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THE ELDERCARE DIALOGUES

A Grassroots Strategy to Transform Long-term Care

A REPORT BY:

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DWU

DAMAYAN

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NATIONAL DOMESTIC WORKERS ALLIANCE

ABOUT THE AUTHORS

Adhikaar:

Adhikaar, meaning rights in Nepali, is a New York-based nonprofit organization working with Nepali-speaking communities to promote human rights and social justice for all. To achieve our mission, we facilitate access to information and resources on immigration, health, workers' rights, and other issues; organize the community to collectively advocate against social injustices and human rights abuses; conduct participatory action research and policy advocacy on issues affecting our community; and build leadership of members, with the focus on marginalized groups within the Nepali-speaking community.

B'nai Jeshurun:

B'nai Jeshurun (BJ) is a passionate nonaffiliated Jewish synagogue community that inspires spiritual searching, lifts the soul, challenges the mind, and requires social responsibility and action. We strive to experience and express God's presence as we study, pray, and serve together. We are unified yet diverse and explore the living tension between tradition and progress. BJ strives to meet the challenges of the present and to remain relevant in the search for justice, understanding, and peace in the traditions of Rabbi Abraham Joshua Heschel and BJ's Rabbi Marshall T. Meyer (z'l). The community consists of over 1,700 households and its members come from many different places geographically, socially, economically, in terms of sexual orientation, and in Jewish background.

Community Development Project at the Urban Justice Center:

The Community Development Project (CDP) at the Urban Justice Center strengthens the impact of grassroots organizations in New York City's low-income and other excluded communities. We partner with community organizations to win legal cases, publish community-driven research reports, assist with the formation of new organizations and cooperatives, and provide technical and transactional assistance in support of their work towards social justice.

Domestic Workers United:

Since its founding in 2000, DWU has been organizing workers from the Caribbean, Africa and Latin America. DWU collaborates with other domestic worker organizations in New York, across the US and internationally to build the power of the domestic workforce as a whole. At the first US Social Forum in 2007, DWU became a founding member of the National Domestic Workers Alliance (NDWA).

Damayan Migrant Workers Association:

Our mission is to educate, organize, and mobilize low-wage Filipino workers to fight for their labor, health, gender, and im/migration rights; to contribute to the building of the domestic workers movement for fair labor standards, dignity and justice; and to build workers' power and solidarity towards justice and liberation. We promote discussions on gender, race, class, globalization, and forced migration to raise public awareness and support against the systemic causes of the exploitation of low wage workers, particularly migrant women domestic workers.

Jews For Racial and Economic Justice:

We pursue racial and economic justice in New York City by advancing systemic changes that result in concrete improvements in people's daily lives. We engage individual Jews, key Jewish institutions, and key Jewish community leaders in the fight for racial and economic justice in partnership with Jewish and allied people of color, low-income, and immigrant communities.

The National Domestic Workers Alliance:

NDWA is the nation's leading voice for dignity and fairness for the millions of domestic workers in the United States, most of whom are women. Founded in 2007, NDWA works for the respect, recognition, and inclusion in labor protections for domestic workers. The national alliance is powered by 42 affiliate organizations—plus our first local chapter in Atlanta—of over 10,000 nannies, housekeepers, and caregivers for the elderly in 26 cities and 18 states.

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PART 1

DIALOGUE PROCESS

The first portion of this report documents the best practices and challenges of the Eldercare Dialogues, a two-year long process to bring together elders, direct care workers, and their family members. The second half of the report is a toolkit that provides insights and guidelines for how others can conduct a similar Dialogue process in their community.

I. INTRODUCTION

BJ members Debra Eder and Sandy Soffin and Domestic Workers United (DWU) member Monica Braithwaite act out a complex scenario related to communication and alliance. Photo: Red Papillon Photography

On the evening of October 9th 2013, over one hundred people gathered in the basement of B'nai Jeshurun (BJ), a large synagogue on the Upper West Side of Manhattan. The crowd included a large number of Jewish seniors and their family members -- members of BJ, Central Synagogue, and Jews for Racial and Economic Justice. It also included a substantial number of domestic workers and informal sector care workers--Afro-Caribbean, Latina, Filipina, and Nepali-speaking members of the New York affiliates of the National Domestic Workers Alliance.

Those gathered in the BJ basement were transfixed by a humorous and poignant skit being played out by BJ members Debra Eder and Sandy Soffin and by Domestic Workers United (DWU) member Monica Braithwaite. They were working through a tough scenario that clearly resonated with and felt familiar to the participants in the audience:

> *Claudia is a mother of two. She has been a home-care worker with Francis for three years. Francis is a former school-teacher who had a stroke a few years ago. Since then she has lived with her daughter and receives personal assistance with many daily activities. In the last year, Francis has become more forgetful. She gets confused and frustrated more often. Francis' daughter Joanne has taken charge of her finances. Francis values her independence, and wants to make decisions about every aspect of her life including food, money, and especially her care. She trusts Claudia and appreciates her labor. The two have a strong bond. Due to her long-time service and the increase in her work-load, Claudia has asked repeatedly for a wage increase and for paid leave. Joanne has*

refused. She's very worried that her mother will run through what little savings she has too quickly. Francis feels that her power to make decisions about her life has been taken from her. Claudia cares for Francis and wants to keep working with her, but the job is not sustainable.

Over the past year and a half, the Eldercare Dialogues have brought together domestic workers, seniors, and their family members to explore real-life scenarios like the one above. Participants sought to share values for dignified care for seniors and dignified jobs for eldercare and homecare workers. They were inspired by a vision of caring communities that value interdependence, and where everyone receives the care, autonomy, and respect that they deserve. Moreover, the elder participants were motivated by tremendous fear and anxiety related to their ability to afford quality care and to age in place with dignity in New York City while the care workers engaged out of a need to win real respect on the job and earn living wages. Many of the care workers also recognized their own need for long-term care and support.

The Dialogues were convened by the National Domestic Workers Alliance and Jews for Racial and Economic Justice. They were anchored by three New York domestic worker organizations (Adhikaar, Damayan Migrant Workers Association, and Domestic Workers United) and by one synagogue (B'nai Jeshurun) representing seniors and their family members.

Together, these organizations wanted to build a movement to transform long-term care in this country and ensure that caregivers and recipients have the support they need to age and work with dignity. The values and vision were fueled by Caring Across Generations, a national initiative led by the National Domestic Workers Alliance and Jobs with Justice to transform the way we care. CAG harnesses the power of social action, social media, and storytelling to spark connections across generations and to strengthen family and caregiving relationships. CAG is also building a national campaign to create several million new dignified jobs in the homecare sector, expand workforce development opportunities, and ensure that all individuals and families have the support they need to age in place with dignity. The eleven Eldercare Dialogues that took place between December 2012 and December 2014 were part of the overall field strategy of the Caring Across Generations campaign.

Research Methodology

To document the best practices and challenges encountered throughout the Dialogue process, researchers conducted observations, interviews, and focus groups utilizing a participatory action research method where those that are directly impacted by the research were part of the design, collection, and analysis of the data.

Observations: At each Dialogue an observer took detailed notes about what occurred, such as who was in the room, who participated, what was said, what worked well, and what was a challenge.

Interviews and Focus Groups: After the first year of the Dialogues 15 interviews were conducted with participants and organizers from the Dialogues and six focus groups, one with each participating organization. The interviews and focus groups served to go beyond the observations and answer questions like why did people decide to participate, how did participants change and grow by participating, and what did they see as the strengths and weaknesses of the Dialogue process.

Secondary Data: In addition to this primary data, researchers also reviewed reports and news articles that relate to domestic workers and the home care industry. The data and findings from the research process were a key component in the development of this report and toolkit.

II. BACKGROUND

Domestic Worker's Bill of Rights, the Age Wave, and the Care Gap

In 2010, New York State passed the first bill of rights for domestic workers in the United States.[1] This legislation included basic labor rights such as overtime standards, one day off every week, three paid days off every year, and protection from discrimination and harassment.[2] The passage of the Domestic Worker's Bill of Rights was a historic step forward. Up until the passage of this law, domestic workers had been excluded from all major labor laws and regulations, a remnant of the Jim Crow era and a systemic expression of racism and sexism.[3] This bill also sparked change around the country; in the years since New York's passage of legislation, Bills of Rights have been passed in Massachusetts, California, and Hawaii and legislative campaigns have been launched in Illinois and Connecticut.

The passage of this groundbreaking legislation coincided with another historic moment: the "Age Wave." With the baby boomer generation growing older, record numbers of people will be in need of care. In the United States today, 10,000 people turn 65 and 4,000 people reach retirement age every year.[4] However, despite the increasing population of seniors, AARP, a prominent interest group for people over 50 years old, projects that there will be increasingly fewer numbers of people to care for the elderly population.[5] In 2010 the caregiver support ratio (the number of potential caregivers to the number of people 80 years and older) was 7 to 1.[6] This ratio of workers to care recipients is expected to drop to 4 to 1 by 2030 and further fall to 3 to 1 by 2050 if the workforce is not developed to keep pace with growing demand for in-home care support.[7] This reduced amount of support is known as the "Care Gap" and it represents a looming challenge for homecare in the U.S.

As a result of the "Age Wave" and "Care Gap", homecare workers and domestic workers make up the fastest growing workforce in the country.[8] Despite the important role they are playing, they often earn poverty wages, work under a tremendous amount of stress, and are not able to support their own families. This is especially true of care workers in the informal or "Grey Market." The Grey Market refers to workers that are privately hired (not through an agency) and may be paid off the books.[9] These workers are often isolated in the homes of their employers and do not receive even the minimal legal protections afforded to other workers.

Domestic Workers and Immigration Reform

A briefing paper by the Economic Policy Institute estimates that 15% of domestic workers are undocumented immigrants, compared to 5% of the overall labor force.[10] However domestic worker groups on the ground estimate the figure to be much higher. Because of their precarious legal status, undocumented immigrants are particularly vulnerable to exploitation in the workplace. Accordingly, any discussion of the working conditions of domestic or eldercare workers must also consider immigration reform so that undocumented care workers may be able to seek employment without fear of reprisals based on their immigration status.

Recognizing this, the National Domestic Workers Alliance has launched the "We Belong Together" Campaign to mobilize women in support of common-sense immigration reform that will keep families together and empower women. According to NDWA, *"Millions of immigrant women who are part of the fabric of our communities, workplaces, and schools are blocked from achieving their full potential because of a broken immigration system. They perform essential jobs, like taking care of our children and our aging parents, and are central to family and community well-being."*[11] The campaign is calling for the following provisions in any immigration reform legislation:

- Include a broad and clear roadmap to citizenship that recognizes the contributions of women's work and women workers;
- Keep all families together;
- Recognize women's work in future employment categories and protect women workers on the job;
- Ensure protections for survivors of violence and trafficking;
- Protect families and ensure due process; and
- Promote immigrant integration that includes and empowers women.

Home Care vs. Institutional Care

In the U.S. almost 79% of people who need long-term care live at home or in community settings[12] and 90% would prefer to receive care at home rather than being placed in a facility.[13] Despite these facts, states spent 66% of their Medicaid long-term care budgets on nursing homes and only 34% on home-based care in 2010.[14] These statistics show the disconnect between the needs and desires of care recipients and how resources are allocated.

Caring Across Generations and the New York Strategy Post-Domestic Worker Bill of Rights

With the leadership of the National Domestic Workers Alliance, the domestic worker movement began to raise questions about how to care for the aging population in a way that brings dignity to both the caregiver and care-recipient while simultaneously creating good jobs and strengthening the care workforce in order to close the care gap. This led to the formation of Caring Across Generations (CAG), a social movement that uses social action and storytelling to highlight issues with the care system in the United States and advocates for change. Ai-jen Poo, Director of the National Domestic Worker Alliance explains the critical importance of CAG:

> *We have found that homecare and supporting our growing elder population in our country to age in place is an incredibly powerful entry point to bring these interests together, to improve and create more jobs, and to create more choices for our seniors and people with disabilities to live independently. We have also found that it is an incredibly powerful entry point for the kind of values conversation we need to be having about what kind of country we are, what kind of country we are becoming, and who we want to be as a country going forward and creating a vision that is truly inclusive of all of us.*[15]

While the Bill of Rights legislation was historic and this progress continues to spread across the country, activists in New York realized that the work surrounding domestic worker justice was far from over. The next step was to ensure that the provisions of New York's Domestic Worker Bill of Rights were enforced and that justice for domestic workers would become the norm rather than the exception. To do this, NDWA and JFREJ, with partner organization at Hand in Hand: The Domestic Employers Network, selected specific neighborhoods in New York City with high concentrations of domestic workers and domestic employers for targeted base-building, institutional organizing, and program development. They set out to pilot organizing strategies with employers and workers in these neighborhoods, innovating together around "Know Your Rights, Know Your Responsibilities", outreach, and other grassroots approaches to implementation. Following the lead of Caring Across Generations, they sought to connect these strategies to the broader conversation about the Age Wave and Care Gap as a way to engage more people and more institutions than ever before.

Local Initiative to Build Relationships between Employers and Workers

The values of compassion and interconnection were guiding principles in the campaign for the New York Domestic Workers Bill of Rights. These principles served as the basis for a critical alliance between Domestic Workers United (DWU) and the Shalom Bayit project of Jews for Racial and Economic Justice (JFREJ), which was born in 2002. Shalom Bayit, which means "peace in the home" in Hebrew, was the name of JFREJ's project to organize a network of domestic employers, "Employers for Justice." Initially, JFREJ members who were either former or current employers of domestic workers were invited to come to events and speak about why they supported domestic workers' rights. This evolved into a more concerted effort to bring together progressive employers and the broader Jewish community to support domestic workers' rights, drawing upon traditional Jewish values and a long history of Jewish progressive unionism. JFREJ started to organize in a small handful of synagogues and later expanded to reach many more.

Staff and leadership from all organizations talked through shared values and vision, long-term goals, and process at an all-day planning retreat in October of 2012.

One of the synagogues that took action in the campaign for the Domestic Workers Bill of Rights was B'nai Jeshurun (BJ). In 2009, JFREJ partnered with BJ to engage nearly fifty of their congregants in a campaign to "take one step up" in their employment practices and pledge support for the Domestic Workers Bill of Rights. Several years later, in the Spring of 2011, BJ held a community "listening campaign" designed to engage the community in choosing a new advocacy campaign. Over the course of this process, aging concerns emerged as a key theme. Nearly half of the 1700+ households that make up BJ's membership are 55 and older and members were increasingly grappling with questions such as: What will happen when I get older and need help? What kind of support network will we have in order to age in place, comfortably and with dignity? As a result, BJ formed a new social justice committee aptly named "Aging in New York."

