the first out generation;
- 3. Form intentional relationships and community around LGBTQ+ older adult experiences; and
- 4. Build a "living library" of stories that can be used in OUTReach program advocacy efforts

At the end (the sixth week), cohort members participate in a virtual showcase to tell their finalized stories to previous cohorts and stakeholders who work in the aging sector. Upon completion they receive a certificate of completion and a stipend.

In 2022, the cohort consisted of 8 new members who attended weekly workshops to decide on their story topic and practice telling their stories with each other. The series is led by Nic Weststrate and Archy Jamjun. We also included an additional facilitator who is an alumna of the first cohort to provide peer-to-peer feedback. The additional peer facilitator was especially helpful with ensuring the cohort's understanding of expectations and the process leading up to the showcase.

STORYTELLING FOR CHANGE FACILITATOR BIOS

Archy Jamjun is a writer and storyteller in Chicago. He was recently crowned Chicago's Biggest Liar and is a Moth StorySlam winner. He has, seemingly forever, been working on a collection of short stories and even while writing this bio, he is promising himself that he'll get it done this year! Archy is the curator and a frequent storyteller for OUTSpoken LGBTQ+ Stories, the monthly storytelling show that takes place at Sidetrack the Video Bar.

Nic M. Weststrate is an Assistant Professor in the Department of Educational Psychology and member of the Center for Research on Health and Aging at the University of Illinois Chicago. Nic studies positive aging and intergenerational relationships within the LGBTQ+ communities. Currently, he has been exploring the potential for intergenerational storytelling between LGBTQ+ elders and youth to bolster their health, well-being, and psychosocial development, while also sustaining the LGBTQ+ communities' rich cultures and histories. In Nic's community-engaged research, he partners with the Senior Services Program at the Center on Halsted and Pride Action Tank of the AIDS Foundation Chicago.

Advocacy for Change engages LGBTQ+ older adult community members in a fourweek workshop series to:

1. Familiarize with LGBTQ+ terminology and history

- 2. Learn about national and state trends in LGBTQ+ older adult experiences and outcomes
- 3. Improve knowledge about the rights of LGBTQ+ older adults
- 4. Create personal and collective stories for use in advocacy work

Unlike the Storytelling for Change series, each week invites a new speaker(s) to lead the training according to the topic (please see Table 1 below for an example of topics covered in the 2022 sessions). The training guidelines were as follows:

- Sessions are 10 a.m. 12 p.m. on the dates listed in the table.
- Start every session with an ice breaker.
- Provide a 5–10-minute break.
- Use breakout rooms for discussion and community building, if the group is large enough.
- Encourage people to take risks.

TABLE 1. ADVOCACY FOR CHANGE TOPICS

LANGUAGE AND COMMUNITY BUILDING

- The Q word and other rainbow identities
- Cultural considerations
- The journey of self

AGING SERVICES IN ILLINOIS AND LGBT+ OLDER ADULTS

- Illinois' aging sector structure & services
- Disrupting Disparities
- Long-term care and concerns for LGBTQ+ older adults

KNOWING & PROTECTING YOUR RIGHTS

- Public Policy: Housing, Disrupting Disparities, PrEP pharmacy, Healthcare for all, Basic housing rights
- Getting your documents in order

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- How to effectively engage with State and Local Lawmakers
- Types of advocacy
- State and Local Legislative Process

In 2022, participants in the Storytelling for Change Workshops and Advocating for Change workshops received a \$50 stipend per workshop session attended. Participants featured in Storytelling Showcases received an additional \$75. On average, participants who completed a full workshop series received a \$250 stipend.

ADVOCACY FOR CHANGE POST-TRAINING SURVEY DATA

Note: Post-training surveys for the Storytelling for Change workshop were not conducted

Participants were not required to attend all four Advocacy for Change training sessions, but incentives were given to those who completed all four (monetary stipends were paid out for each session as well as a certificate of completion). In 2022, we averaged 15 participants per training. Post-training surveys (for each week) were conducted to gather input from participants about their experience and improve future programming. Below are the response rates to each survey:

TABLE 2. ADVOCACY FOR CHANGE SURVEYRESPONSE RATES		
WEEK 1	10 responses	
WEEK 2	10 responses	
WEEK 3	6 responses	
WEEK 4	3 responses	

On average, participants rated the training sessions highly according to the following areas: 1) how satisfied they were with the trainings, 2) how much it met their expectations, and 3) how likely they would recommend the trainings to their friends. On average,

- 86.75% of participants rated their satisfaction with the trainings as somewhat or very satisfied.
- 91.5% of participants reported that the trainings either met, exceeded, or far exceeded their expectations.

• Most participants reported that they would recommend the training to a friend (Of the total 29 completed surveys, 26 out of 29 respondents reported that they would somewhat or most likely recommend one of the trainings to a friend).

Overall, participants reported that the trainings were informational and useful, and many expressed enjoyment learning from different presenters each week. Although a portion of the group held more awareness of topics, the trainings still proved helpful. One respondent reported, "Although I was familiar with many of the programs and services discussed I was still able to learn something new to put in my toolbox." They also enjoyed that community was built in at the beginning and that learning topics were scaffolded. Another respondent reported how impactful it was to connect with the presenters and be connected to resources: "Receiving information from the various organization was helpful as I had questions and did not have resources, but this session was helpful in trying to provide some of the answers."

Although many were happy with the sessions, respondents did report areas for improvement. The following list includes all points of constructive feedback received through the post-training surveys:

- Better framing of agenda and objectives for each training
- More time to engage with one another/main facilitators
- More time to ask questions
- Less reading of presentation
- Guidance and instructions for small group discussions to allow everyone a chance to contribute
- Better facilitation of discussion so that no one person "holds the mic" for too long and to allow the expertise of participants to be shared
- Ensuring that jargon and acronyms are explained so that participants who are new to the field are not left out

Since sessions were held virtually over Zoom, no accessibility issues were reported, though participants did express a desire to have in-person sessions in the future.

To view full data reports for each week, please see Appendix A.



WHY FOCUS GROUPS?

Because the training programs are within their first couple years of inception, the OUTAging committee decided to create a Research subcommittee to focus on evaluating the programs' effectiveness. We elected for focus groups to gather input because feedback in this format would elicit richer discussions based on peer-to-peer interactions (versus individual interviews or survey feedback). The Research Subcommittee was led by Nic Weststrate.

SUMMARY OF FOCUS GROUPS PROCESS

The Research Subcommittee began planning in early spring of 2022 by:

- Creating a focus group guidebook that includes a facilitator script and set of questions;
- Curating a list of potential candidates according to the training series they attended;
- Developing an outreach template to begin scheduling focus group sessions; and
- Creating a research framework to guide the process from the focus groups phase to the analysis phase.

To view these guiding documents, please see Appendices B-D.