It was at this time that JFREJ, DWU, and NDWA approached B'nai Jeshurun with an idea to build on its past involvement with the Domestic Worker Movement and at the same time have an impact on the aging concerns that were affecting BJ members. They invited two more local affiliates of NDWA—Damayan and Adhikaar—to join the coalition. Thus, the project took shape by fusing the national vision for scale and culture shift with the local vision for depth and effectiveness. It was the grassroots leadership of local organizations that enabled the Eldercare Dialogues to emerge as a successful strategy.

There were ultimately six groups that sat on the Eldercare Dialogues leadership team and invested significant energy in the process. For every organization at the table, the Eldercare Dialogues project was a departure from the way they had traditionally approached organizing and leadership development. In taking on the project, they prepared to take real risks, face tough challenges, and push themselves to expand their conception of what it means to organize with love and creativity.

Spotlight on Organizing Model: From Solidarity to Interdependence

The Eldercare Dialogues emerged as a strategy out of the need to adjust an organizing model to fit the new movement challenges that lay ahead. Following passage of the New York Domestic Workers Bill of Rights and the launch of Caring Across Generations, DWU and JFREJ, together with the National Domestic Workers Alliance and Hand in Hand: The Domestic Employers Network, began to explore an organizing model that would go beyond solidarity and towards a conception of mutual interest between workers and employers. They looked at the Age Wave and looming care crisis and began to draw new connections between workforce strategies and the social safety net. They asked: what becomes possible when we meaningfully link the concrete and material interests of domestic workers and domestic employers? How can our movements grow when we organize to provide services and benefits that meet the immediate needs of our constituencies and then tie those services and benefits to a broader struggle to strengthen the care workforce and expand the social safety net? These aforementioned groups determined that a series of structured, strategic Dialogues, meaningfully rooted in these mutual interests, would be a key phase in making the transition towards a new organizing model.

This shift from a solidarity model to one rooted in interdependence, or mutual interest, required a fundamentally different relationship to the pace of organizing. The Dialogues involved a slower organizing process than these organizations were accustomed to. At the outset, organizers understood that building a caring majority would require a field strategy that can bring together powerful local coalitions of seniors, care workers, and people with disabilities committed to fighting for the Caring Across Generations vision and showing up for each other's struggle. They also understood that building those coalitions would depend on deep political education and trust-building to move care workers and consumers to see their struggles as connected. Only through the Dialogues themselves could organizers completely understand just how deep and slow this process must be.

The resulting organizing model required leadership of these six organizations to continually stay connected to the guiding values of the project and to maintain commitment and investment from their base. Ultimately, it was the long-term goals related to the Eldercare training program and the opportunity for dignified jobs and trained workers that kept most members--both workers and seniors--engaged and motivated. Yet the trusting relationships and beloved community that emerged through the Dialogues has created a sturdy foundation for coalition work that would not have been possible before the Dialogues.

The following section provides detailed information on the goals, process, and impacts of the NYC Eldercare Dialogues.

III. UNPACKING THE ELDERCARE DIALOGUES

A. Guiding Questions and Goals that Led to the Dialogues

Emerging from the historic Domestic Worker's Bill of Rights victory and considering the complex political and social context of the care industry, the domestic worker movement and its allies asked a series of big questions:

- What is it going to take to implement this hard-won legislation?
- How do we respond to the Age Wave and the challenges and opportunities that it presents?
- How can we go beyond what the bill stipulates towards truly transforming our communities?
- How can we begin to explore collective bargaining and new strategies for building domestic worker power and building caring communities that value interdependence?
- What is the role of workforce development and a care sector career ladder in achieving these goals?
- How can we provide resources, support, and information to consumers and domestic employers in recognizing the home as a workplace and maintaining ethical employment standards?
- How can we build deep community and trusting relationships between seniors, care workers, and their loved ones?
- How can we address the unique organizing challenges that exist in the Grey and Private Pay Markets where there are few employment standards, no opportunities for workforce development, and minimal support for workers and employers to build and maintain positive and mutually beneficial relationships?

From these questions, the idea of Dialogues emerged as a way to bring together care workers, seniors, and their families to connect all of these areas of work and to serve as an organizing strategy. Further development of what the Eldercare Dialogue process would look like led to specific goals for the process. The goals of the Eldercare Dialogues were:

- Build deep and caring community between private pay elder caregivers, seniors, and their families.
- Identify shared values in the care relationship as well as contradictions or challenges; think through strategies to address these challenges, lift up our values, and secure quality care and quality jobs.
- Develop powerful and compelling spokespeople for local Caring Across New York organizing and communications.
- Prepare workers, consumers, and their families to be committed to developing and piloting workforce development and consumer training curricula with formal institutional partners.
- Explore strategies for community-based matching registry to serve workers, consumers, and family members who have participated in the training programs.

B. Process of Implementing Dialogues

To accomplish the goals listed above, the coalition of groups conducted eleven Dialogues from December 2012 through December 2014, as well as an initial all-day planning retreat with staff and leaders from each organization in October of 2012. While every Dialogue focused on building relationships and community between care workers, seniors, and their family members, each Dialogue explored a different theme. Each topic served as a way to delve into at least one aspect of either the care relationship or homecare system. Overall, the eleven Dialogues engaged nearly 700 seniors, family members, and care workers as

participants. The Dialogues were made up of many of the same core group of 60 participants month to month, but always included between 15 and 50 new participants recruited to join each conversation.

What follows is a brief summary of the issues, purpose, and impact of each Dialogue. Full agendas and sample activities from each session can be found in the Appendix.

Dialogue #1, Introduction to Eldercare Dialogues, December 2012, 48 participants

The first Eldercare Dialogue took place in December 2012 and focused on introducing the process, values, and goals of the Dialogues to participants. The purpose of this first Dialogue was to garner communal investment in the project, create structures and work groups, and build a space where workers and employers could learn and share together.

Dialogue #2, Experiences of Domestic Workers, January 2013, 52 participants

The main topic for the second Dialogue was the experience of domestic workers. The purpose was to highlight the stories of workers, build a shared vision of what makes dignified eldercare, and identify the obstacles that exist in establishing this vision. The Dialogue also explored the importance of workforce development in empowering workers and securing quality care and jobs. At the Dialogue, workers shared their stories in a fishbowl-style discussion. After hearing the stories, participants split up into pairs, and reflected upon how what they heard related to their own experience.

Dialogue #3, Experiences of Seniors and their Family Members, April 2013, 64 participants

Complementing the Dialogue in January, the third Dialogue explored the experiences of seniors and family caregivers. The purpose of this Dialogue was to highlight the common experience of aging and caregiving and expand participants' understanding of how aging is experienced differently based upon power and identity in society. Using the circle of sharing and fishbowl activities, the Dialogue lifted up several stories of seniors and their family members, including Rose, a member of Damayan, who shared her story about being diagnosed with cancer (See page 10: Rose's Story) and Toni, a member of BJ, who shared her story about caring for her husband after he was diagnosed with Parkinson's disease (See page 11: Toni's Story).

Dialogue #4, Care, Migration, and Gender, May 2013, 84 participants

The topic of the Dialogue in May was immigration and its link with domestic work. Its purpose was to explore the relationship between migration, care, and gender and engage participants around current legislation on immigration and paths to citizenship for workers. Participants shared migration stories in large groups and then took action in the campaign to win comprehensive immigration reform.

Dialogue #5, The Care Economy, July 2013, 52 participants

July's Dialogue took place in Queens, NY in the office of Adhikaar, a Domestic Worker organization, and focused on the structure of the care economy. The goals were to learn about the care economy and understand systems underlying wages for workers and access to care for consumers. This meant delving into workers' experiences with living wages and fair hours and exploring consumers' experiences accessing affordable quality care. The Dialogue used popular education around the Care Gap and care as a commodity, as well as a fishbowl activity to explore experiences with the care economy.

Rose's Story

Rose is a board member of Damayan Migrant Workers Association and worked as a caregiver for an elderly woman and as a nanny. In 1993 she was diagnosed with Leukemia and needed care for herself. Her story exemplifies the interconnectedness of those that give and receive care.

Damayan board member Rose Alovera shared her story at the April 2013 Dialogue.

When I first came into the country my first job was a caregiver to a legally blind elderly woman with no family. She was 80 years old. At first she didn't trust me, and after helping her every day, I gained her trust. At the same time I was also a baby sitter, taking care of a child. In 1993, I was diagnosed with Leukemia, having no insurance at all, it scared me to death. I checked myself into Elmhurst hospital. I was crying because I could not pay the bills of the hospital. The doctor got mad at me and said, you better stop crying and take care of yourself. I was only out for a year or two from work. I had to do chemotherapy. I was lucky that my employer then, who actually sponsored me, paid for disability insurance, she facilitated and submitted my application for emergency Medicaid. If it was not for that, my first hospitalization was $70,000, the second was $90,000, the third for $120,000. If it was not for Medicaid, I don't think I would have survived. When I was discharged and going to my visits to the doctor, several of my friends took turns driving me. With this experience it makes me really scared of aging. I have no family here, I will be depending on the community. I just hope the money I have been putting aside is enough and social security is still here.

Dialogue #6, Alliance, Interdependence and Communication, October 2013, 112 participants

The topic of October's Dialogue was the meaning of alliance, interdependence, and communication in the care relationship. The purpose was to explore what alliance, interdependence, and communication look like in a care relationship between seniors, caregivers, and family members and to develop concrete ideas of how care workers and domestic employers can be allies to one another. At the Dialogue, the facilitators used skits to illustrate the importance of interdependence and communication and the difference between being an ally and a helper.

Dialogue #7, End of Life, December 2013, 108 participants

The final Dialogue in 2013 explored the issue of caregiving at the end of life. The purpose of this Dialogue was to explore the experiences of seniors, family members, and caregivers at the end of life and learn and discuss ideas about the relationship between caregiving and dying with dignity. It centered around a fishbowl activity where participants shared stories of losing a family member or someone for whom they provided care. The Dialogue included a brainstorm on what was next for the Eldercare Dialogue process.

Toni's Story

Toni is a member of B'nai Jeshurun. She explained that she and her husband were just normal, everyday people until her husband was diagnosed with Parkinson's disease. Now at age 70, he has 24-hour care. Toni described the confusing and difficult process of finding and managing his care and navigating the complex relationship with his caregivers.

BJ and JFREJ member Toni Siegel shared her story at the April 2013 Dialogue.

Challenges come to mind first, joys sneak in around challenges. The reality is you are in it alone, the reality is even if you have the most wonderful caregiver. You guys who are doing the caregiving have a really hard job. You are trying to satisfy the family member who wants you to get your loved one out of the house and be active while also caring for the person who doesn't want you around, doesn't want to be cared for. The concept of 'we are all family.' This is not true. I didn't go to my job and say we are all family. That takes away boundaries, which is so important. You are so dependent on someone, they are doing the most intimate things in your home, but you still need to maintain professional distance. For the joys: our family has come together, he has gotten enormous support; to help him find the joys, that he still matters, the divine spark that was in him when I met him and fell in love with him when he was powerful and successful still exists.

Dialogue #8, The Care Gap, March 2014, 114 participants

The first Dialogue of 2014 delved into the issue of the "Care Gap," or the gap that exists between a community's need for care and the amount of care provided. The Dialogue focused on understanding and sharing stories related to the Care Gap and learning about local campaigns to close it. Participants took part in a popular education activity and then learned about lobbying and how it can be used to advocate for policies and funding that can help close the Care Gap. The advocacy focus was on restoring funding for a New York City program called EISEP: Expanded In-Home Services for the Elderly Program.

Dialogue #9, Employment Agencies, June 2014, 109 participants

The June 2014 Dialogue focused on employment agencies and their place in the care system. The goals of the Dialogue were to learn how homecare employment agencies affect workers, seniors, and their family members: explore visions for alternative community-based institutions to support interdependence, and take action to support the Justice for Job Seekers campaign. This campaign, convened by NDWA affiliate New Immigrant Community Empowerment (NICE), aims to build public awareness and make policy changes to address fraudulent, substandard and abusive predatory practices on the part of employment agencies, which are targeting the immigrant community. These goals were achieved by having workers, seniors, and family members share their stories about working for and with employment agencies and by having breakout groups that each explored a different model of community-based homecare. Break-out groups explored contemporary and historical models of mutual aid, cooperatives, social innovation, and enforcement. The Dialogue ended by learning about the Justice for Job Seekers campaign and using social media activism to support the campaign.

Dialogue #10, Dementia and Cognitive Disabilities, September 2014, 53 participants

This Dialogue was held in Queens at the office of Domestic Worker group Adhikaar and focused on dementia and cognitive disabilities. The goals of the Dialogue were to build community, trust, and solidarity between seniors, care workers, and their family members; learn about what dementia is; share stories related to dementia and other cognitive disabilities; and explore shared values and vision for social justice in relation to dementia. The fishbowl activity included care workers and family caregivers with direct experience with dementia, as well as artists and writers who specialize in doing transformative creative work with people experiencing memory loss. The Dialogue ended with the whole room singing, dancing, and reciting Nepali poetry—all effective methods of stepping into the world of a person with Dementia.

Dialogue #11, Showcase of Training Program and Report Release, December 2014

The purpose of this Dialogue is to release and share the report and toolkit with those who have participated and helped shape the Dialogue process. At the time of print, this Dialogue has not yet taken place.

Dialogue Participant Profile: Teresa

Teresa is 47 years old and from the Philippines. She is a member of Damayan and has been in the U.S. since 2002 working as domestic worker and mostly as an eldercare provider. In the Philippines, she was an accounting graduate--she worked in an office then had her own medical supplies business. She left the Philippines for a better life. Her family is still in the Philippines, including brothers, sisters, and a son. She has only been home once in the 12 years she has been in the United States.

Teresa is currently employed as a live-in eldercare provider in New Jersey. She works six days per week, and is on-call 24 hours a day to assist with daily living, housekeeping, and other emergencies that may arise. She lives in the basement of the family's house with the woman that she cares for and the family lives upstairs.

She explained: *"Caregivers really do their best to take care of the elderly but sometimes it is hard with the family and we get paid very low."*

She shared an experience from a previous employer:

The lady [senior consumer] keeps complaining she is constipated. The daughter wants her to take laxatives. I don't think that is the solution, I think she needs to eat better food. The daughter was not listening to me and I cannot insist. You have to feel out the family because maybe they are trying to save money. But sometimes it is frustrating if people don't want to give their parents healthy food.

Why did you get involved with the Eldercare Dialogues?

Working with the elderly, you don't know what is going to happen. The job is unstable, she [the consumer] could fall one night or go into the hospital. You don't know when you might be out of work. The Dialogues are educational; you meet other people doing similar work and it becomes like family.

With this Dialogue consumers and their families can learn a lot. It is different if you are working in a nursing home or assisted living, but when it is in someone's home you want to prolong your job and you want to develop a relationship with the family.

What stood out to you from the Dialogues?

The benefit is consumers can learn from the caregiver's perspective and understand their emotions. This is important because caring for the elderly is team work especially if only the families are involved. Caregivers are extensions of the family.

What have you learned through the Eldercare Training Program?