Every step was done in a collaborative revision process to ensure expectations, planned questions and the flow of each facilitated session were clear (with both members of the subcommittee and of the larger, general committee).

In total, there were four, 2-hour focus group sessions (one for those who attended only the Storytelling for Change Series, one for those who attended only the Advocacy for Change Series, one for those who attended both training series and another for facilitators of each workshop). Each focus group averaged 3-4 participants (except for the facilitator's focus group, which included 6 participants).

Once focus groups were completed, transcripts were developed to conduct a deeper analysis. Since there was overlap in participants' reflections of both the Storytelling and Advocating for Change workshops, the Research Subcommittee decided to analyze the transcripts together instead of as separate programs.

FOCUS GROUP GUIDEBOOKS

In preparation for the focus groups, the Research Subcommittee created focus group guidebooks to standardize each focus group session, one for participants of

the For Change workshops and one for facilitators. In developing these questions, the Research Subcommittee wanted feedback not only on participants' experiences in the workshops, but also on their experiences as LGBTQ+ older adults. Because of this, discussions during each session became richer and contextualized their evaluations of the program.

The focus group questionnaire included the following:

- Self-identifying questions
- Descriptions of their involvement in the For Change workshop series
- Questions specifically dedicated to storytellers
- Questions specifically dedicated to advocates
- Workshop evaluation questions (i.e., what worked, what could be improved, how participants have used what they learned outside of the workshop)
- Questions about LGBTQ+ aging and significant issues facing LGBTQ+ elders
- Questions about LGBTQ+ older adult joy

The Research Subcommittee developed the questionnaire for the facilitators to be the same set of questions, with the exception of an added discussion on their reflections of the past 5 years since the beginning of OUTReach programming and the OUTAging Summit.

QUALITATIVE ANALYSIS

After the focus groups were conducted and transcribed, we used *reflexive thematic analysis* to interpret the data (Braun & Clarke, 2022; Clarke et al., 2015). Reflexive thematic analysis is a popular and widely used qualitative data analysis method in the social, behavioral, and applied sciences. It is a flexible approach to identifying patterns of meaning in qualitative data. In our specific approach, we were interested in coding the surface meanings of explicit statements made by our participants, and we assumed that participants' spoken words were valid indicators of their experiences, internal thoughts and feelings, and ascribed meanings. Reflexive thematic analysis typically proceeds sequentially in six stages:

PHASE	DESCRIPTION
1. Familiarization	This phase involved reading and re-reading the data with the objective of becoming immersed in the data and intimately familiar with its content. Throughout this process, we made notes on initial analytic observations and insights.
2. Coding	This phase involved generating succinct labels or descriptions that captured important features of the data. This involved coding the entire dataset, sometimes requiring multiple rounds of iterative coding before collating all of the codes and data extracts for later stages of analysis.

3. GENERATING INITIAL THEMES	This phase involved examining the codes and data extracts with the goal of beginning to develop broader patterns of meaning that might eventually be considered themes. This involved moving data around so that it is located in proximity to other data extracts that are relevant to a specific candidate theme.
4.	This phase involved checking candidate themes against the
DEVELOPING	coded data and the entire dataset. In this phase, themes were
AND REVIEWING	further developed, which can involve them being split,
THEMES	combined or discarded.
5.	This phase involved a detailed analysis of each theme,
REFINING,	identifying its scope and focus and determining the story each
DEFINING, AND	theme has to tell. At this stage, each theme was assigned an
NAMING THEMES	informative name.
6.	This final phase involved writing the overarching analytic
WRITING UP	narrative supported by data extracts and contextualizing the
RESULTS	analysis in relation to research objectives.

These phases are designed for sequential implementation, given that each phase builds on the previous; however, analysis also operates in an iterative process, as emerging findings in the data require that a previous phase is re-visited in order to confirm developing codes.



Our analysis yielded seven themes. Some of these themes centered on the impacts and outcomes of participating in the Storytelling for Change and Advocating for Change workshops, whereas others are better described as process themes. In all cases we provide practical recommendations related to each theme. The seven themes are:

- 1. The Joys of Being in Community with LGBTQ+ Elders
- 2. Being Seen and Heard as LGBTQ+ Elders at all Intersections
- 3. Gaining a (Re)new(ed) Sense of Purpose in and Through Advocacy
- 4. Learning to Tell "A Different Kind of Story"
- 5. Learning About Oneself Through Learning to Help Others
- 6. The Cost of the Story: Creating Space for Vulnerability
- 7. Cultivating a Community of Support

Each theme will be discussed in turn with focus group excerpts provided for illustration.

THE JOYS OF BEING IN COMMUNITY WITH LGBTQ+ ELDERS

It is well documented that older LGBTQ+ adults are more likely to experience social isolation and loneliness than their cisgender heterosexual counterparts. Our participants expressed that these challenges were especially salient for them during the height of the COVID-19 pandemic. We discovered that the workshops were important not only because they would help raise awareness about this key LGBTQ+ aging issue through subsequent advocacy, but also because participation in the workshops provided an antidote to social isolation in itself, meeting an immediate need of our participants.

For this reason, our first theme uplifts the joy of being in community with other LGBTQ+ elders. Take, for instance, the following participant who expressed how the workshops helped him to feel socially connected during the pandemic:

"These workshops were an anchor... It was having that sense of community. I didn't think about it as, "Oh, jeez. I'm gonna go hang out at the club." But the idea that when we met every other week or whatever it was, it was an anchor, it was a way that I knew that I could check in with other folks—that just on the basis of me being a member of the LGBT community, they were curious about my welfare and well-being. So, because at that time I was in a place where I was not getting that kind of treatment... it was an anchor for me... It was nice to have that little sense of community."

Beyond meaningful social engagement, these workshops were an "anchor" for this participant. In another instance, this elder referred to the workshops as a "lifeline."

This elder reminded us that a sense of community, even a little one, can tether us to the world.

The unique challenges of social isolation for LGBTQ+ older adults were made vivid in the following quote, pointing to a specific historical context—the AIDS crisis—that continues to shape many LGBTQ+ older adults' lives. As this older adult describes, the AIDS crisis devastated friendship circles, making the opportunity come together in community even more precious.

"As I've gotten older my community has gotten smaller and smaller and smaller. I mean I lost most my friends back in the early and mid-80s. Mid-80s and early 90s sorry. I'm old. I forget dates. But from mid-80s to the early 90s there was a period of time that I was going to funerals on a weekly basis, so I didn't have a big group when I got to this point in life to begin with. So, meeting the other folks in the Storytelling workshop and the Advocacy for Change workshop, that was nice."

Finally, elders commented that being members of the "first out generation" meant that not only were LGBTQ+ older adults invisible to society until recently, but that LGBTQ+ older adults were invisible to each other. Therefore, they relished the opportunity to share space with and learn from each other, making up for many lost years.

Recommendations: Participants recommended that we create space for ongoing interactions between workshop participants, such as alumni events or new engagement opportunities. To the extent that public health advisories allow, participants also expressed a strong desire to be together in person. While they felt that Zoom was a fine option during the pandemic, they expressed that future workshops should be held in a physical space. Should this be possible, participants pointed out the need to consider accessibility and transportation to and from the venue.

BEING SEEN AND HEARD AS LGBTQ+ ELDERS AT ALL INTERSECTIONS

The next theme centered on the importance of being seen and heard as LGBTQ+ elders both within these workshops and through subsequent advocacy activities. The problem of invisibility was bluntly articulated by the following older adult:

"I think that LGBT older adult stories are majorly erased. It's like you hit 55 and you disappear. It's not that you hit 55 and become straight or binary or any of those things. You just sort of – poof - disappear. And of course, that's not the case. And so, I think that's part of why it's so important to focus on it."

In response to this statement, another participant said, "I don't know that we're erased, I think we're just ignored, which is even worse. That's even worse." Either way, the need for visibility, validation, and affirmation was a strong theme among the participants and one that they felt the workshops would help remedy.

Not only did the elders feel seen through their own opportunities for storytelling and advocacy, but they also recognized the importance of providing representation for other people as those other people gain the chance to see themselves in the participants' stories and realize they are "not alone" in what they are experiencing. This power of feeling seen through hearing someone else's story, is described in the following excerpt:

"Storytelling is important mainly, for me anyway, because there are people that will listen to our stories and will say, "Yes, that was my experience. Yes, I feel the same way about that." And so, we offer a space where people can feel connected and maybe less alone if they are feeling alone. And I think that that is really, really important. I really do.

I know what it feels like to believe that I'm the only [one] who actually feels this. I've had several moments in my life, throughout my life where I've felt that, and then when I heard someone's story I said, "Oh, I'm not alone." And this came through other people telling their stories in formal or informal ways. And I think that that's a very powerful consequence, not in a bad way, of telling our stories. It's advocating. Sure, it is. But it's also a way of connecting with people that maybe aren't connected or feel left out or feel alone. So, that's an important aspect for me. Yeah."

While storytelling seemed to be a key opportunity for people to feel seen, the work of generating that visibility through storytelling is difficult. As we can see from the quote below, there are very logical reasons why the stories of LGBTQ+ older adults aren't being told, and yet, this only perpetuates the invisibility:

"And overall, I was really happy to come to this because just a place to have conversations don't exist as much as I believe they should. And part of that is because many people in our communities are unwilling to have conversations. Whether it be around AIDS, I'm a long-term survivor of that, so I've known that since it's started and watched tons of people die.

A lot of people in our own communities don't want to go there. And I can understand it to an extent, and yet it must be talked about. You can't sweep something like that under the rug again unless we repeat it, which is a real fear for me."

We will return to the topic of trauma and vulnerability in a later theme, but we include it here because it helps to illustrate the challenges associated with claiming visibility—a process that can require a great deal of courage.

Finally, several of our participants named the specific need for *intersectional visibility*, that is, advocacy work that renders visible the intersections between LGBTQ+ identities and other identities and experiences related to disability, race/ethnicity and even geographic context. The following participant, an older Black and disabled ciswoman living on the south side of Chicago, spoke about feeling "like an outsider" due to lack of racial representation in a north side LGBTQ+ neighborhood where aging service agencies are concentrated.

"And then this one last thing about community, is when I go up north and go on Halsted I feel like an outsider. I don't feel welcome even though that's supposed to be my people. And a lot of the organizations come across just the organizations in the straight community, that they're all run by middle aged white men. And that in itself is not a problem, but it becomes a problem when you look at the body of the organizations and they don't reflect the community you're supposed to be serving."

Another Black elder echoed this sentiment and added that, in addition to needing to travel significant distances to access resources, those resources are not equipped to provide culturally responsive care:

"But I cannot walk into an organization with the color of my skin, and who I am, and how I've lived my life as easily as many others can and access those resources, because nobody is really gonna say to me, whether I'm at a gay organization or a straight organization, right, I know that your experience might be a little different. I know that you might be hesitant to even let me know who you are and what you are dealing with. And most importantly, I don't even understand you. I have had many caretakers, and I ask them directly, "Were you trained on working with people within my community?" The answer is no."

These excerpts reminded us that the LGBTQ+ communities are not monolithic, and that advocacy work must adopt an intersectional lens to ensure people are seen in the fullness of their identities.

Recommendations: Participants expressed their desire for workshop organizers to connect them to future opportunities to tell their stories beyond legislative breakfasts and other advocacy events to maximize visibility.

GAINING A (RE)NEW(ED) SENSE OF PURPOSE IN AND THROUGH ADVOCACY

Several participants described that one of the more meaningful outcomes of their involvement in our workshops was either a newfound or renewed desire for civic engagement and advocacy work. The workshops had kindled or rekindled a fire within the participants to create positive social change. This manifested in different ways for different participants.

The timing of the workshops, in terms of where they landed in relation to other life events and transitions, was important for some participants. For example, the transition to retirement left some participants directionless and in space of searching for new meaning and purpose in life—a meaningful occupation or cause to dedicate themselves to. As if by divine intervention, the workshops seemed to answer such a prayer for the following participant:

"It's like, well, no, you need to do [these workshops]. This is what's supposed to happen. Because once I was retired, I said – and I prayed. Boy, did I pray. It's like, God, what is it you want me to do? And now, all of these doors are opening, and there are [advocacy] opportunities, and I'm learning so much about myself, and I'm learning so much from other people, and that's what I think is important about it."

For another participant, the workshops helped to clarify where she "fits" in the big world of advocacy, providing direction for future activities:

"The Advocacy for Change workshop was... informative and learning about ways of advocating. I really benefited from all of that. I really did. I got to know some people that I didn't know before and it helped me to see where I fit in the world of advocacy. It's a big world and I'm still learning. But I think I got closer to what would be my little niche in it all and approach."

For another elder, it was after her first public storytelling event that she realized the importance of sharing her story. After this event, she received several invitations to share her story in educational settings, like high school and college classrooms.

"I wanted to say that something else that has occurred since we the did the workshop for storytelling, and then we had a showcase... on Zoom and there were a lot of different people listening. That was really exciting. And we told our stories. From that I was contacted by two or three people that wanted to know if they had my permission to use my story that I presented for other things. A couple of them in college classroom settings, one was at a high school classroom, and another was for something else. And so, I said, "Sure." It all seemed fine to me.

And all these places were credible and so forth. And I thought that that was great. I mean I thought, "Gee, there are people who heard my story and thought it would be relevant to the work that they were doing." And that to me was really the point of it, I guess. I just thought, "Telling my story? All right. I'll tell it." I also asked, "Is it relevant? Can it help other people? Can they use what it is that I have to say to be of benefit to others?" And that's really the part of it that I really love."