I did a home health aide training, but there are things that they didn't cover in that training. For example, we didn't get to share experiences with other caregivers.

C. Individual and Collective Impacts

Participants' Reflections on the Dialogue Process

BJ member Sylvie Heyman and Santa Maria member Nicia Hassell sharing migration stories at the May 2013 Dialogue.

Beyond learning about what makes a positive and dignified homecare relationship and the homecare system in the United States, the relationships formed at the Dialogues were just as important to participants as the information presented. In interviews and focus groups conducted after the first year of the Dialogues, participants repeatedly noted that the process was more than the sum of the activities and information presented at any individual Dialogue. What follows are quotes from the interviews and focus groups where caregivers, seniors, family members, and Dialogue organizers discussed the impact the Dialogues have had on them.

People were deeply moved by their participation in the Dialogues.

"I think everybody should be very, very proud. It's really breaking boundaries and it's hugely important in a way I would have never understood it could be."
– Judith Felsenfeld, Participant, BJ and JFREJ

"I guess I would say I loved participating in this group. I feel like this brought out the best in me and I feel like it brought out the best in other people too. I feel like it was really a magical space, it was really special, not just a special group of people but just such skillful organizing and so well-timed and so strategic and smart. I just really value being able to participate in it."
– Lezlie Frye, Trainer, Hand in Hand

Participants built impactful relationships and developed mutual understanding.

"I think that we looked at the Dialogues as a way to get to know partner organizations and understand and uncover mutual values, and to be able to grapple with and discuss challenges in the relationship between consumers or employers depending on the circumstance. And really be able to hear each other's stories and build relationships there." – Channa Camins, Organizer, BJ

"I got to know people in all the different Domestic Worker unions. It helped me see them more as equals, people I could be friends with or people I could know on a level. I found I learned a lot about their culture, I hope they learned about my culture. I think it will ultimately lead to each of us understanding our role in any future kind of commitment to work together, in whatever way we had to." – Marilyn Williams, Participant, BJ and JFREJ

Storytelling highlighted important and difficult issues in the care economy and in the employer-worker relationship.

"I think the biggest connection was the stories – the stories of the workers, the stories of the employers, the stories of the elderly. There was a connection and I think that's why it worked well."
– Barbara Young, Organizer, NDWA

"It was a very powerful process because once you get to know someone and you get to know their story, you get to know all the multidimensional aspects of an issue and how it's all interconnected. It does sort of shift the way you think about organizing and the work that you do."
– Yomara Velez, Organizer, NDWA

"We allowed peoples' stories to come through in a way that was infused with the kinds of political values that we need…for aging workers or a worker with a disability who's a woman of color and migrant to be able to share her story. Just through her story [we were] able to illustrate all of those things and then in facilitation we could draw out the connections."
– Rachel McCullough, Organizer, JFREJ

Dialogues fostered deep listening and practicing of empathy.

"What I think I learned most is that we got to listen to one another, and I mean really listen. We got to empathize with one another and know that sometimes what we think my normal is not some person else's normal." – Barbara Young, Organizer, NDWA

"That was a big part of the whole thing, not to make assumptions, to learn about people and to learn about people's differences and stories and ways, even if they're in the same group, they're not the same people. So not to make assumptions I think, and to listen. Good listening."
– Marilyn Williams, Participant, BJ and JFREJ

"Sharing [with] one another face-to-face. I think it's very important to communicate eye-to-eye, really come and listen to one another. It's really inspiring and [you] really learn a lot."
– Lydia Catina Amaya, Organizer, Damayan

Participants began to see themselves as needing care and recognizing the importance of interdependence in their own lives.

"…I think that creating this forum gave people the permission to bring up their fears, their own fears of being alone, of not having someone to take care of them. And certainly highlighted my own fears around that, who's going to take care of me..." – Rochelle Friedlich, Participant, BJ and JFREJ

"I want to go there [the Dialogues] to learn more about disability because…I was hit by a car… so I have to be prepared for what's going to be because I'm already 50, and it's a long way to go so I have to prepared." – Pema Sherpa, Participant, Adhikaar

"We are going to need care, we all need care. Interdependence is something that impacts, it's part of our lives. We need to universalize the notion of care and not just suggest that some people need it and some people don't, but at the same time some of us do need more care than others, and it's not just elders and it's not just children…" – Lezlie Frye, Trainer, Hand in Hand

Participants in the Pilot Eldercare Training Program prepare to engage in applied theater games exploring alliance and interdependence.

The Dialogues built new leaders and influenced participants to take action publicly in support of concrete systemic change to benefit the lives of care workers, seniors, people with disabilities, and their family members.

> *"When Damayan asked us to be allies and help them protest human trafficking…I wanted to be there to support them. But also, I think that as we show up for one another, we build strength and capacity through our reliance on one another…It is like if someone makes a call to me and says I really need you to show up to this thing, that relationship is important so I'll go. The same is true for showing up [for each other's issues] on a larger level." – Rochelle Friedlich, participant, BJ and JFREJ*

Dialogue Participant Profile: Ram

Ram is from Kathmandu, Nepal. She has a Bachelor's degree in Arts. She started as a typist, became a clerk, and was eventually promoted to the post of government officer at Nepal's National Bank. She worked there for 23 years. It has been almost 15 years since she moved to the U.S. and she still has many family members in Nepal. Initially, when she came to the U.S. she started working as a caregiver for people that were sick. Then she became a nanny. Most recently, she has been doing eldercare work but has been out of work for the past 10 months. She is also a member of Adhikaar. In her last eldercare job, Ram looked after a woman whose right side was paralyzed. She helped her with prepping food, bedding, and cleaning after cooking.

She explained, *"I had a good relationship with my employer; she was like my mother."*

She shared this experience from another previous eldercare job:

I used to work for a woman who lived by herself and she didn't communicate a lot. One day I found her lying on the floor and we called 911 and the old woman didn't want to go the hospital. It happened again a second time, I don't know how long she was on the floor. It was more severe. She might have fallen the night before. She couldn't speak so this time they took her to the hospital. After two weeks she passed away. It was very emotional for me.

Why did you get involved with the Dialogues?

Because I wanted to learn more and gain more skills for my employers.

What stood out to you from the Dialogues?

The issue that stands out for me is how elderly folks lose control, sometimes it is children taking control of money and then they can't have control over the worker. We need to do something about that. It is sad to see them [the seniors] lose control.

What was challenging about the Dialogues?

Hearing how we are overworked and there is not enough pay and the elderly are also suffering is difficult to hear. It is very challenging even when elderly people want to pay more to the worker they may not be able to because others may control their money. Consumers and their family members must know that workers are overworked and need to be heard.

What have you learned through the Eldercare Training Program?

I've learned about the relationship between the employer and worker and the fact that we have to give them [the employer] respect and they should respect us and treat us with dignity. I've also learned a lot on the topic of respect: what are the ways to provide respect to elders? Some examples of what I've learned: before if someone needed to take a shower, I'd just undress them in the bathroom, but now I am more aware that they still have dignity so being more aware of how they feel and that they may feel shy or ashamed. Sometimes elderly people may get angry or stubborn and not want to do certain things and we may get angry too, so now I think more about being patient and taking time to let them be.

From Talk to Action: Leadership and Political Development of Dialogue Participants

Dialogue participants experienced real shifts in their consciousness and relationships, and their growth did not stay in the room. Over the course of the two years of Dialogues, participants took action in an array of local and national campaigns aimed at transforming long-term care, winning protections for care workers, and protecting or expanding the social safety net.

At the federal level, participants took part in the historic campaign to eliminate the "companionship exemption" and extend minimum wage and overtime protections to homecare workers. Dozens of seniors and domestic employers submitted comments to the Department of Labor emphasizing that living wages and overtime pay for care workers also show that we value the lives of seniors and people with disabilities, and that better conditions for workers also ensure continuity of care for consumers.

Workers and employers also took action in the campaign for comprehensive immigration reform, ensuring that the voices of women and caregivers, both domestic workers and domestic employers, were included in the fight. Members' perspectives were especially important in fighting back against increased worksite immigration enforcement, such as the electronic employment eligibility verification system (E-Verify) to verify employees, regardless of the employer's size.

BJ and JFREJ members Rochelle Friedlich and Sylvia Vogelman participate in a rally to raise wages for homecare workers as part of a Care Worker Summit in St. Louis, Missouri. October 2014

Damayan organizer Lydia Catina Amaya speaks at a rally in support of restored funding for EISEP—Expanded In-Home Services for the Elderly Program. April 2014

At the local level, ally organizations came together around a campaign to restore funding to a vital New York City homecare and case management program called EISEP: Expanded In-home Services for the Elderly Program. EISEP supports non-Medicaid-eligible low-income seniors 60 years and older, including those who are undocumented, to pay for part-time home care services. When participating organizations determined that the program is a lifeline to almost 3,000 seniors, offering respite to family caregivers, and providing living wage jobs to home care workers, they decided to fight to expand the program. Damayan, one of the domestic worker movement organizations on the Eldercare Dialogues leadership team, chose to mobilize and lend support to this campaign even though it was not directly within the short-term interests of their base of domestic workers and Lydia Catina of Damayan spoke at a rally in support of increased funding for EISEP in May of 2014.

D. Challenges and Critical Reflections

There were several key challenges that were encountered in developing and implementing the Dialogue project. This section outlines some critical reflections as well as suggested strategies to grapple with these challenges.

Access challenges related to physical, visual, auditory, and language needs were a barrier to authentic and equitable sharing and communication.

The Eldercare Dialogues Consortium defines access as a set of resources that make it possible to participate in every part of personal and public life. It can refer to physically accessible spaces, but also to the culture of a group, institution, or society. Access can be economic, and can come from class privilege. It can be cultural and come from the privileges of race, gender, or citizenship. Access can also come from a collective experience of mutual support and solidarity.[16]

Caracol Interpreters Cooperative supporting through interpretation at the October 2013 Dialogue. Photo: Red Papillon Photography

Each Dialogue had a diverse set of participants and thus created a complex environment with numerous access needs. It was necessary to plan for physical access for walker and wheelchair users, simultaneous interpretation in multiple languages for those with limited English proficiency, and other critical accommodations for visual and auditory access. The organizers prioritized access and viewed these practices as central rather than secondary to the success of the program. Nonetheless, there were Dialogues where the organizers fell short. Sometimes seniors had a difficult time hearing because the sound system was not working properly. Often times, interpretation was not available in some participants' first languages, making it so that they had to struggle to participate in English. All of these access challenges were real barriers to authentic community-building and communication.

The location of Dialogues was not always easily accessible for all participants.

The majority of Dialogues were held at the synagogue on the Upper West Side because of the availability of a space with high capacity and in order to prioritize access for the seniors who lived in the neighborhood. However, this often meant they were less accessible for care workers who lived or worked in Brooklyn or Queens. The two Dialogues that were held at the Adhikaar office in Queens had lower turn-out among seniors from Manhattan but higher turn-out among workers who lived or worked nearby. These Dialogues were far more accessible and empowering for the Adhikaar and Damayan members who had the opportunity to host employers on their turf and on their terms. In addition, organizers rented vans in order to make it possible for most of the Upper West Side seniors to make the trip. Upon reflection, organizers agreed that even when travel and transit feel like obstacles it is best to push for a more equitable break-down in terms of where Dialogues are held.

Dialogue organizers should view accessibility as encompassing best practices related to disability, aging, culture, and language. They should work to build a multilingual space where the mobility, vision, auditory, and learning needs of all participants are heard and respected. For tips on how to build multilingual space and plan an accessible event, see Appendix 12.

Power dynamics between domestic workers, seniors, and family caregivers were often unequal.

In planning and implementation, there were real challenges surrounding power dynamics between workers, seniors, and family caregivers. These groups often had different cultural relationships to public speaking, conflict, and facilitation, as well as vastly different social experiences with power and oppression. This often meant that the primarily white baby boomers felt more comfortable taking up space and expressing their opinions at planning meetings and at Dialogues themselves. In the face of this, workers were often more inclined to be silent or deferential. In the absence of very explicit and proactive anti-oppression facilitation, the power dynamic in the room could start to resemble the asymmetrical dynamic that usually prevails in one-on-one relationship between domestic workers and their employers.

It is important to build an organizing and facilitation team that is capable of having open and honest conversations about these dynamics if and when they emerge. This will help participants to be more mindful and intentional when entering the shared space. It is important that facilitators build agendas with a careful eye towards lifting up and centering the voices of the people most likely to be silenced. This means creating ample space for women of color to speak, facilitate, and lead. It also means ensuring that seniors themselves, rather than their often more vocal family caregivers, are empowered to speak to their own experiences.

The Dialogue process requires a high level of resources and capacity.

The New York Eldercare Dialogues required a lot of staff capacity and resources from the six organizations that took part. Considerable effort was required to build the leadership team, plan and prepare for the Dialogues, document the process, and sustain engagement with other ongoing local and national campaigns. The most capacity was required of the JFREJ community organizer, who at times devoted up to 40% of her staff time towards driving and managing the overall process. Organizers at Adhikaar, Damayan, BJ, and NDWA rotated responsibility for each Dialogue, and at times expended more capacity than others. Organizations also rotated payment for food, interpretation, and other logistical or access needs that arose. Organizers agreed that the process was worth it for the level of depth and energy that it generated in the Dialogues. And yet, they agreed that it ought to be possible to reach this many people at this level of depth with smarter use of limited capacity and resources.

In Part II, the toolkit spells out recommended questions to ask of a coalition that is considering taking on Dialogues. At the top of the list is a capacity check. Organizations who seek to organize with this level of depth must be prepared to devote significant staff and member capacity to make it happen. Otherwise, coalitions run the risk of developing a hollow or surface-level project that doesn't achieve the level of depth intended. That said, the toolkit also includes a few recommended options for downsizing and scaling the NYC Eldercare Dialogues (see Appendix 11) in the hopes that other coalitions will be able to figure out how to achieve adequate levels of depth without expending as much organizational capacity.

IV. RESULTS/WHERE WE GO FROM HERE

There were two major outcomes that leaders and organizers hoped to achieve in connection with our Dialogues program. The first was the development of an Eldercare training program infused with our values to serve workers and employers side by side. The second outcome was a broader culture shift and standard-setting initiative to transform individual homes into fair workplaces.

Eleven of the fifteen participants in the Pilot Eldercare Training Program along with trainers from SEIU 1199 Training and Employment Funds.

Pilot Eldercare Training Program for Workers and Consumers

One of the primary outcomes of the Dialogue process was the establishment of a pilot workforce development training program for eldercare consumers and workers that explores the following question: how do we build caring communities that recognize and value our interdependence? The goal of the training program was to bridge the needs of employers and workers through quality training that ensures both the dignity of seniors living at home and of paid caregivers who support them in living independently.

Eldercare Training participants engage in cooking and culture sharing at a workshop in September 2014.