This participant now sees herself and her story as a valued educational resource that can be useful for change-making. This recognition was both surprising and deeply satisfying for the elder, who now generously shares her story whenever she is invited.

For another participant, the workshops were a reminder, rather than a realization, that he has the potential to make positive change. Before attending the workshops, the participant had the sense that his activism days were in the past. But, as he articulated in our focus group, attending the workshops quite literally mobilized him into action to confront a negligent housing management company:

"Yeah. I see I think where the thread started for me is how I've used what I learned in the trainings because for me the trainings were a reinforcement of how important our stories are and when I moved into where I'm living now I thought, "Okay. This is cool. I can just be an old guy now. I don't have to worry about anything else." But I just thought I was at a point in my life where I didn't have to take on the kind of responsibilities that I'm taking on now. Taking on a management company for an entire nine-story building is a direct result of my interaction with both of those workshops because they just reminded me of the importance of doing that kind of work.

And I am grateful that I was reminded that I have these abilities because having them and not using them is, I don't know, it's a sin. And we were given gifts for a reason, and it isn't to keep them to ourselves. So, being able to do this and being reminded – yeah, that's why I got out of the workshops. I got the reminder that what we do, our stories are important. And it's important for those communities that are marginalized. But there are more marginalized communities than just the LGBT[Q+] community. The elderly poor is probably as marginalized as we are. So, yeah. I mean I know what to do so."

Recommendations: Participants expressed needing help finding future opportunities for advocacy. They were grateful for the chance to contribute to, say, a legislative breakfast that we had organized, but some didn't feel they had the knowledge, skills, or connections necessary to find new opportunities that would sustain their advocacy in the future. They recommended that the workshop organizers make a long-term commitment to helping connect alumni to future advocacy work and possibility offering additional advanced workshops that will build on the foundation laid.

LEARNING TO TELL "A DIFFERENT KIND OF STORY"

Related to the previous theme, the participants reported liking that the workshops had a very specific focus, namely, to develop skills that could be applied to advocacy contexts. This gave them a sense of direction for their efforts. This was particularly true for the storytelling workshop. One participant remarked:

"For me I thought the connection to advocacy worked well. The immediate connection to telling our stories to lawmakers. That was like, "Oh, this... is a different kind of story."

The participants enjoyed the unique challenge of learning how to adapt their stories so that they would have optimal impact among policymakers. It provided them a different lens through which to filter their lived experiences. Through the workshops, the participants were able to see the difference between a story they might tell friends versus a story that they might tell in an advocacy setting. For example:

"It's one to thing to have a story that we could go on and on about, and again everybody's story is important no matter how long it is, but to be able to tailor it down to the real essence and then... connect that up to a piece of legislation that is going to highlight what that legislation is about, is going to make people sit up and take notes, it's going to help push that legislation through." Knowing that their stories would eventually be presented to policymakers gave the participants a target to focus on and a strong sense of purpose that kept them motivated:

"The stakes here are high in terms of the good that we can do. This is beyond meeting some nice people, having an opportunity to hear their stories and share your own, and support each other. I mean, all that's good, but the opportunity to be of service to the broader community in the way of that this was set up I found very inspiring. It gave me some energy to put effort into working on that story."

While participants conveyed that policy provided a target, many reported that the true energetic basis for their involvement was coming from a place of wanting policy to improve the lives of others. As one participant reflected:

"Most people are not doing their stories because they think that the story is gonna make a policy be signed into effect the following day after their story. They're doing their story because it's coming from the heart, because they're serving a purpose. They wanna help their community, and maybe they don't wanna hear that story repeated."

This is an important reminder that participants are deeply invested in this process and its outcomes. It also illustrates that participation in our workshops provided an opportunity for older adults to satisfy their need for generative action and to leave a legacy.

Recommendations: Participants recommended providing greater clarity even before the workshops begin that the purpose of the program is to affect policy change. They expressed differing levels of awareness of this at the beginning of the workshops. Participants mentioned that there were obvious disparities among participants when it came to prior experience with advocacy work. They emphasized that managing those differing levels of knowledge and experience is something workshop facilitators should remain mindful of. Finally, because the commitment to advocacy and change-making is so important to the participants, they emphasized an ethical obligation on the part of the workshop organizers to ensure every participant has to chance to tell their story at an advocacy event.

LEARNING ABOUT ONESELF THROUGH LEARNING TO HELP OTHERS

Participants reported several ways in which they were positively impacted through their participation in the workshops. The participants had expected to acquire new knowledge and skills, but were somewhat surprised to learn that, through the process, they would also be changed in broader and deeper ways. This theme highlights the many dimensions of growth made available through these workshops.

In terms of skill development, the following participant reported learning how to "really" listen in the workshops:

"Listening. Really. It's so easy for me to get caught up in a world of myself. But the storytelling for sure and the advocacy workshop really helped me to listen more deeply to what other people were sharing about themselves and really connecting with it and just sitting with it and then thinking about what it must be like for that person to engage the world in the ways that they talked about. My ability to listen, and deeply, was improved as a result of those two programs. Yeah."

Listening with this level of depth and intentionality, as many participants did, led to new self-understandings as participants reflectively engaged with the stories and experiences of their peers.

Through such engagement, the next participant described a new recognition of his own aging process, which ultimately motivated him to modify his healthcare strategy:

"Well, the first thought that pops up for me is the fact that I just – I'm up for a checkup, a regular checkup just to see how I'm doing. Living with HIV I get checked at this point in my life every four months. I decided I've been a patient of Howard Brown Health Center since they acquired Triad, so forever. I mean I've been – I don't know. That was at least 20 years ago I think that they acquired it.

But at any rate, this time when I called to make an appointment, actually what I'd done was I'd decided that I wanted to see a doctor who focuses on LGBTQ gerontology or geriatric medicine. I want someone who's looking at older LGBTQ adults regardless of HIV status. I want somebody who is – I want a doc who is focusing on geriatrics, and it turns out that Dr. X at Howard Brown actually is. She is their expert on geriatrics.

So, I think that that is a direct result of being involved with those workshops because I mean I've had to acknowledge my senior status it seemed almost immediately the day after I turned 65 whether I wanted to or not because the world was acknowledging it. So, as time has gone on, I've recognized that I need to acknowledge all aspects of my senior citizenship and this year I'm going to be 69. Next year is a big one."

In the following quote, the participant describes how the workshops helped her to identify and appreciate what her gifts are and how best use those gifts to help others:

"We all have gifts, and we all have strengths, and these are all things that we can bring to the table so to speak and put into action quite effectively. I would say that the Storytelling and Advocacy for Change workshops helped me to answer a question that I had... Where could I best use my gifts and what are my gifts actually? Best use my gifts to reach other people, to touch other people, to advocate for others in important ways. And those two workshops helped me with that. And then especially when I was hearing back from people who had seen me and heard my story and found ways of using it for themselves. That helped me to understand what it was about my story – and not just about my story, but about me that people found appealing and something that they wanted to share with others and that they learned from. And both of those workshops helped with that for me."

Notably, the opportunity to share her story with various audiences—both within the workshops and beyond—provided a rare opportunity for feedback that was both self-clarifying and transformative.

THE COST OF THE STORY: CREATING SPACE FOR VULNERABILITY

While participants reported that the experience of engaging in the workshops was overwhelmingly positive, this didn't mean that it was necessarily easy for them. Our participants had 'skin in the game,' so to speak. As one participant put it:

"I think in a situation like this that it brings up a lot of feelings, [because] these are true stories. This is not cinema, okay? These are true stories of individuals' lives."

It is crucial to remember that, in most cases, our participants were advocating for policy changes that were directly related to the challenges they have encountered in their own lives.

"There were a couple of people in our group that weren't able to proceed with finishing off the public showcase part of the storytelling because I think it got either socially or emotionally too complicated for them, and I can't figure out what it would be but I kind of wish there was some way to provide greater support for them. Especially emotional. Because a lot of times people start – the primary story they want to tell, especially if they haven't been a storyteller, is usually about something that's quite difficult."

Through our focus groups, we learned that several participants found the workshops emotionally challenging and, in particular, the storytelling workshops were especially difficult. As one participant said, "Speaking out loud your own stories, the things that you think in your head, is – I have yet to meet a human being that doesn't find that a challenge." A few of the participants left the process early or opted to stay engaged but not present their stories in public. When we probed people's reasons for leaving or not sharing their stories, we found their responses were multilayered, but mostly came down to two factors:

First, some participants found the process of writing a story to be unexpectedly anxiety provoking. Our sessions relied heavily on peer feedback, and receiving feedback of any kind on a work-in-progress story can be difficult, especially when the story is close to one's heart. This prompted some fears and worries about evaluation and judgement, as well as participants' own self-imposed desires to "get it right."

Second, and more consequentially, for some participants, storytelling meant revisiting unprocessed trauma from the past. In some cases, the storytelling brought back to light painful memories that had been repressed or compartmentalized for years and, in some cases, even decades. This was overwhelming for a few participants.

Some participants were navigating not only old wounds, but fresh one's too. In the following example, the participant refers to talking publicly, for the first time, about a serious health diagnosis:

"It was really kind of difficult for me because this was something new for me, and in some ways, I'm a very private person. And so, it was real difficult for me to share my story, and it became very emotional for me because this is the first time that I really became public with what I was dealing with."

It was clear from our focus groups, and from our involvement in the workshops, that storytelling among LGBTQ+ older adults can involve significant vulnerability. This raises important practical questions about privacy and confidentially. One participant suggested that it might help to be clear about what will be done with the recording of a participant's story once they've completed the workshop:

"I would also add some clarity is necessary on who owns your story and how it's used... I need to control who and where I tell my story to because it is my story."

Honoring the desires of the participants in this regard might help to manage vulnerability. In the last storytelling workshop, we added an alumna from a previous cycle to our facilitation team to provide peer support to participants.

Recommendations: Participants recommended transparency around how and when their stories may be used in the future. They asked for the facilitators to monitor privacy and encourage confidentiality. Participants also suggested that the workshop organizers had an ethical obligation to provide support and resources in the event that the older adults disclosures about unmet needs (e.g., access to housing and healthcare). Continue the practice of having a peer support person among the facilitator team. To minimize anxiety associated the process of writing their story, the participants recommended one-on-one feedback sessions with the facilitators as an added feature of the storytelling workshops.

CULTIVATING A COMMUNITY OF SUPPORT

In addition to skilled facilitators and a peer support person, given the challenges and potential vulnerabilities that we've just described, it is essential to cultivate a community of support in the workshops. That is to say, supporting the emotional well-being of the participants is not one person's job, but the job of the community of workshop participants to support each other. As one participant said:

"I think there's a sense of shared struggle that when you meet someone within our community, you know they struggled, and if you have any humanity, that should give you a sense of empathy with them."

Another participant spoke to this collective responsibility when he said:

"We're here to lift each other up, we're here to support each other, we're here to help each other get the word out and make things change. We can't do that if we're shutting people down for whatever the reason is."

Investing in cultivating a community of support from the start allows participants to give themselves permission to take risks and participate more fully and openly, as one participant reflects:

"What was really nice is that the people in the group were really open. I mean I don't know exactly how many people knew each other in the group, but I think we were all pretty open about – we were open and kind of willing to risk ourselves and willing to get to know the other people in the group. And so, it was really kind of a wonderful experience."

To the credit of the workshop participants, they were successful in creating this community of support without much intervention from the facilitators, although we strongly encourage that such a discussion is incorporated into the first session. Here is one example of a brief exchange that exemplifies the supportive culture that participants creating in the workshops:

"Your [story] was so incredible with the things that you had to deal with, and I'm so glad that you're here today, because some things were – I'm like, gosh, you know? You're really a strong individual, and I totally respect that."

In response, the participant responded with:

"You know, I'll be living 11 years with an uncurable disease, and I know that it's not easy. Every day, you wonder how long is it gonna be, you know? I wanna say this to you, all the things that you have done as you go through this process and you tell me how strong I am, I'm not sure that I have as much to give as you have to give. And I say that with tears coming in my eyes, right? So, I honor you, and I know that God has given you a purpose, and I know that you believe in God, and only God has a final say."

Recommendations: We recommend that future workshops open with a transparent discussion about the potential risks and vulnerabilities associated with the difficult work of storytelling, followed by a facilitated discussion of what a community of support can look like in spirit and in practice.

CONCLUSION

"And I would just say this: all those wonderful people, and they know who they are, just keep doing what you're doing. It works. It really does. And try not to overthink it. I mean I feel the whole thing was excellent. I'm just in awe of the people that can actually put on these workshops and these programs and also, I continue to be stunned by being asked to participate. That's such a blessing for me. So, yeah. That's all." — For Change Workshop Participant

Through the focus group sessions, we have gained deep insight into the importance and need of programs like the For Change workshop series. We learned the many ways OUTReach programming can be improved to create safer and more inclusive spaces for LGBT older adults, such as providing emotional supports for participants or ensuring clarity of purpose.

Most importantly, participants have shown how vital it is to continue creating spaces and events for LGBT older adults to build relationships among community. The focus group sessions themselves proved to be essential simply because they brought participants back together. So, the outcome of conducting focus groups was twofold: Collecting evaluative feedback from LGBT older adult participants to improve programs developed for and by them, and combatting the isolation many LGBT older adults feel by creating a space for LGBT older adults to reconnect.