This community-based curriculum engaged 20 potential employers and 16 eldercare workers from July through October 2014. Employers had a total of 20 hours of training, 14 of which were spent side by side with workers, while workers had a total of 64.5 hours of training. For employers, the training provided information and promoted the skills needed to hire, supervise, and maintain clear and open communication with a caregiver. Topics covered included legal rights, conflict resolution, planning, budgeting and decision-making, the role of family in care management, and managing collaborative relationships. For workers, the training focused on technical skills and core

competencies in personal care services to support elders and other care recipients in the activities of daily living. Workshops covered workplace safety, body mechanics, toileting, bathing, nutrition, understanding the aging process, and caring for a person with dementia. Workers also received training in communication, conflict resolution, CPR, and First Aid, as well as consumer and worker's rights.

Pilot Eldercare Training Participants engage in interactive and hands-on learning and community-building at one of the three workshops that included care workers, seniors, and their family members.

Care workers and seniors participating in a sharing circle as part of the Pilot Eldercare Training Program.

The worker curriculum is based on the Paraprofessional Healthcare Institute (PHI) personal care services curriculum; the employer workshops were developed in partnership with Hand in Hand: The Domestic Employers Network. Worker training units were administered by experienced 1199/SEIU trainers who also participated in a PHI-led train-the-trainer session focusing on adult-centered learning. All participants received a certificate of completion from the Worker Institute of Cornell University School of Industrial and Labor Relations and the Cooperative Extension Program. This pilot will be evaluated in order to learn from best practices and challenges with the aim of expanding the program's scope and reach. As the pilot program neared completion, organizations participating in the Eldercare Dialogues began to experiment with how to create space for participants to exchange information and connect to one another more easily while meeting mutually agreed upon standards for work and care.

Fair Care Pledge: My Home is Someone's Workplace

In addition to workforce development for caregivers and training for employers, another major outcome of the Dialogues was the creation of the "Fair Care Pledge," a commitment to dignified and respectful employment practices for domestic employers everywhere. An initial priority in developing the Dialogues program was to develop new models for setting standards and engaging in collective bargaining in the domestic work industry. "My Home is Someone's Workplace" emerged as an innovative public education initiative that starts by encouraging employers to identify that their homes are indeed someone's workplace. Hand in Hand: The Domestic Employers Network developed this paradigm as an entry point for implementation of new standards won through Domestic Workers Bills of Rights campaigns, as well as even higher community standards for the domestic workplace.

In connection with My Home is Someone's Workplace, the Fair Care Pledge is a joint project of Hand in Hand and NDWA. The organizations hope to organize broadly with the pledge toward the overall goal of transforming the industry. The Fair Care Pledge invites employers to publicly commit to make their home a workplace they are proud of by being respectful, clear, and fair. The Pledge guides individual employers to improve employment practices, helps Hand in Hand build its base of supportive employers to draw from in advocacy efforts, and is an initial entry point for employers who can then take action and become

spokespeople in the movement. Since the launch of the Pledge in April of 2014, NDWA and Hand in Hand have been building online awareness of the Fair Care Pledge by getting the word out through partner organizations, progressive foundations, and donor circles as well as parent and caregiver listserves. In this way, the Fair Care Pledge can become the norm where employers congregate and help change the cultural conversation about domestic employment to become grounded in dignity and respect.

On the afternoon of Sunday, October 26th 2014, over 75 loved ones and supporters gathered in the B'nai Jeshurun sanctuary to celebrate the graduation of the fifteen eldercare workers and fifteen domestic employers who had participated in the pilot Eldercare training program. The graduates received certificates of completion from Cornell University and were showered with respect and congratulations by elected officials, labor movement allies, and faith leaders. At the close of the ceremony, workers and employers read aloud an extended Fair Care Pledge that they had all taken at the close of the course. Three pledges--one for employers, one for workers, and one for both parties--together made up what the organizers call a Covenant of Care, a moral commitment to each other's dignity and interdependence (see Appendix 14 for the full Fair Care Pledge).

30 care workers, seniors, and family caregivers at the graduation for the Pilot Eldercare Training Program celebrate with their certificates of completion and signed Fair Care Pledges.

V. CONCLUSION AND CALL TO ACTION

This report and toolkit are geared toward Caring Across Generations and all organizations, congregations, and communities—as well as allied public officials and funders—that want to build a more caring and just America and are looking for effective local strategies to build the movement that is needed. This movement advocates for a comprehensive approach that expands and supports a strong home care workforce and makes long-term services and supports affordable and accessible.

There is a dire need to create more dignified jobs in the homecare sector and to ensure that the care workforce—or *care force*—has real opportunities for training and advancement. The fight should go on for a path to citizenship for care workers, domestic workers, and all caregivers.[17] Common sense immigration reform is necessary to close a growing long-term care gap in the United States and to ensure the well-being of immigrant women who provide this care.[18] These things can only be won through organizing, and organizing must start by building a grassroots base of care workers, seniors, and people with disabilities, then mobilizing that base to fight for justice.

Following two years of Eldercare Dialogues and the successful launch of a workforce development and employer training program, the Eldercare Dialogues Consortium is preparing to take its organizing to the next level. The coalition hopes to expand trainings and workshops for domestic workers and employers to implement the Domestic Workers Bill of Rights, advance the Fair Care Pledge, and support all parties to build and maintain trusting and dignified relationships. Ultimately, these Dialogues and trainings can be built into the life cycle of faith communities, the programming of community organizations, and the menu of offerings of countless service providers. Taken together, this can build a local organizing and care workforce

development strategy that is rooted in values of interdependence, disability justice, and feminism.

When the Eldercare Dialogues Consortium came together around a campaign to restore funding for a homecare and case-management program for low-income and undocumented seniors called The Expanded In-Home Services for the Elderly Program (EISEP), they modeled the kind of powerful care coalition work that is most needed. These are the kinds of local struggles that care workers and employers can wage together out of an investment in our shared interests and mutual dignity. It is these wins that secure concrete improvements in job quality and expanded access to care that make real the belief that caring homes and just workplaces go hand in hand.

But these local coalitions can only emerge out of story-telling, leadership development, and deep community-building. Transformation is necessary within communities of care workers, elders, people with disabilities, and their loved ones in order to build power and create a more caring America. Dialogues foster political education, base-building, leadership development, and campaign development. They are one key field strategy for building and revealing the caring majority that is out there. If the movement is to succeed in transforming long-term care, real investment on the part of organizations, funders, and elected officials is required. This movement to build a culture that supports care will enable all of us to age with dignity and security, and to do it by truly valuing the care of our elders.

BJ member Ruth Jarmul takes action in support of a path to citizenship and full rights for all immigrants at the May 2013 Dialogue.

PART 2

TOOLKIT FOR IMPLEMENTING A DIALOGUE PROCESS

This section lays out the steps and tools needed to plan and implement a Dialogue process, based on the New York model. It also offers questions to ask when considering if this process is right for your community as well as some alternative scales and structures to the model used in New York City.

I. CRITICAL QUESTIONS FOR DETERMINING IF THE DIALOGUE PROCESS IS RIGHT FOR YOUR COMMUNITY

The New York experience proved that Dialogues provide fertile ground for real base-building, leadership development, political action, and coalition-building. The Dialogues were a powerful and transformative organizing process for all of the organizations that took part. At the same time, the organizing process may not be right for every organization, coalition, or community. The Dialogues were labor-intensive and required a high level of facilitation experience. The program was also developed on a strong foundation of trust and history of coalition building between domestic workers and employers through the Domestic Workers Bill of Rights Campaign.

In order to determine if a Dialogue process is right for your organization, coalition or community, there are several important questions to consider, including the following:

Who are the stakeholders?

- What is the nature of the problem we are seeking to address or transform? Who are the constituencies we need at the table in order to do so? Be specific. What kinds of seniors? What kinds of care workers? What conditions do they face?

What stage of strategic development is your organization or coalition in?

- Are we conducting Dialogues as part of a campaign that has already been developed and launched? Or do we need to conduct Dialogues in order to get clarification on what kind of campaign is needed?
- Do we already have a coalition in place that includes all the constituencies we need, or is our goal to create the conditions for that coalition to emerge? If working within a preexisting coalition, does each organization's leadership already share vision and values around what is needed?

What is the human and financial capacity of your coalition?

- Do we have at least three organizations representing these key constituencies that are committed to making Eldercare Dialogues a core component of their organizing? How much staff time are they prepared to devote to this program over the course of one year? [Note: the organizations on the New York Eldercare Dialogues leadership team each devoted between 10 and 40% of a full-time organizer's staff time to this program. The total hours were about equivalent to that of a single full-time staff member.]
- What is the level of facilitation and conflict resolution experience in our leadership?
- Do we have the financial, material, and human resources to take on this project?

II. DESIGNING YOUR DIALOGUE PROCESS

Step One: Identify and begin to bring together stakeholders.

The Dialogue process must begin with the bringing together of leaders and organizers from stakeholder organizations. With the first Eldercare Dialogues in NYC, this meant organizations with a base of seniors and family caregivers who were falling in the Care Gap (BJ and JFREJ) and organizations with a base of domestic workers and elder caregivers in the private-pay market (Damayan, Adhikaar, Domestic Workers United, and the National Domestic Workers Alliance).

Step Two: Engage in internal political education at each organization.

Of course, concerns and questions exist when trying to build deep community between workers and consumers. For workers these include: Will this generate quality jobs? Why so much focus on the experiences of the seniors? For seniors: Will workers ever understand our needs? Can we trust them to work with us? Other challenges and roadblocks include racism, ageism, ableism, etc. It was necessary to spend time building commitment to the process and engaging in political education internally at each organization before bringing together our membership across stakeholders for Dialogues. This took the form of workshops, living room gatherings, and one-on-one meetings.

Tools that correspond to this step of the Dialogue process:

Appendix 10: One-on-One Guide

Appendix 13: Sample Political Education Material

Step Three: Bring together organizers and leaders to identify shared goals, vision, values and timeline.

The Dialogue process kicked off with a day-long retreat with organizers and leaders from all of our organizations. At this retreat, organizers and leaders built relationships and got on the same page about the context of their movement. They also discussed their shared values and shared vision for quality care and quality jobs. Finally, organizers and leaders spelled out specific organizing, base-building, and leadership development goals to be shared across their organizations in the Eldercare Dialogues process. They also agreed on a specific timeline for Dialogues and organizing.

Tools that correspond to this step of the Dialogue process:

Appendix 1: Retreat Agenda

Appendix 3: Goals for Eldercare Dialogues

Appendix 4: Timeline for Dialogues

Step Four: Create a budget.

As mentioned earlier in the toolkit, the Dialogue process can be resource intensive. It is important to have a budget in place that lays out your expenses both in terms of personnel costs as well as other than personnel items such as translation, food, printing, meeting space, etc. It is also helpful to include all the revenue sources for the project including foundations, individual donors and the in-kind resources that will be donated.

Step Five: Build a leadership team.

After the initial retreat, organizers and leaders began to build a formal Eldercare Dialogues leadership team made up of workers, seniors, family caregivers, and staff from all participating organizations. The team would meet monthly and maintain an overview of the process. This meant developing Eldercare Dialogue agendas, participating in meetings to explore partnerships with larger institutions, making key decisions about curriculum development and pilot training, as well as collaborating to secure funding and resources to support the project as a whole. It is best to schedule regular meeting times well in advance. The leadership team is an excellent space for leadership development and long-term relationship-building between the members and staff of our organizations.

Tools that correspond to this step of the Dialogue process:

Appendix 2: Eldercare Dialogue Leadership Team Roles

Step Six: Begin to have Dialogues.

Steps One through Five will lay strong groundwork in the form of buy-in and leadership development for beginning to hold community Dialogues. The leadership team can brainstorm and decide on themes for Dialogues and identify facilitation/planning teams made up of members of each organization. See the following section of this toolkit on planning individual Dialogues for a run-down of all the moving pieces that make up a successful Dialogue.

Step Seven: Regular debrief and evaluation.

After each Dialogue, it is critical to bring together facilitators, leaders, and planners to debrief and evaluate. Throughout the process, leaders would assess which components worked especially well and which areas required improvement or strengthening. Debriefs were especially crucial in learning to create a truly accessible multi-lingual and intergenerational meeting space complete with all forms of support to ensure that all present could participate fully.

III. PLANNING INDIVIDUAL DIALOGUES

In addition to planning the overall goals and strategy for the Dialogue process, it is important to have a plan in place for each individual Dialogue. Below are some suggested steps for planning each Dialogue session.

1. Choose a Theme for Each Dialogue.

At the beginning of each year, the Eldercare Dialogues leadership team met and brainstormed topics and themes for all upcoming Eldercare Dialogues. They came to consensus on which themes they wanted to address and when, trying their best to limit each Dialogue to a single theme. Well in advance, they determined who would plan and facilitate each Dialogue and where it would be held.

2. Develop a Planning Team for Each Dialogue with Specific Roles and Responsibilities.

For each Dialogue, leaders would build a planning team of at least four people, including at least one domestic worker and one senior. More than a month in advance, the planning team would meet to identify goals, draft an agenda, and divvy up roles. A typical break-down of roles might be:

- Person One: Organize logistics (food, space, interpretation, amplification).
- Person Two: Write facilitation guide for the popular education section and prep two more facilitators to help.
- Person Three: Write facilitation guide for the fishbowl discussion and prep six speakers or story-tellers.
- Person Four: Prepare and print materials.

3. Prepare Leaders to Facilitate and Play Roles in Each Dialogue.

Preparing a handful of leaders including domestic workers, elders, and family caregivers to speak, facilitate, or share their stories was a major task to be completed for each Dialogue. For organizers, it was vital to make time to speak with each leader ahead of time, practice their story or facilitation role, then print out a few bullet points to support them. For each speaking role, it worked best to adhere to a limit of one or two key discussion questions so as to allow the most salient points to come across.

4. Review Group Agreements at Each Dialogue.

At each Dialogue, things got started off on the right foot by revisiting a set of group agreements that the leadership team developed at the outset (see Appendix 7).

5. Choose facilitation and popular education techniques to ensure participation of all stakeholders.

There were four primary facilitation and popular education techniques that groups found worked best at Eldercare Dialogues:

The Pair and Share

Early on in each gathering, have people turn to a neighbor and answer a discussion question that a) builds a relationship and b) gets people thinking and reflecting on the theme of the Dialogue. See Appendix 9 for a sample.

Role Plays and Skits

Applied theatre techniques allow people to begin practicing the values and ideas being discussed by actually embodying them. Through humor, intervention, interaction, and vulnerability, participants were able to laugh in spite of their struggles, engage in creative problem-solving, and build community.