RECOMMENDATIONS

Based on focus group discussions, we gleaned the following recommendations for future workshops and for organizations or agencies hoping to develop programs for and with LGBT older adults:

- 1. Include LGBTQ+ older adults in the planning process
- 2. Create spaces for ongoing interactions between workshop participants, such as alumni events or new engagement opportunities
- 3. Share new advocacy or storytelling opportunities with alumni to maximize visibility of LGBT older adults
- 4. Prioritize in-person/hybrid events and convenings when possible and to the extent that public health advisories allow
- Commit to connecting alumni to future advocacy work and advanced workshops to continue building their skills and experiences in advocacy or storytelling
- 6. Ensure clarity of the purpose and objectives of workshops at the beginning to diffuse any confusion around participation
- 7. Develop strategies to manage differing levels of experience and knowledge in advocacy/storytelling
- 8. Ensure transparency around how and when participants' stories may be used in the future and monitor privacy/confidentiality

- 9. Provide support and resources to participants in the event that they disclose unmet needs (such as access to housing or healthcare)
- 10. Include a peer support person among the facilitator team to minimize anxiety associated with the process of writing their stories, as well as incorporate one-on-one feedback sessions with facilitators as an added feature of the storytelling workshops
- 11. Open programming with a transparent discussion about the potential risks and vulnerabilities associated with the difficult work of storytelling/advocacy, followed by a facilitated discussion of what a community of support can look like in spirit and in practice

APPENDIX A. ADVOCACY FOR CHANGE POST-EVENT SURVEY DATA



To view survey data from each week of the 2022 Advocacy for Change workshop, please click on the corresponding URLs below.

<u>Week 1</u>

<u>Week 2</u>

<u>Week 3</u>

<u>Week 4</u>

APPENDIX B. STORYTELLING/ADVOCATING FOR CHANGE: AMPLIFYING THE POWER OF LGBT ELDERS' VOICES



RECRUITMENT EMAIL FOR FOCUS GROUPS

Dear NAME,

We are writing to you today about the "Storytelling/Advocating for Change" workshop series that you participated in fall 2020/2021. Along with your fellow participants, we would like to invite you to a focus group to gather your thoughts and feelings about your experience with the workshop series. This focus group will help us to continue to provide meaningful engagement opportunities for LGBT older adults in the Chicagoland area. To conduct these focus groups, we are partnering with a researcher from the University of Illinois at Chicago, Dr. Nic M. Weststrate. Through this partnership, we hope to publish our findings in scholarly outlets that will reach a broad audience of researchers, practitioners, and service providers who work with LGBT older adults.

The focus group will last between 1.5 to 2 hours and will be facilitated by a member of our research team. Focus groups will occur over Zoom. Participants will be asked to allow us to record the interview. For your effort, you will be given a \$50.00 cash payment.

To convey your interest in learning more about this study, please indicate so by replying to this email. If you are interested, we will send you more information.

Thank you, **Kim L. Hunt** Executive Director Pride Action Tank, AIDS Foundation Chicago <u>KHunt@aidschicago.org</u>

Dr. Nic M. Weststrate Principal Investigator Assistant Professor, Dept of Educational Psychology nicwest@uic.edu

APPENDIX C. AMPLIFYING THE POWER OF LGBTQ+ ELDERS' VOICES: PARTICIPANTS FOCUS GROUP GUIDE



A. INTRODUCTIONS

My name is Iana Amiscaray, and my pronouns are she/her/hers. It is my pleasure to facilitate this focus group today. I will first ask you to introduce yourselves, then we will spend our time talking about two main topics: First about your thoughts, ideas, and experiences with LGBT aging, and second about your experience with our workshop series.

1. To start us off, please introduce yourself to the group by sharing your name, pronouns, and anything you else feel is important to your identity. As a reminder, your name won't be used in any reporting of the information we gather today.

B. OPENING SCRIPT

Thank you for agreeing to participate in this focus group. We will spend up to 2 hours discussing the "Storytelling for Change" and/or "Advocating for Change" workshop series that you participated in. The information gathered in this focus group will help Pride Action Tank to continue providing meaningful engagement opportunities for LGBT older adults.

We have prepared a list of questions for you, but you are free to choose not to answer any of the questions I ask. There are no right or wrong answers to these questions. Please answer with whatever you feel comfortable sharing and if you want to skip a question, please just let me know.

I want to remind you that we are taking measures to keep the information you share with us confidential. We will use today's recording to create a written transcript of our session. We will "de-identify" that transcript, meaning that any reference to personally identifying information will be removed and your identity will be replaced with a pseudonym or numeric code. Once data analysis is complete, we will destroy the recording of this session. I ask everyone in this focus group to respect each other's privacy and not repeat what is said here to others outside of this group.

Prior to arriving today, you had the chance to review an informed consent form and agree to its terms. Before we begin, we want to give you the chance to ask any clarifying questions about the content of that form or any other questions that come up for you now. Do you have any questions about the research we are conducting?

[Pause for questions.]

Excellent, thank you. There are just a few more things before we start:

- I want to confirm that you're in a space that is private and free from distractions. If possible, please ensure that your video is turned on and you are unmuted.
- If you are unable to answer a particular question because of your surroundings, feel free to type your response into the chat feature, if you are able. We will be asking questions regarding both Storytelling and Advocating for Change. When responding, please specify which training you are referring to.

- I want to remind you that this focus group is all about <u>you</u>. We want to hear about *your* experiences with our programs, so please freely share your thoughts, feelings, and reflections. Anything that pops into your mind is relevant and important.
- Finally, we want this focus group to feel natural and conversational, so please allow yourself to feel comfortable and speak as though you are amongst friends.

C. QUESTIONS ABOUT WORKSHOPS

You participated in the "Storytelling for Change" and/or "Advocating for Change" workshop series.

In the "Storytelling for Change" workshop, you tapped into the rich oral storytelling tradition in the LGBT community, working with two facilitators and a group of your peers to strengthen your storytelling skills and to develop a personal story about LGBT aging that could be used in advocacy contexts to create change.

In the "Advocating for Change" workshop, you learned about LGBT terminology and history, about national and state trends in older LGBT adult experiences and outcomes, and about the legal rights of LGBT older adults, including the Equity for Elders Act. You also strengthened your advocacy skills, such as the ability to respond to challenging questions in advocacy settings.

1. For storytellers only:

- a. What was it like to come together as a group of LGBT elders to reminisce, write, and tell your stories? Is there anything you would like to share about your experience with this storytelling process?
- b. Why do you think it is important for LGBT older adults to share their stories?
- c. How was your overall experience with the workshop series?

2. For advocates only:

- a. What was it like to come together as a group of LGBT elders to learn about advocating for change? Is there anything you would like to share about your experience with this process?
- b. How was your overall experience with the workshop series?
- 3. What parts of the training do you feel worked well?
- 4. What parts of the training do you feel need improvement, including topics that were not covered?
 - a. Are there any ways you feel the trainings could better serve the aging LGBT community?
 - b. If you were designing the training, are any things that you would add or take away?
- 5. How have you used the information provided in the trainings? Have you been able to engage in any advocacy activities since the trainings? What have those been?
- 6. Do you plan to use the information provided in the trainings in the future? If yes, how so? If no, why not?

- 7. For storytellers only: We have learned through the storytelling workshop that storytelling about the past can bring up difficult memories and current struggles. Are there things we can do to better support storytellers as they do this work? What advice do you have for us in terms of creating a "safe space" for storytelling?
- 8. Are there any additional comments/thoughts you wish to share?

D. QUESTIONS ABOUT LGBT AGING

The following questions are about your experiences as an aging LGBT person. In addition to learning about your unique experiences with aging, we hope to understand how you see the LGBT aging process as similar or different from the aging process of non-LGBT older adults. Please keep this in mind as we go through these questions.

- 1. LGBT elders like you have been described as members of the first 'out' generation. Can you say more about what it means to be members of the first 'out' generation?
 - a. What does it mean that some LGBT elders have been invisible until recently? If this describes your experience, how have you experienced this invisibility? What are the implications of invisibility?
 - b. Did you have role models of LGBT aging to look to? If yes, who are they and what did you learn from them? If not, what has it meant to not have models of aging that you can look up to?
 - c. How is the reality of aging different from what you expected it to be?
- 2. What do you see as some of the most significant issues facing LGBT elders today? As an LGBT person, what are your greatest worries and concerns related to aging? What are things that you worry about that non-LGBT older adults do not need to worry about?
- 3. One of the goals of the OUTReach program is to create safer and more inclusive spaces for LGBT older adults. We'd like to speak about what exactly needs to change and how we can imagine such change happening. What are some things that people in the aging services sector can do to create safer and more inclusive spaces for LGBT older adults?

E. CONCLUSION

I want to take this opportunity to thank you for your time and generosity in sharing your thoughts and experiences with me. I have one final question:

1. A goal of the OUTReach program is to educate others about the realities of LGBT aging. Yet, we've talked mostly about the challenges and issues associated with LGBT aging. Let's flip the narrative for a moment and explore the other side—that is, the joys of being an LGBT older adult. What do you find joyful about being an LGBT elder?

Before we leave, do you have any questions for us about our experience with our workshops or anything else that has come up for you in our session?

PROBING FOR MORE INFORMATION:

- "You mentioned _____, can tell me a little more about that?"
- "You mentioned _____, what was that like for you?"
- "You talked about _____, describe that experience in as much detail as possible."
- "What else happened?"
- "Can you say a little more about that?"
- "Why do you think that matters?"
- "Why was that important to you?"
- "What was significant about this to you?
- "Can you share an example that demonstrate this point you're making?"

PROBING FOR CLARIFICATION:

- "What do you mean when you say _____?"
- "I'm not really sure what you meant when you said ______. Can you say more about that?"

APPENDIX D. AMPLIFYING THE POWER OF LGBTQ+ ELDERS' VOICES: FACILITATOR'S FOCUS GROUP GUIDE



A. INTRODUCTIONS

My name is Iana Amiscaray, and my pronouns are she/her/hers. It is my pleasure to facilitate this focus group today. I will first ask you to introduce yourselves (for the purpose of transcriptions), then we will spend our time talking about three main topics: First about your thoughts, ideas, and experiences with OUTAging, second about your experience with our workshop series, and lastly, about your experiences or perspectives on LGBT aging.

- 1. To start us off, please introduce yourself to the group by sharing your name, pronouns, and anything you else feel is important to your identity. As a reminder, your name won't be used in any reporting of the information we gather today.
- 2. Describe how you were involved in the Storytelling or Advocating for Change cohort training series, along with your involvement with OUTAging programs.

B. OPENING SCRIPT

Thank you for agreeing to participate in this focus group. We will spend up to 2 hours discussing the "Storytelling for Change" and/or "Advocating for Change" workshop series that you helped organize or facilitate. The information gathered in this focus group will help Pride Action Tank to continue providing meaningful engagement opportunities for LGBT older adults.

We have prepared a list of questions for you, but you are free to choose not to answer any of the questions I ask. There are no right or wrong answers to these questions. Please answer with whatever you feel comfortable sharing and if you want to skip a question, please just let me know.

Excellent, thank you. There are just a few more things before we start:

• I want to confirm that you're in a space that is private and free from distractions. If possible, please ensure that your video is turned on and you are unmuted.

- If you are unable to answer a particular question because of your surroundings, feel free to type your response into the chat feature, if you are able.
- I want to remind you that this focus group is all about <u>you</u>. We want to hear about *your* experiences with our programs, so please freely share your thoughts, feelings, and reflections. Anything that pops into your mind is relevant and important.
- Finally, we want this focus group to feel natural and conversational, so please allow yourself to feel comfortable and speak as though you are amongst friends.

C. QUESTIONS ABOUT OUTAGING JOURNEY

1. It's been 5 years since the OUTAging Summit, what has it been like to get from there to here? At that time, what were your expectations for what the next 5 years were going to look like, and were those expectations met? How did they evolve? What have you learned along the way?

[Facilitator note: we want to understand the process behind creating a summit and carrying the work beyond the event.]

D. QUESTIONS ABOUT WORKSHOPS

You participated in the "Storytelling for Change" and/or "Advocating for Change" workshop series.

In the "Storytelling for Change" workshop, you tapped into the rich oral storytelling tradition in the LGBT community, working with two facilitators and a group of your peers to strengthen your storytelling skills and to develop a personal story about LGBT aging that could be used in advocacy contexts to create change.

In the "Advocating for Change" workshop, you learned about LGBT terminology and history, about national and state trends in older LGBT adult experiences and outcomes, and about the legal rights of LGBT older adults, including the Equity for Elders Act. You also strengthened your advocacy skills, such as the ability to respond to challenging questions in advocacy settings.

- 1. For storytellers only: Nic, Kim, and Don
 - a) What was it like to gather a group of LGBT elders to reminisce, write, and tell your stories? Is there anything you would like to share about your experience with this storytelling process?
 - b) Why do you think it is important for LGBT older adults to share their stories?
- 2. For advocates only: Britta, Terri, and Kelly

- a) What was it like to gather a group of LGBT elders to learn about advocating for change? Is there anything you would like to share about your experience with this process?
- 3. How was your overall experience with the workshop series? –Britta left off here
- 4. What parts of the training do you feel worked well?
- 5. What parts of the training do you feel need improvement, including topics that were not covered?
 - a. Are there any ways you feel the trainings could better serve the aging LGBT community?
 - b. If you were designing the training, are any things that you would add or take away?
- 6. How have you used the information provided in the trainings?
- 7. Do you plan to use the information provided in the trainings in the future? If yes, how so? If no, why not?
- 8. We have learned through the storytelling workshop that storytelling about the past can bring up difficult memories and current struggles. Are there things we can do to better support storytellers as they do this work? What advice do you have for us in terms of creating a "safe space" for storytelling?
- 9. Are there any additional comments/thoughts you wish to share?