Fishbowl Discussions

Four to five chairs are arranged in an inner circle, or a fishbowl. The remaining chairs are arranged in concentric circles outside the fishbowl. A few pre-selected participants—a mix of care workers, elders, family caregivers, and other kinds of "experts"—step in to fill the fishbowl, while the rest of the group sits in the chairs outside the fishbowl. In Eldercare Dialogues, fishbowl discussions worked especially well in creating a smaller and safer container for leaders to show vulnerability and model deep listening and engagement. It was especially powerful to create a conversation between paid and unpaid caregivers, elders, and people with disabilities together with academics, artists, workforce development specialists, and Rabbis. It allowed participants to shift traditional conceptions of who is an expert. See Appendix 8 for a sample.

Fishbowl discussion as part of the December 2013 Dialogue on End of Life.

Circle of Sharing

It was often useful to foreshadow each fishbowl discussion with smaller group conversations at each table. A facilitator should be prepared to moderate at each table, ensuring that groups are kept within time limits and that the voices of domestic workers and elders are prioritized and balanced. Offering space for folks to share stories in small groups helped to deepen their investment in the theme and draw connections between their personal experiences and the wider group discussion.

IV. APPENDIX

The appendix includes examples of agendas, facilitator guides, and other materials used throughout the Dialogue process and referenced in the report and toolkit. These are broken into tools for planning, implementation, scale and replication and "other."

IV. APPENDIX: TOOLS TO HELP PLAN AND IMPLEMENT A DIALOGUE PROCESS

Planning

Appendix 1: Retreat Agenda

This agenda for the initial Dialogues planning retreat shows the intentional goal-setting and values discussion that provided the foundation for the events that were to come. It illustrates the ways in which participating organizations entered the project with a very clear sense of short, intermediate, and long-term goals. At the same time, the agenda includes ample space for additional creativity and visioning related to process. This balance helped to create real trust and commitment on the part of the leadership team members.

Appendix 2: Eldercare Dialogue Leadership Team Roles

This one-pager outlines roles and responsibilities for the leadership team that organized and developed the Eldercare Dialogues and pilot Eldercare training program. It was useful to spell out in very clear terms what each member of the team would be responsible for, and what the team as a whole would do. This outline was accompanied by a calendar that included all upcoming Dialogues, training and curriculum development sessions, and leadership team meetings.

Appendix 3: Goals and Shared Values for Eldercare Dialogues

The primary outcome of the October 2012 Planning Retreat was consensus on the guiding values and overall goals of the Dialogues. Organizations were able to return to these goals and values throughout the program to reground and ensure that the organizing was in line with the initial vision.

Appendix 4: Timeline for Dialogues

This timeline was filled in as the organizations developed clarity on Dialogue themes and order. The leadership team mapped out each arc of the Dialogues at least one year in advance. The plan was developed with an eye towards members' political and leadership development, as well as broader movement context and opportunities for mobilization.

Appendix 5: Sample Agenda

This agenda shows one Dialogue process that organizers found effective. After determining Dialogue goals, organizers would identify and prepare members to facilitate or share stories in each section. This agenda showcases the ideal balance between community-building, fishbowl-style political education, and action.

Implementation

Appendix 6: Sample Facilitator's Guide

This facilitator's agenda shows the high level of preparation required for Dialogue facilitators to support a large and diverse group of people through a complex process of story-telling and political education. It is useful to include plenty of detail in the facilitator's agenda; extensive preparation creates more openings for flexibility and improvisation in the moment.

Appendix 7: Sample Group Agreements

At each Dialogue, organizers start things off on the right foot by revisiting a set of group agreements that the leadership team developed at the outset. These group agreements set the tone for mutual respect and accountability and can be referenced throughout the evening if tension emerges or the core shared values are not being upheld by all participants.

Appendix 8: Sample Fishbowl Script

This guide shows an effective flow for an intimate and illuminating fishbowl discussion. As with other aspects of a Dialogue, plenty of preparation is necessary to ensure that learning and community-building goals are met. This guide includes sample prompts as well as ideas for pair and share questions to create space to process what's being shared. It also shows how each participant was prepped to hit two or three key ideas or reflections in their remarks. This facilitation guide was useful to the fishbowl facilitator to know what to listen for and draw out of the conversation.

Appendix 9: Sample Pair and Share Handout

This guide models clear and concise instruction for a pair and share activity. The handout is useful for prepping a facilitator to spell out the process in very precise terms. This level of clarity is key when coordinating movement with a very large group of people.

Appendix 10: One-on-One Guide

This guide is a helpful tool to support leaders to do outreach and conduct one-on-one meetings with domestic employers. It outlines the main areas for probing that can bring domestic employers towards action, accountability, and partnership with domestic workers. This guide was very useful in engaging and developing the senior and family caregiver leaders who came to be compelling facilitators and story-tellers as part of the Dialogues. This tool was in use prior to the initiation of the Eldercare Dialogues and was used even more heavily as organizers began to reach more domestic employers through the process.

Scale and Replication

Appendix 11: Alternative Structures for Smaller Scale Dialogues

This item suggests a few potential downsized versions of the program that could still achieve many of the same key outcomes in terms of base-building and leadership development. Each one could be implemented over the course of a few months or one year, and with a clearer end point in sight.

Other Materials

Appendix 12: Tips and Best Practices for Access

Dialogues organizers understood access as encompassing best practices related to disability, aging, and language. These guides support us to build a multilingual space where the mobility, vision, hearing, and learning needs of all participants were heard and respected.

Appendix 13: Sample Political Education Material

This material is used with members to delve into power, identity, the care economy, and other systemic forces at play in the coalition's organizing. Each tool shows popular education methods that draw out participants' own wisdom and experience, layer on new political framing, then invite participants to apply or enact what they've learned. These tools were very useful for creating a shared political framework and power analysis within which to share stories and learn from each other.

Appendix 14: Fair Care Pledge

The Fair Care Pledge invites employers to publicly commit to make their home a workplace they are proud of by being respectful, clear, and fair. The Pledge guides individual employers to improve employment practices, helps Hand in Hand build its base of supportive employers to lift up in advocacy efforts, and is a first entry point for employers who can then take action and become spokespeople in the movement. This appendix also includes additional fair care pledges for workers to commit to and for workers and employers to commit to together.

APPENDIX 1: RETREAT AGENDA

Workforce Development Project

Kick Off Meeting

Date:	October 5, 2012
Duration:	10:00am-2:00pm (Kick-off Meeting w/ Membership & Workers) 2:20pm-4:30pm (Organizers & Leaders continue planning & developing time-line)
Location:	B'nai Jeshurun: 2109 Broadway

Purpose for October 5th BJ Meeting

- Develop long-term, intermediate, and short-term goals for the elder care Dialogues
- Develop long-term, intermediate, and short-term vision for eldercare
- Agree on our process for working together
    - Timeline and benchmarks, flow and structure of the Dialogues
    - Shared needs and goals for learning
    - Sense of how we hope to engage our members deeply; how to build deep and transformative community together

To write up on butcher paper:

- Values (Rachel)
- Agenda/Purpose (Channa)
- Spider for vision (5x) (Yomara)
- Goals of the Dialogues (Channa)
- Bike-rack (Yomara)
- Timeline (Rachel)

Other next steps

- Food and invoice Channa-Yomara
- Prep Kate, Allison, and Rochelle (Rachel)
- Get training dates, Jason will call Faith, Rachel could follow up with Deb Friedman; follow up with Ai-jen for kick-off date (Jason/Yomara)

Agenda:

Time Frame	Item for Discussion	Facilitator
10:00-10:15am	Welcome & Overview of Agenda Name, Organization, what's one thing that would make our time together productive and caring. Review agenda Start with ourselves, our stories Build on that: what are our values? Then our vision Then our process: How will we reach our vision? Through the Dialogues What are the goals of the Dialogues Implementation, how are we going to work together?	Channa Yomara
10:15-10:35am	Getting to know each other Pair and Share (3x) How did you get involved in this work? Why are you here today? Share an organizing or community-building experience that transformed you—changed you. What's something that you love about your community?	Kate
10:35-10:55am	Background and Context for the project	Jason
10:55-11:10am	Present Values (lay the foundation for the next agenda item)	Rachel
11:10-11:40am	Creating a vision! Small group breakouts: what is our vision for eldercare? 12 minute break-out and 8 minutes report-back Each group works with spider worksheet	Channa
11:40-12:00pm	Weaving our vision into our goals for the project Long-term Goals of Eldercare Dialogues Build deep + caring community between workers, consumers, and their families Identify shared values in the care relationship; Identify challenges or contradictions in the care relationship Think through strategies to address those challenges and lift up our values X # of workers, consumers, and their families prepared and committed to develop and pilot WF dev and consumer training curricula How do these goals sound? Are they the right goals? Is anything missing? Would we change anything here?	Rochelle and Allison
12:00-12:30pm	LUNCH-Opportunity for folks to mingle & get to know each other	
12:30-1:30pm	Introduce activity What do we mean by Dialogues? Dialogues are everything we do together to learn, share, build community and trust. Encourage folks to think outside the box. Think about format, activities, etc. Activity-4 corners: 1. What do we want to learn about/from each other? [Jason] 2. What do you want to share with each other? 3. How do we want to build community? How will we build trust and create a safe space? 4. What do we want to do together?	Yomara Kate, Yomara, Jason, Channa, one in each corner
1:30-1:45pm	Present preliminary time-line w/ activities, proposed dates for Dialogues, home care training dates for folks to check out. Launch, holiday party, training dates, target for pilot kick off in the spring	Jason and Rachel
1:45-2:00pm	Closing	Joyce

APPENDIX 2: ELDERCARE DIALOGUE LEADERSHIP TEAM ROLES

Members

- DWU: Beatriz and Vilma
- Damayan: Linda and Lydia
- Adhikaar: Namrata and Narbada
- NDWA: Yomara and Barbara
- BJ: Channa, Rochelle, Sylvia, and Ellen
- JFREJ: Rachel and Andrea

With support from Alexa Kasdan from UJC Community Development Project

Long-term Goals of Eldercare Dialogues

- Build deep + caring community between workers, consumers, and their families
- Identify shared values in the care relationship; Identify challenges or contradictions in the care relationship
- Think through strategies to address those challenges and lift up our values and secure quality care and quality jobs.
- 15 workers, consumers, and their families prepared and committed to developand pilot workforce development and consumer training curricula

Leadership Team Responsibilities

- Maintain bird's eye view of Eldercare Dialogues Project
- Facilitate and develop eldercare dialogue agendas (with support from members)
- Participate in meetings to explore partnerships with larger institutions (e.g. PHI, Cornell, CUNY, 1199 Funds)
- Prepare to make decision about curriculum and pilot by gathering input from members/board
- Make final decision about partner institutions, curriculum, and pilot process
- Collaborate to secure funding and resources to support all organizations' participation in dialogues and pilot

Process

- The team will meet monthly, on the final Thursday of every month from 6:30-8PM. At least one representative from each organization should be present ateach Leadership Team meeting so that decisions can be made.
- Members of the Leadership Team will take at least one the following roles in theservice of our goals:
    - Bottom-line logistics or program for Eldercare Dialogues
    - Serve as point-people for curriculum development and feedback
    - Participate in institutional fundraising efforts to support our project]

APPENDIX 3: GOALS AND SHARED VALUES FOR ELDERCARE DIALOGUES

Goals

- Build deep and caring community between 150 private-pay elderly caregivers, seniors, and their families.
- Identify shared values in the care relationship; identify contradictions or challenges; think through strategies to address challenges, lift up our values, and secure quality care and quality jobs.
- Develop 20 powerful and compelling spokespeople for local Caring Across New York organizing and communications.
- Have 30 workers, consumers, and their families prepared and committed to develop and pilot workforce development and consumer training curricula with formal institutional partners
- Explore strategies for community-based registry to serve workers, consumers, and family members who have participated in the training programs to find each other for private hire and employment.

Shared Values

Caring and Organizing Across Generations

- We value quality and affordable care; we value quality jobs and living wages; we will fight for dignity and justice for all; we must organize across generations for the dignity and support we need.

Cooperation, Coordination, and Partnership

- We value clear and open communication as well as cross-cultural understanding

Respect, Compassion, and Trust

- We're all in this together for the sake of the greater good; we value the worker, we value the senior, we value the human being

Interdependence

- All of our grievances are connected and all of our struggles are linked; we are all aging; people who receive care also give care, people who give care also need care

Information, Resources, Opportunities for Growth

- We value career ladders and opportunities for growth for workers; we value information, resources, and supports for seniors and their family members.
- We value quality training and professional supports for workers to provide quality care; we value training and resources for consumers to be ethical employers.

APPENDIX 4: SAMPLE TIMELINE FOR DIALOGUES

October 2012	Launch
December 2012	1st Eldercare Dialogue: Shared values and long-term vision for quality care and quality jobs
January 2013	2nd Eldercare Dialogue: Stories of elderly caregivers. Why workforce development? What's the relationship between workforce development, quality care, and quality jobs?
April 2013	3rd Eldercare Dialogue: Stories of seniors and family caregivers. Highlight common experience of aging and caregiving. Prepare to begin observing training programs
May 2013	4th Eldercare Dialogue: Mother's Day of Action, full rights for all immigrants. What's the relationship between care, migration, and gender?
June 2013	Olmstead Teach-in: What's the connection between aging and disability? What can our project learn from the disability community? How can caregivers and consumers be in meaningful alliance?
July 2013	5th Eldercare Dialogue: Learn about the care economy, living wages for workers, access to affordable care for consumers. How do we build trust and respect in the care relationship?
October 2013	6th Eldercare Dialogue: Explore the meaning of alliance, interdependence, and communication between care workers, seniors, and family caregivers; develop concrete ideas to help care workers and consumers be allies to one another; generate strategies for alliance to inform our training programs
December 2013	7th Eldercare Dialogue: Explore our experiences of caregiving at the end of life; discuss our ideas about dignity for seniors, caregivers, and their family members at the end of life; learn about the relationship between caregiving and dying with dignity
January-March 2014	Curriculum Development
March 2014	8th Eldercare Dialogue: Learn about the "Care Gap"; share stories related to the Care Gap from employers and workers; learn about local campaigns to close the Care Gap
June 2014	9th Eldercare Dialogue: Explore the role of employment agencies in the care system; hear stories from both employers and workers of using employment agencies; learn about alternative community-based institutions
July 2014	Pilot Workforce Development and Consumer Training
September 2014	10th Eldercare Dialogue: Share stories related to Dementia and other cognitive disabilities; Explore our shared values and vision for social justice in relation to Dementia: How can we respect the dignity and humanity of people with dementia? How can we respect the dignity of their caregivers?
December 2014	11th Eldercare Dialogue: Report and toolkit release

APPENDIX 5: SAMPLE AGENDA

Eldercare Dialogue Draft Agenda
April 18th 2013
7pm-9pm
Congregation B'nai Jeshurun Community House
270 West 89th Street

Goals:

1. Build relationships and community between seniors, caregivers, care workers, and family members

2. Highlight the common experience of aging and caregiving

3. Expand our understanding of how aging is experienced differently based on our position and power in society

4. Share the observation guide for our Eldercare Research Group and give people the opportunity to sign up to observe trainings

Emphasis will be placed on the experiences of seniors, the process of employing care workers, and the experiences of care workers who are themselves facing aging and disability

i. Schmooze and nosh (15 min.)

a. Nigun (melody)...Rochelle

I. Welcome (15 min) *Deloris, Marilyn, and Namrata*

II. Circle of Sharing (20 min) *Linda*

Instructions: These questions will all focus on your experience and understanding of aging. Form into groups of three. Try and find partners who are from different organizations. Each person will have 2 minutes to answer each question.

Questions:

- What do you believe is one thing everyone needs so they can age with dignity?
- When it comes to aging, what is your biggest concern or worry?
- Have you ever felt someone was disrespectful to you because of your age? Or conversely, have you ever disrespected someone because of their age?

Ten Minute Break

III. Fishbowl Discussion (30 min) *Catlin*

Intro: Tonight in our Fishbowl we are lucky to hear a variety of perspectives on aging and homecare from members of our different organizations

IV. Fishbowl Debrief (20 min) *Sue*

Instructions: Break out into groups of 3 or 4 and discuss the following questions. Each group can write their responses on individual post-it notes, which are placed on the wall.

Questions:

- What sticks out in your mind from the Fish Bowl Discussion?
- How could your family or community support you to have dignified aging experience?
- How would you like the government to support a dignified aging experience for everyone? What would you want the government to be doing differently?

V. Observation Guide and Closing (10 min) *Molly, Barbara, and Lydia*

a. Explain the observation guide and invite everyone to attend a training

b. Thank you and close-out (Lydia)

APPENDIX 6: SAMPLE FACILITATOR'S GUIDE

Eldercare Dialogue 5/21, 7-9pm
BJ Community House, 270 West 89th Street between Broadway and West End

Goals:

- Build relationships and community between seniors, caregivers, care workers, and family members.
- Learn about the relationship between migration, care, and gender.
- Take action together to support a fair and inclusive path to citizenship for care workers, caregivers, and all our families.

Arrive (7:00 PM)

As people arrive, they are given one postcards:

- Postcard 1 has three questions: When did your people migrate to the U.S.? Circle one: 1654-1820, 1820-1924, 1924-1945, 1945-1965, 1965-today; Where did your people come from?; and Why did your people migrate to the U.S.?

Welcome (7:15 PM) Beatriz/Ellen

Housekeeping
Review Agenda
Group Agreements: Deep listening

Popular education (7:20 PM) Catlin/Linda/Rachel

1. 7:20 Make your way to the section of the room marked with the era of your people's migration. Find a partner and share what you wrote on your postcard.

2. 7:30 Now we're going to create groups of four or five, with one representative from each group. [Direct people where to sit] Each group will have a discussion guide with three big questions and three big facts. In the next 25 minutes, try to make it through all three questions and all three facts, but don't rush. Make sure that everyone in your group has a chance to share their experience and perspective. The questions are there to help dig deep into your people's experience and the ways in which identity, conditions, and era of migration shaped their experience. The facts are meant to help frame the conversation.

Offer 5 minute reminders

- What was going on in your country when your people migrated? What was going on in the U.S. when your people migrated?
- What was the promise that brought your people here? Was that promise kept? If so, in what ways? If not, what was the unkept promise?
- Who did your people leave behind? What happened to them?
- What did your people bring with them that contributed to U.S. culture? What did your people lose by migrating to the U.S.? What was the sacrifice?
- If you migrated or were forced to migrate, share a memory of your experience. If it wasn't you but a member of your family who migrated or was forced to migrate, share a story that they shared with you.
- When your people migrated, how did being a woman affect one's experience?

3. 7:55 *Hand out 1-pager with five big take-aways*

The piece of paper you've just received has 5 big lessons related to the connections between migration, care, and gender. Read all five of them aloud. Choose 1 or 2 and discuss them as a group. What does this mean to you? What's the key lesson for our work? Whether that's in relation to the eldercare Dialogues, long-term care, immigration reform, or workforce development.

- The need for long-term care and support services is projected to grow to 27 million care consumers by 2050, with more than 70% of individuals aged 65 or older requiring some kind of long-term services and supports. The current direct care workforce numbers approximately 3 million workers, leaving a huge gap between the services that are needed and the workforce currently available to deliver those services.
- At the beginning of the 1980's, an increasing number of Filipino women domestic workers came to the US in search of livelihood or work that can support their families. Currently, over 10% of the 96 million Filipinos overseas are migrant workers. 70% of them are women and 80% of these women become domestic and care workers in about 200 countries around the globe.
- Women are the major providers of long-term care in this country, but they also have long-term care needs of their own. Women live longer than men, tend to outlive their spouses, and have less access to retirement savings such as pensions. In 2000, almost seven percent of all women were age 75 or older. A common scenario is an older woman who cares for her husband and who discovers that there are few resources—financial or otherwise—to meet her own needs for assistance.
- The term "global care chain" was first used by Arlie Hochschild to refer to "a series of personal links between people across the globe based on the paid or unpaid work of caring." The global care chain is a characteristic of an increasingly globalized world in which demand for migrant workers in developed countries as well as the supply of migrants from less developed countries continues to grow. The underlying causes of this phenomenon include:
    - The entry of masses of women into the labor force in wealthy countries, resulting in a reduced ability to care for children and elders
    - A lack of family-friendly policies and childcare facilities at places of work increases the demand for in-home care workers
    - Changes in family structure
    - The "care deficit": A shortage of public care services in wealthy countries
    - Increasing longevity and size of the elderly population in wealthy countries
    - Growing prosperity in wealthy countries
    - Lack of employment opportunities in poor countries and disruptions to traditional modes of aging and care

BREAK 10 MINS (8:10 PM)

Take Action (8:20 PM)

Now let's take action to support fairness for women, domestic workers, and all caregivers in immigration reform!

1. Explain current moment...Julia/Damayan rep

YOUR CALLS ARE MAKING A DIFFERENCE! LEAHY3 and KLOBUCHAR2 PASSED,

providing work authorization for women who are seeking protection from domestic violence while their VAWA petitions, T or U visas are pending; and adding elder abuse to the list of U visa eligible crimes.

Yesterday, the Senate Judiciary Committee started voting on amendments to Title II of the immigration reform bill. Amendments to title II will determine who gets access to and who gets left out of pathways to citizenship. This is a critical moment for us to raise our voices to demand that women, children and families are ensured fair access to citizenship and just means for family unification.

Urge members of the committee to vote YES on the following amendments, ALL of which would be positive for immigrant women.

- Leahy8 and Hirono12: Makes the roadmap to citizenship more accesible for women and families by allowing fines for RPI states to be paid in installments.
- Blumenthal11: Acknowledges wage theft as a factor in determining eligibility for RPI status renewal.
- Blumenthal1: Creates an expedited roadmap to citizenship for the approximately 630,000 undocumented children in the U.S., increasing family stability.
- Leahy 6 and 7: Allows bi-national same-sex partners of U.S. citizens and lawful permanent residents to obtain lawful permanent resident status in the same manner as heterosexual spouses of LPRs or US citizens.
- Hirono 5 though 10: Strengthens the family-sponsored immigration system, allowing more families to be together.
- Hirono14: Allows people with RPI status to petition for family members, allowing more families to be together.
- Hirono 16: Removes the 5-year waiting period for CHIP, Medicaid and SNAP for children, pregnant women, and lawfully present individuals.

Urge members of the committee to vote NO on:

- All of Senator Grassley's, Lee's, Hatch's and Sessions' amendments that increase penalties, fees and income requirements for RPI application and renewal, blocking many families from the roadmap to citizenship.
- Grassley14: Removes the section of the Senate bill that would provide an exemption to the work requirements for RPI renewal for circumstances beyond an applicant's control, further reducing the number of people who would qualify.
- Sessions24 and Grassley11: Blocks the return of deported parents of U.S. citizen children and Dreamers.
- Grassley21: Prevents immigration judges from exercising discretion to prevent deportations that would separate families.
- Cornyn3: Expands the list of those excluded from RPI status. People convicted of single misdemeanor offenses, regardless of how long ago they occurred, would be excluded, and no discretion would be available, even in sympathetic or hardship cases.

2. Visit action stations to craft and deliver our message. Each "station mistress" will explain the station (25 mins at your own pace -- perhaps you visit four stations)

- Learn to tweet: Rory
- Placard and photo: Andrea and Barbara

- Phone calls: Rachel
- Button Station: Julia and Namrata
- Song: Jenny and Christine
- Caregiver Cards (for Judiciary Committee?) (for Mother's Day?): Molly

3. Share from stations (8:55 PM)

4. Closing (9 PM) Marilyn/Mel

APPENDIX 7: SAMPLE GROUP AGREEMENTS

1. Speak one at a time
2. Take an equal share of the talking time – Move in, Move Out (Step up, Step back)
3. Help others to participate
4. Listen and attempt to understand the perspective of others
5. Speak from the "I" stance, rooted in personal experience
6. Share and speak only about what is comfortable for you
7. Create safe space: Respect other people's stories – they are not for gossip
8. Don't label, judge, criticize, or question other participants' motives
9. Assume good will from other participants and facilitators
10. Trust the process
11. Have fun!

APPENDIX 8: SAMPLE FISHBOWL SCRIPT

Facilitator: In this fishbowl discussion we're going to explore our experiences of caregiving at the end of life. We're also going to discuss our ideas about dignity for seniors, caregivers, and their family members at the end of life. Together, we're going to begin to learn about the relationship between caregiving and dying with dignity. We're going to do this by reflecting on a few quotes and texts. We're also going to hear some stories and make space for listeners to share with each other one on one.

[This is the recommended flow; create space for fishbowl participants to interject and respond to each other, and be mindful that everyone is getting a chance to partake.]

To Roly:

Rabbi Huna taught that one who visits the sick lessens one-sixtieth of the pain. But other scholars challenged him, saying, "If that is true, then why not send sixty people to visit a patient?" Huna replied: "Sixty people? You have misunderstood me. It is not the number of people that lessens the pain - it is the visit itself!" Nedarim 39b

What might it look like for someone caring for another to lessen one-sixtieth of their pain? Have you ever seen or felt a transfer of pain between a person approaching death and a person caring for them?

To Nimfa:

What is it about another's presence that allows for some amount of healing? What kind of healing might this be?

Follow up: What kind of support might both parties need in this relationship and process?

- Experience of caring of an elder back in the Philippines, the importance of presence and touch. How this experience made Nimfa want to be a caregiver.

To Sandy:

Peace, my heart, let the time for the parting be sweet.
Let it not be a death but completeness.
Let love melt into memory and pain into songs.
Let the flight through the sky end in the folding of the wings over the nest.
Let the last touch of your hands be gentle like the flower of the night.
Stand still, O Beautiful End, for a moment, and say your last words in silence.
I bow to you and hold up my lamp to light you on your way.

-Rabindranath Tagore

What do you think "completeness" means? What would completeness for someone, for you, look like, in the context of death and dying?

- The role of care workers in ensuring your mother's dignity and happiness towards the end of life; the importance of your being close to her, and of getting closer to her in that period of her life
- The challenges of having a direct, honest, and intentional conversation about end of life with our loved ones
- Your regret at not being able to stay in touch with the care worker who'd be with your mother at home

To Deloris:

Have you ever felt someone's death was not a "completeness?" What did this look and feel like?

- The loss of loved ones back in Jamaica, the lack of closure and connection when you've been unable to go home and be with them at the end of life, or to mourn them.

8 minutes: Pair and Share

Turn to a person near you--someone you don't know well--and share what's coming up for you.

In this context, what does completeness mean to you? How is death thought about in your culture?

20 minutes: Fishbowl

To Pema:

Pema, tell us about your experience caring for someone at the end of life, and feeling grief not as a family member but as a care worker.

- Story about not being able to stay in touch with a gentleman she'd cared for, the grief and pain that this caused to both her and the consumer.

The Bustle in a House
The Morning after Death
Is solemnest of industries
Enacted upon earth-

The Sweeping up the Heart
And putting Love away
We shall not want to use again
Until Eternity.

--- Emily Dickinson

To Pema and Nimfa:

Emily Dickinson writes about the kinds of work that must be done following a death. There is the work of healing and grieving but there is practical work as well. Tell us about your experience with this. As a caregiver whose job ends with the death of a person, what is it like to have the work of grieving on top of all the other kinds of work?

To Freeman:

"I say to people who care for people who are dying, if you really love that person and want to help them, be with them when their end comes close. Sit with them – you don't even have to talk. You don't have to do anything but really be there with them."– Elisabeth Kubler-Ross

Tell us about your experience. Why is just "being there" with someone helpful and healing? What enabled you to be there? When was a time that you felt your mere presence was appreciated?

- The importance of the direct, intentional, and honest conversation you had with your wife.
- The important role of caregivers, hospice workers, and other professionals in helping you, your wife, and your family through the process.
- The role that a care worker played in recognizing that your wife was about to pass, and in ensuring that you could be by her side during her final moments.

APPENDIX 9: SAMPLE PAIR AND SHARE HANDOUT

Hi,

The goal of this activity is to get to know each other better. Some of us have met before and there are people here who know each other pretty well. What we'd like today is for you to get to know some others that you don't yet know well, by pairing up and sharing answers to four questions. We are passing out the questions so that you have them.

Each person will have 3 minutes to answer the question, and after 6 minutes I will call time and you will find a new partner.

I'd like to encourage you to be open and honest with your answers, at the same time, set your own boundaries, only share what you feel comfortable sharing. I'd like to

encourage the listeners to engage in active listening which means you'll not interrupt or ask questions, but just listen to the other person.

Please find a partner from a group other than your own.

<Wait for people to find partners>

The first question is . . .

<Wait 3 minutes>

If you haven't already, please change speakers

<3 minutes>

Please wrap up this conversation and find a new partner. The second question is . . .

1. How are elders regarded and treated in your community?
2. Share an experience you have had of caring for someone else.
3. Share an experience of being cared for.
4. What do you think makes a good job.

APPENDIX 10: ONE-ON-ONE GUIDE

Talking to Domestic Employers: Tips for doing outreach & having 1:1 conversations

What do you want to learn from employers about their personal experience?

- Why they chose to be an employer? Were they conscious about their decision to be an employer?
- How they feel about being an employer?
- Where do they see parallels between the DW job and their own? between liberation for DW and their own liberation?

Guidelines for how to approach employers / knowing what they might be thinking and how to understand their mindsets before you talk to them:

- **Basics:**
  - We should aim to support an employer to talk about what they're struggling with and what restricts them from being the kind of employer they want to be.
  - We should remember that employers often have no info and don't know it exists.
  - We should try to really understand what makes people not want to be bad employers. We're trying to move people **from guilt and frustration to confidence and action.**

- **Talk about their perspectives:**
  - Lack of information and isolation, ask: have you found this process difficult? Do you have support? Has it been hard to let someone else take care of your child?
  - Confusion about communication, ask: do you find it difficult to talk with your worker? do you have guidelines for communication with somebody you've hired?