E. QUESTIONS ABOUT LGBT AGING

The following questions are about your experiences as an aging LGBT person. In addition to learning about your unique experiences with aging, we hope to understand how you see the LGBT aging process as similar or different from the aging process of non-LGBT older adults. Please keep this in mind as we go through these questions.

- 1. LGBT elders, like some of you on this call, have been described as members of the first 'out' generation. Can you say more about what it has been like to work with other members of the first 'out' generation?
- 2. From your perspective, what do you see as some of the most significant issues facing LGBT elders today? What are some of the greatest worries and concerns that you have heard related to aging, especially compared to non-LGBT older adults?

[Facilitator note: Pull from folks' personal/professional perspectives]

F. CONCLUSION

I want to take this opportunity to thank you for your time and generosity in sharing your thoughts and experiences with me. I have one final question:

1. A goal of the OUTReach program is to educate others about the realities of LGBT aging. Yet, we've talked mostly about the challenges and issues associated with LGBT aging. Let's flip the narrative for a moment and explore

the other side—that is, the joys of being an LGBT older adult. What do you find joyful about being an LGBT elder?

- 2. What are the joys you experience or have observed when working with LGBT elders?
- 3. Before we leave, do you have any questions for us about our experience with our workshops or anything else that has come up for you in our session?

PROBING FOR MORE INFORMATION:

- "You mentioned _____, can tell me a little more about that?"
- "You mentioned _____, what was that like for you?"
- "You talked about _____, describe that experience in as much detail as possible."
- "What else happened?"
- "Can you say a little more about that?"
- "Why do you think that matters?"
- "Why was that important to you?"
- "What was significant about this to you?
- "Can you share an example that demonstrate this point you're making?"

PROBING FOR CLARIFICATION:

- "What do you mean when you say _____?"
- "I'm not really sure what you meant when you said ______. Can you say more about that?"

APPENDIX E. RESEARCH VALUES FRAMEWORK

Q

GUIDING QUESTIONS

- What values and principles will guide our research?
- How will we embody such values in our research practice?

STATEMENT OF VALUES

- I. WE WILL ADOPT A "COMMUNITY ENGAGED" RESEARCH ORIENTATION, MEANING THAT WE WILL CONSULT WITH AND INVOLVE COMMUNITY MEMBERS AND STAKEHOLDERS AT ALL STAGES OF THE RESEARCH PROCESS
 - a. Our work will adopt the "Not for us, with us" principle
 - b. We will "share power" in the research process
 - i. Every person will have the opportunity to be involved in every aspect of the research process
 - ii. Decision-making will be driven by consensus
 - iii. Co-authorship will be available, but needs to be negotiated--coauthorship depends on involvement, but what type of involvement is flexible

II. WE WILL MAINTAIN A STRENGTHS OR ASSETS-BASED PERSPECTIVE ON THE COMMUNITY WE SERVE AND OURSELVES

- a. This means recognizing the unique resources, resiliencies, and potentials of LGBT older adults (note: do we want to go with "elders" or "older adults"? Look into our use of language--"elderhood" concept)
- b. This also means utilizing and building the assets and capacities within our research community
- c. Affirming language: LGBT, LGBTQ+, LGBT+; older adult, elder, elderhood?

III. WE WILL CONDUCT ACTION-ORIENTED, TRANSFORMATIVE RESEARCH

- a. From the outset, the purpose of our research efforts will be to <u>improve</u> the lives of LGBT+ elders
- b. Our work will strive to maximize <u>practical applications</u> for community members and practitioners
- c. We will generate "products" for the community we serve
- d. We will specifically explore *Participatory Action Research* and *Community-Based Research* to select an overarching framework for our research (also look at articles on "community-academic partnerships")
- e. Dissemination

IV. WE WILL CENTER THE LIVED EXPERIENCES OF LGBT ELDERS

- a. We will ensure that LGBT elders voices and stories are amplified through our research
- b. We will uplift the knowledge held within our community, recognizing that LGBT elders are a source of incredible wisdom and insight into their own experiences and lives

V. ETHIC OF CARE, SUPPORT, COMPASSION

- a. What can we promise around safety?
- b. Creating a brave space
- c. Trauma-informed approach to research (know that research can be retraumatizing and traumatizing)
- d. Connect our participants to care/support

VI. WE WILL COMPENSATE RESEARCH PARTICIPANTS FAIRLY FOR THEIR TIME AND EFFORT

- a. Our research will not be exploitative (i.e., inadequate compensation)
- b. At the very least our research will be transactional (i.e., based on fair exchange)
- c. Ideally, our research will be transformative (i.e., researchers and participants leave the research experience with something better, new, or different than before)

VII. WE WILL ENSURE THAT OUR RESEARCH PROCESS AND PRODUCTS ARE ACCESSIBLE

- a. Accessibility means accommodating diverse abilities and maximizing comfort for our participants (e.g., adopting principles of universal design)
- b. Accessibility also means that practitioners and community members will have access to our research publications and products by ensuring we publish in "open access" journal

VIII. WE WILL ENSURE OUR RESEARCH IS REPRESENTATIVE OF ALL MEMBERS OF THE LGBTQ+ Communities

- a. We will intentionally seek representation from LGBT elders who are underrepresented in dominant research discourses and underserved in the community
- b. We will take an intersectional approach to understanding lived experiences

IX. WE WILL BUILD STRUCTURES THAT ENSURE THE SUSTAINABILITY OF RESEARCH

- a. We will build capacity across the entire OUTAging Committee, so that if one person leaves the group, the research can continue
- b. We will develop strategies for ensuring "memory" of the work we're doing

X. WE WILL COMMIT OURSELVES TO ONGOING LEARNING AND SKILL DEVELOPMENT

- a. We will do readings on the use of *Participatory Action Research* and *Community-Based Research* in the LGBT community
- b. We will do readings on, and invite guest speakers, to discuss strategies for successful "community-academic partnerships" (e.g., OCEAN-HP at UIC)
- c. We will offer trainings on ethical research and IRB processes

XI. WE WILL CAPITALIZE ON THE DIVERSE AND SYNERGISTIC STRENGTHS REPRESENTED IN THE OUTAGING COMMITTEE

- a. What do our researchers bring? What do our researchers want to learn?
- b. What do our practitioners bring? What do our researchers want to learn?
- c. What do our community members bring? What do our community members want to learn?