- Ambivalence, ask: has it been hard to make the decision to go back to work?
- Connection, ask: how do they value the work of the person they employ? What support do they wish the worker had that they may or may not see as in their control (ie. job training, healthcare, etc.)?
- ***Important points:***
  - Employers must experience working with this project as a discussion that is in support of them as well as their workers and that all these things will make their jobs and lives easier and that their worker will be a better hire and a better worker and better able to take care of their loved ones: that it is a campaign to improve their experience as well.
  - Sometimes employers get defensive or overwhelmed by feelings that they have to do everything at once. Focusing on their experiences and showing them small steps they can take is important.
  - We have all had some experience with privilege and oppression. By sharing your own experiences, you can model both showing vulnerability in the challenges you've faced and the reasons you chose to take action. (Maybe you aren't an employer of a domestic worker, but you have had some experience where you had access to institutional power & someone else didn't. If you share how that was challenging for you and what made you move through it and take action as an ally to someone who was marginalized or oppressed in that situation, it will create space for the employer to tell her story.)

Moving the conversation: Some points to bring into the conversation and to start to move employers from anxiety/guilt to confidence/action. Urge employers to:

- See themselves as employers of professional workers;
- Formalize the relationship is to respect the work (and this will alleviate stress on both sides), particularly around setting up clear expectations and a format for regular communication;
- See the power they have as employers and how it plays out inter-personally and systemically; understand their power and privilege and how they can shift power from "power over" to "power with", through working for DW justice;
- Connect their own experiences with oppression to oppression of DWs as a way to build a sense of collective power; for example, is the burden of care-work in their family on their shoulders as the woman of the household? Are these employers in professional care-fields as well that are under-valued? How is that "women's work" under-valued and how is that connected to DW's work being under-valued?
- See their liberation as bound up in DW liberation - as Jews, Queers, feminists, elders, people with disabilities, etc.

One last tip*: Don't get bogged down in questions you don't know the answer to. Let employers know that this is all VERY new and that their questions are good ones, and it's up to all of us in the campaign to figure the answers out- that's why we're here!*

Hand in Hand: the Domestic Employers Network & Jews for Racial & Economic Justice (JFREJ)

September 2013

APPENDIX 11: ALTERNATIVE STRUCTURES FOR SMALLER SCALE DIALOGUES

It is not necessary to hold upwards of ten Eldercare Dialogues in a single community in order to bring about a real shift in consciousness. We believe that it is possible to lead a downsized version of the program and still achieve many of the same key outcomes in terms of base-building and leadership development. Here are some sample ways to imagine your Eldercare Dialogue series:

Three Sessions

Session One: Shared values and vision
Session Two: Story-telling
Session Three: What's next?: Preparing to take action

Six Sessions

Session One: Shared values and vision
Session Two: Story-telling
Session Three: Migration, Care, and Gender
Session Four: End of Life
Session Five: Alliance and Interdependence
Session Six: Celebration: What's next?

APPENDIX 12: TIPS AND BEST PRACTICES FOR ACCESS

GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

Introduction:

This guide is intended to support organizers to plan events that allow all people, including disabled people*, to participate fully and be in leadership of our organizations, movements and campaigns. It takes intention and work to make events accessible to everyone-- whether it be interpretation into different languages to allow non-English speakers to participate; scholarships to make events affordable for working class and low-income people; or childcare to allow parents and caregivers to be present.

Though this guide will integrate other aspects of access, it will particularly focus on how to make public events accessible in relation to disability. Disability is a spectrum that includes people with physical, sensory, auditory, immune, chemical, developmental, intellectual, and psychiatric disabilities. This means you may not always be able to tell if someone has a disability just by looking or interacting with them since many disabilities, such as Diabetes and Epilepsy, are invisible.

It is important to always ask if someone needs support or an accommodation instead of assuming you know what their needs are. Disabled people are in the best position to say what their needs are and should be consulted whenever possible when making arrangements for accommodations.

Disabled people have been marginalized from many communities for much of history. Given Hand and Hand's work, it is politically imperative that we challenge our internalized ableism and transform our practices to reflect justice for all people and ensure appropriate accommodations and access for all community members. We must fully include all people and benefit from their wisdom, perspectives, experience, and leadership. Simply put, our events, organizations and movements must reflect our belief that disabled people have the same right to respect, dignity, and agency as our non-disabled peers.

Engaging and including disability communities and immigrant communities is critical in fulfilling the mission of Hand in Hand and the goals of the coalitions and campaigns we work with. Disabled people are members of our multiple communities and should be encouraged to participate in our events and become leaders in organizations and movements. If programs do not reflect the value of a community by not being accessible to those community members, it is unlikely they will return to another event and become involved. For information about the common goals of the disability community and domestic workers, please see Hand in Hand's article, Organizing within Disability Communities.

Disability communities, and Hand in Hand members, use different language to talk about ourselves and our communities. Some of us prefer "people with disabilities," known as people first language and is common in the disability rights movement, though there are diverse preferences. This highlights the person, for whom disability is one characteristic. Others of us prefer "disabled people," which marks disability as a primary part of identity, and the basis for forming community.

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

Things to Consider Before the Event:

- Form an Access Committee along with a contact person to specifically address access needs such as coordinating language interpreters or childcare. This is helpful especially for finding out beforehand if the building where an event is held meets the accessibility standards determined by your organizers.
- The event is free or has a sliding scale payment system that doesn't require "proof" or public disclosure of class status and should also be decided by the person paying, not the event organizers.
- Childcare.
- Interpreters for non-English speakers.
- Consider hiring attendants to support people with bathroom breaks and otherwise. Coordinate directly with the people who need this support about identifying and paying the attendants.

Invitations/ Notifying About the Event

Addressing accessibility on your invitation is a crucial step in including disabled people in your outreach efforts. Often, disabled people encounter physical and attitudinal barriers that make it difficult to participate. By having information about access on your invitation, it shows that disabled people are fully welcome and that there is a plan to ensure everyone can participate fully.

- The invitation should use:
    - Arial or other plain, sans serif fonts
    - At least 14 point
    - Black ink on white non-glossy paper
- Clear and concise alternate text in your online images (http://webaim.org/techniques/alttext/)
- Accessible color contrast (http://www.un.org/webaccessibility/1_visual/13_colourcontrast.shtml)
- Thoughtful representation in poster images. Are bodies used? How? Which bodies? Why?
- Accessibility information should be easy to find and highlighted. Include an access request form similar to:

"to request disability accommodations, please contact _name_____ at least 3-7 days in advance at __ phone # __,__e-mail address __"

- Include information such as:
    - Wheelchair accessible
    - Disability parking available
    - ASL interpreters provided
    - "Out of consideration for people who are chemically sensitive, please refrain from wearing perfumes and other scented products,"
    - The closest accessible public transit stop
    - If participants will need to show ID to enter the event space since this is a barrier for some to coming
    - Any other relevant accessibility information about the event
- Provide the option of Skyping into the event for those who cannot join in person

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

Finding an Accessible Space

Holding your event in an accessible space is one of the most basic and important steps to including all attendees in your event. Physical barriers like stairs and chemical barriers like scented cleaners and perfumes prevent many disabled people from joining your event. Simply put, if someone cannot enter the building or a meeting room, they cannot participate.

- The only way to guarantee that the meeting space is fully accessible is to verify in person that it has the following:
    - Has a wheelchair accessible entrance
    - Has meeting rooms that are all wheelchair accessible
    - Has gender-neutral and wheelchair accessible bathrooms (don't assume because the building is accessible there are accessible bathrooms)
    - Has a quiet room or quiet area for participants to use if they need a break or become overwhelmed by people and stimulation
    - Isn't visually overwhelming and/or cluttered (can be distracting or overwhelming)
    - Is close to public transportation and has nearby accessible parking
    - Is available for an accessible time of day (not too early in the morning or too late at night, accounting for various routines and transit requirements
    - Has ramps leading to all areas including stages, and has an adjustable lectern if applicable
    - Has a well-lit space provided for language interpreters
    - Has Skyping capabilities
    - Has non fluorescent light options
    - Has the option of heat and/or turning off heat
    - Can have audio channels available for audio description
    - Has a space for childcare if it is being made available on site, including safe diaper changing stations
- When making arrangements for indoor events, discuss with the event space staff beforehand what chemicals they use to clean bathrooms and rooms and request they use scent-free products the week before the event if at all possible. When this is not possible, provide Skype or video-access for those who are unable to attend.

Transportation to Event

Accessible transportation can be a barrier for many disabled people, especially if they live in suburban or rural areas where public transit is limited. Think about locations that are easy and convenient for people to reach via public transit or how you can arrange for other ways to attend like carpooling or booking an accessible taxi in advance.

- Event should be within close walking distance from accessible public transit routes, with an easy-to-traverse accessible sidewalk
- Supply accessible transportation if it's not on a public transit route, including accessible taxis when needed
- Develop a way for event-goers to organize carpooling arrangements

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

Preparing for the Event & Setting up the Space

Preparing in advance to make your event accessible is extremely important since access needs must be planned ahead of time (interpreters, etc.). When setting up the event, it is helpful to have multiple volunteers to ensure all access requests are in place for when your participants arrive.

- Plan the event so that it ends on time, especially events that are at night so participants can make arrangements for getting home accordingly
- Account for break times for long events to allow time for self-care
- Have agenda with session times available to participants ahead of time so people can plan for bathroom breaks or other physical and emotional needs
- When a room does not have fixed seats, remove chairs so that wheelchair locations are integrated with other seating areas
- Identify wheelchair accessible seating if there are fixed seats
- Clear aisles for participants to navigate the space comfortably
- Set up Skype for those who cannot join in person
- For indoor events, be mindful of environmental noises like fans, air conditioners, open windows and doors, music, glaring lights etc. that can make it difficult for people with sensory disabilities to fully participate
- Have relevant language interpreters booked (American Sign Language, Spanish, etc)
- Arrange for CART captioning (Communication Access Real-Time Translation is a system that converts speech to text http://ccacaptioning.org/faqs-cart/)
- Notify the speaker and/or performers of their role in making the event accessible as soon as they are confirmed participants, such as captioning videos, providing audio descriptions, etc. (see section on materials for specifics)
- Have audio descriptions for visual parts of the program (a recording that describes the images used in a presentation/ performance) so those who are blind/ low vision can fully participate
- Integrate descriptions of photos and visuals into the event so all can participate
- Purchase scent free soaps and other personal care products relevant to the event
- Organizers can model and reinforce to participants that the event is "scent-free" by using scent-free products the week before the event. This may not always be possible, but the most important thing is to explore every avenue to make the event accessible by communicating directly with people about their needs
- Make sure to have scent-free markers for folks to write nametag
- Check that sound equipment is high quality, clear, and at the right volume
- Order nametags with a space to list preferred pronouns for event goers, so that everyone can define for themselves what pronoun feels most comfortable and appropriate for them.

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

Food & Catering

Ensuring that attendees have appropriate food and beverages is necessary for including all participants in your event. Food allergies and conditions such as celiac disease and diabetes can be life-threatening if the right food is not offered or is labeled inaccurately.

- Provide an opportunity for participants to indicate their dietary needs on any registration form or invitation to an event where meals are being served
- Where beverages are being served, bendable straws and lightweight cups should be made available within easy reach of individuals in wheelchairs or scooters
- If catering staff is not present, ensure that someone is assigned to assist those who need help getting food
- Check to make sure that an alternative to pastries and cookies, such as fruits, vegetables and gluten-free choices, are available for people with dietary concerns
- Make sure food is labeled accurately with ingredients.
- Have extra tables available for those who can't eat on their lap
- Place food and utensils near the edge of the table if buffet style

Presentations/ Participation/ Materials/ Hand-outs/ Videos

Having accessible presentations, handouts, and activities ensures all attendees can actively participate in the event. Presentations are what the participants came for, so it is crucial that everyone is able to engage as much as possible.

- Before introducing the speaker or starting the program announce all the relevant accessibility information of the space
- Have accessible materials. The Canadian National Institute for the Blind provides the following guidelines:
    - Incorporate invitation font guidelines
        - 14 point Arial font
        - Black ink on white or pale paper
    - Integrate techniques to accommodate different learning styles
    - Ask presenters to verbally describe contents of videos, or any written materials, including PowerPoint slides and whiteboard notes
    - During video and slide presentations and live performances, offer to have someone sit beside an individual with visual impairment to describe the scene, people and action as it happens without interfering with already existing narrative
- Ask everyone to say their name before speaking
- Speak slowly, clearly, and loudly
- Have written image descriptions in PowerPoints and other presentations
- Use films and video clips with captioning or an available transcript
- Do not shame and/or comment on participants coming in late or leaving early during the event, since physical routines, attendant schedules, transportation, and various disabilities can have an impact on being present
- Let participants at the event know if you are going to discuss potentially triggering topics. Sensitive topics can can cause some participants to become uncomfortable, so give participants a moment to leave. Make sure to provide a time estimate of how long the conversation is going to last so they know when it will be okay for them to come back in.
- Don't put participants on the spot to share; this can potentially induce anxiety if people do not feel comfortable speaking up
- If there are any action strategies being discussed make sure to include strategies that are inclusive for all participants

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

Access Staff

- Since we want to ensure everyone's participation, it is important to have 1-3 people at the event who act as support staff to ensure accessibility and to resolve unexpected issues. The support we provide at events must reflect our organization's culture and values.
- Access staff should pay special attention to the "Tips for Event Participants" section below
- All access staff will have demonstrated disability awareness and an ability to problem solve in a fast paced environment
- Access staff should ask if anyone has a reaction to flash photos before any are allowed. If someone does, access staff should not take any nor allow others to.

Tips for Event Participants

- Always address people directly, regardless if they use a communication device, if they are accompanied by an interpreter or personal attendant
- Don't make assumptions about someone's access needs
- Ask people if they need assistance
- Ask permission before moving toward touching anyone
- Don't disclose someone's disability status unless you have their explicit permission
- Be conscious of language and receptive to call-outs about using ableist and other oppressive language
- Do not wear fragrances or essential oils for the week before and on the day of the event
- Dog guides are service dogs so it is important that they stay focused. Do not pet the dog

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GUIDE TO PLANNING ACCESSIBLE PUBLIC EVENTS

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CARACOL Interpreters Cooperative

Creating multilingual organizing spaces through interpretation
Compiled by the Caracol Interpreters Cooperative

Language justice is about strengthening the leadership of our membership through promoting the centrality of all the languages we speak and the wisdom and knowledge that is communicated therein. Interpreters facilitate communication between members of our community and they are a key element in creating multilingual environments within social justice movements that (a) promote an understanding of language as a tool for mobilizing across communities, (b) enable the full participation of everyone across languages, cultures, and traditions and (c) challenge and transform dominant structures of language, power, and communication in the U.S. To be able to create truly multilingual spaces within our movements, interpreting must be understood as more than a service. It must be seen as an essential tool for organizing.

Interpretation/Translation 101

Translation: The act of transmitting a written message from one language into another.
Interpretation: The act of transmitting a spoken message from one language into another.
Consecutive interpretation: A message is spoken in one language, there is a pause, the message is then transmitted into another language. Does not require equipment.
Simultaneous interpretation: A message is spoken in one language and is transmitted at the same time into another language. This generally (and optimally) requires equipment.
Sight Translation: A written message is read and interpreted in real time.
Monolingual speakers: People who speak one of the languages being used in the meeting. This helps us to reframe the way we refer to language speakers that connotes a deficiency, i.e. "They do not speak English"

How can we prepare for and adequately facilitate multilingual space?

Whether there is one speaker of a language or many, if there are speakers of different languages participating in a movement, there is a need for interpretation and translation.

2 weeks before the event

Prepare a detailed agenda for the interpreter. The interpreter's agenda should have a breakdown of all topics that will be covered, who the speakers/facilitators will be, what language they will use and whether interpretation will be consecutive or simultaneous. Take break out groups into consideration, because if the smaller groups are multilingual then there will be a need for more interpreters.

Supporting materials. Provide interpreters with all presentation materials, written notes or pre-prepared documents that may be used during the meeting. This includes but is not limited to: notes for speeches, agendas, abstracts, handouts, PowerPoint presentations, videos etc. Ideally, the interpreter should have access to these at least a week before. All materials and visual aids that will be presented need to be printed for the interpreter.

Terminology. Every organization, movement and community uses a different set of language and vocabulary related to the work they do. If you are working towards a sustainable effort for multilingual access, developing an organizational glossary in all the languages you work in is a good idea. Sending this glossary or at least briefing the interpreters around the subject matter and material beforehand will ensure that speakers of all languages will have a proper and consistent understanding of the concepts/language the organization uses.

Fees and Payment. Establishing fees and payment plans prior to the event is essential. While interpreting costs can be a substantial expense for a small organization, the success of multilingual gatherings will in many ways depend on the quality of the interpretation. Keep in mind that interpreters have invested in developing their skills in order to provide high quality service to ensure the integrity of your work.

Days before the event

Review your presentation prior to event to ensure that the material is accessible to a culturally diverse audience. If you use jokes, puns, or specific cultural references, be aware that such messages may be difficult to interpret for speakers of other languages. You may choose to exclude such references to ensure all participants can fully engage in the conversation.

Prepare the equipment. Designate an "equipment techie" to monitor equipment used by the participants, facilitators, and interpreters. This person will hand out and collect equipment, and address any equipment issues during the event. Oftentimes if participants have non-functioning equipment they will come to the interpreter for help. The interpreter will be unable to assist while they are interpreting. Remember to replace equipment batteries before the event.

During the event

Event coordinators/facilitators/presenters should:

- **Conduct an in-room sound check before the event.** "Techies" should test the equipment to see if new batteries are needed, or to determine if the room has spots where the transmission of the interpreting equipment does not work.
- Give the interpreters a sense of **how many speakers** of each language are in the space when the event is about to begin.
- **Create a space** at the beginning of the meeting of about 5 minutes for the interpreter to test equipment with the audience and orient them to the dynamics of interpretation. They will explain why we use interpretation, how the equipment works, who to talk to if there are technical difficulties, things to keep in mind such as pace and volume, and the hand signals they will use to remind people of these things during the event.
- **Speak clearly and enunciate.** Pace yourself when you speak. Be conscious that when we are reading out loud, pace naturally tends to speed up. Be sure to include frequent pauses. When you ask questions to the audience, allow for those who are listening through interpretation the opportunity to hear the full question and respond before you continue.
- **Make sure to say the names of organizations, coalitions, and campaigns clearly and slowly, and to avoid using acronyms when possible.**
- **Find ways to engage all participants.** Event planners can work to ensure that there will be presenters and facilitators using both languages. The facilitator should keep note if one language is starting to dominate the space. If speakers of one language are not being heard, sometimes the facilitator can shift the dynamic by directly asking participants of said language to contribute to the dialogue (without necessarily calling them out based on the language they speak). Facilitators can also pause and do periodic check-ins to make sure everyone is following the material being discussed.
- Make sure that the interpreters have **access to water, snacks, time for lunch and restrooms. For overnight stays they should optimally have access to a single quiet room.**

Interpreters:

- Caracol always stresses the importance of working in pairs. Interpreters should alternate every 20-30 minutes to ensure accuracy in the interpretation for participants and to uphold fair labor standards. Studies show that even the most seasoned interpreters' accuracy is diminished after 20-30 minutes.
- Interpreters do not actively participate in the meeting. Reminding participants to not interrupt the interpreter while the meeting is going on, and sometimes designating a particular "area" for the interpreter to work in can be helpful. Facilitators must also keep this in mind so as not to assign interpreters other roles.
- Honor the message of the participants by rendering everything in the same voice as the speaker, in first person, and must interpret absolutely everything that the speaker says and maintain tone.

APPENDIX 13: SAMPLE POLITICAL EDUCATION MATERIAL

I. Understanding Our Identities and Power (July 2014)
II. Understanding the Care Economy (July 2013)

Understanding our identities: who are we? (Mel) 20 minutes

Who Am I and Where I Am Going? [Past/Future]:

The purpose of this activity is to begin talking about who you are, where you have been in your past, and where you would like to go in the future. As a group of people who are new to being with each other this is an opportunity to begin getting to know one another. Remember to share only what you are comfortable sharing...

- On individual pieces of paper each of you will draw a picture of yourself in any fashion they are comfortable with [stick figure, cartoon like, gingerbread person…]
- Make sure that your picture is divided down the middle, the Left side represents the "past" and the Right side represents the "future"
- Make sure to include the each of the following body parts, one as the past, one as the future:
    - Ears [things you have heard in the past, things you would like to hear in the future]
    - Eyes [things you have seen in the past, things you want to see in the future]
    - Hands [things you have made, or done in the past, things you want to make in the future]
    - Feet [where you have been in the past, where you want to go in the future]
    - Please also include just one of the following organs:
        - Heart [things you love]
        - Liver [things that make you sick]

When you are done drawing we will take a moment in small groups of 3-5 people for you to share what you wrote and drew. After that we will hang these up on the walls around our space.

Understanding Power: Where Do We Come From and What Shapes Us? (Lezlie) 25 minutes

a. Framing the exercise: we build on our awareness of multiple identities by layering on an understanding of how those identities are steeped in history and power, or in external systems

b. Read each question slowly, giving folks an opportunity to both observe where they are in space and in relation to each other and to observe the shape of the group.

c. Instructions: :

In this exercise, we're going to begin by learning a little bit about who's in the room, where we come from, where our ancestors come from, what we carry, and what we face. I will read a statement, and if the statement describes you or your experience, move into the circle, raise your hand, or indicate "YES" in some other way. If you don't feel comfortable moving into the circle or sharing your experience, you're welcome to keep things to yourself. Pay close attention to what's happening.

d. Statements:

- I am an immigrant or a migrant

- My parents or my grandparents were or are immigrants to this country
- Historically or in the present people have faced violence for belonging to my religious or cultural group
- I or my ancestors migrated to this country by choice
- My ancestors migrated to the United States or the Western Hemisphere against their will, through forced migration
- I have the ability to travel freely to the place where I grew up
- I am a parent or grandparent
- I have had to leave my country of origin in order to find work
- I am a union member
- I worry about how I'll pay for care for myself or a loved one
- I feel like people in my racial group are represented enough in government
- I usually feel comfortable asking the Police or other authorities for help in case of an emergency
- People of my racial group face violence on a daily basis based of their race
- I can walk home late at night wearing whatever I want to without fear of harassment
- People in the world who share my gender or sexuality have been murdered because of it
- I can, if I wish, arrange to attend social events without worrying if they are accessible to me
- Sometimes people see me as closed-minded or set in my ways because of my age
- When speaking with medical professionals, I can expect them to understand how my body works, to answer my questions, and respect my decisions
- My neighborhood allows me to move about on sidewalks, into stores, and into friends' homes without difficulty
- When speaking to me, people often assume I'm hard of hearing and raise their voices
- I'm often seen as physically weak or feeble
- I have worked as a paid caregiver or a personal assistant to an elder
- I have worked as a paid caregiver or nanny for a child
- I am a domestic worker
- I or my family currently employ a domestic worker--a nanny, housecleaner, personal assistant or elder caregiver
- I do most of the cleaning in my house
- I identify as a feminist
- I feel connected to the people around me right now
- I would like to feel more powerful to make change in my own life and in the world

e. Closing frame: learning who we are, not simply in terms of our individual histories and experiences, it also in relationship to one another, helps us to understand what shapes our care/work relationships. This opening session is designed to help us unpack how our identities play a role in those relationships, and how power plays out between us, both consciously and unconsciously.

Understanding the Care Economy

Rachel:

In this next section, we're going to talk about the care economy, the system that determines wages for care workers and access to care for consumers. We're going to ground our conversation in the stories of two imaginary people who could easily be part of our organizations and communities.

Let's meet Linda and Angela

Linda is 80 years old and lives in the Columbus Park Towers on the Upper West Side. She worked for 35 years as a nurse and retired at 68 with a pension and some savings for her retirement. When Linda was 79, she was diagnosed with Parkinson's Disease.

Yomara:

Angela is 42 years old and lives in Flatbush. She immigrated to the U.S. from Trinidad 20 years ago and although she was also a nurse in her home country, she has worked as a domestic worker during her time in the U.S. Over the years, she has worked as a nanny, housecleaner, and increasingly as a private pay elderly caregiver.

Both Linda and Angela are caught up in something called: The Care Gap. We'll return to their stories in a little bit. Let's learn about the care gap.

Maya

1. What is the care gap? What are the causes of the care gap?

REVEAL: **The Care Gap: The gap between how much care is needed and the labor available to do that care.**

What are the causes of the care gap? Answers: "Age wave," entrance of middle class women into the workplace, dual-earner families

So these three trends - the rise of the dual-earner family, the entrance of middle class white women into the workplace and the age wave have all contributed to the growth of the care gap.

2. What else do we see going on? What trends do we see in wages for workers and the affordability of care for consumers? What do you think are the causes of these trends?

3. Is this situation working for us? Does it work for our society as a whole?

Yomara:

What challenges does this present for people like us who VALUE BOTH affordability of care and living wages for workers? Turn to your neighbor. What's the tension (real or imagined) between affordability of care and living wages for workers. Take a moment to share what's on your mind.

It's everyday people like all of us who are caught up in the care gap, and it can be very hard to make sense of the larger systems at play. Let's return to Angela and Linda.

Angela began to experience the care gap when she found that more and more of the families that hired her to provide childcare were beginning to ask her to do eldercare work as well. She was happy to help out; she enjoyed caring for elders. But she definitely had not had access to any formal job training to provide this specialized kind of care.

Rachel:

After Linda's diagnosis, she realized she'd need long-term services and supports. But her two adult children couldn't provide the care she needed because they lived in California. Her partner was in good health

but didn't feel that she could provide the care that Linda would need for the long-term. Linda knew she'd need to figure something else out.

ASK: What might she do? How does the care gap get filled? What does Linda do when she can't get the care she needs from her family?

- She pays for it. She hires people to do it. [Yes, Linda could use the market to fill her care gaps. But it isn't inevitable that these care gaps would be solved by the market.]
- She turns to her community
- Government programs [Yes, the government could develop social programs to address the care gap: child care centers, food programs, and elderly care programs. That's how some of these issues are addressed in other nations, like Sweden, where they have a very inexpensive and high-quality government-run child care program.]

Yomara:

As conversation unfolds…

REVEAL: **Care as a commodity: A commodity is produced for sale and sold to make a profit**

REVEAL: **Care as a public good: Definition**

REVEAL: **Care as a private responsibility: Definition**

Let's review: these are the three primary approaches to care that we currently see in our society and in our care economy.

Rachel:

Not simply a dichotomy

If you had to guess, which of these approaches is dominant in the U.S.? Right: government programs haven't really been the solution to the care gap here. For the most part, the care gap in the U.S. has been filled through the market and treated as a private responsibility that often falls on women (both family caregivers and paid caregivers).

So instead of care being a human right and the care gap being seen as a social crisis that should be addressed by the government, care is often treated as a commodity that should be produced and sold for a profit.

Yomara:

Let's talk about how this actually looks for Linda and Angela

When care is approached primarily through the market and thought of as a private responsibility, what happens? When a corporation markets its products and increases profits, what does it do?

ASK: How do corporations profit in this scenario? How do they respond to the care gap? What happens to Linda and Angela? What problems does this generate?

Sample answers:

• They make workers work more (longer hours). • They increase the workload (work faster, more patients). • They lower wages. • They cut benefits. • They raise fees for people who are paying for care. • They try to eliminate cheaper alternatives. • They devalue care work, specifically they devalue this work that has traditionally been done by women and people of color. Draw out: private solutions to social crisis, cuts to social services, neoliberalism

Maya:

REVEAL: Maya's slide on long-term care corporation profits

What do we see happening here?

Juxtapose with wages for workers and affordability of care for consumers.

Rachel:

Let's talk about this public good option. What does it look like when our society treats care as a public good? How would it look for Linda and Angela?

How does the government respond to the care gap? What are the benefits? What potential problems does this generate?

What do individuals and families do to respond to the care gap? What problems does this generate?

Maya:

In this context, what are the long-term consequences of these problems for workers and seniors (lack of a stable workforce, vulnerability, poor quality of life for seniors and workers)

Rachel:

Question: How can we view care and approach the care gap to find solutions that are consistent with our values?

APPENDIX 14: FAIR CARE PLEDGE

I WANT TO BE A

FAIR EMPLOYER

I affirm the value of all care work in our community and believe fair employment practices help create mutually beneficial relationships between employers and domestic workers—nannies/childcare providers, housecleaners, and home attendants for seniors or people with disabilities.

I am committed to making my home a workplace that I am proud of. I pledge to be respectful, clear, and fair as an employer.

NAME

EMAIL

ZIP DATE

☐ You can list my name publicly as a signer of this pledge

Being Fair Begins Right Here!

☐ **Fair Pay**

By paying a fair wage (plus overtime) I am ensuring that my employee has what she needs to sustain herself and her family. This contributes to a positive, long-lasting relationship and healthy home.

☐ **Clear Expectations**

Open and respectful communication will be the foundation for the relationship between the two of us, providing clarity on both sides for daily tasks.

☐ **Paid Time Off**

Paid time off – including medical and sick leave – will ensure that my employee is rested and healthy and ready to do her job well.

For more, check out **www.domesticemployers.org/fair-care**

The Fair Care Pledge is a project of Hand in Hand: The Domestic Employers Network and The National Domestic Workers Alliance

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THE ELDERCARE DIALOGUES

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A REPORT BY: