

# Accelerating Change

How Change AGENTS acquired tools to become effective advocates for practice and policy change



In Detroit, in 2014, a 95-year-old woman was displaced from her federally-subsidized apartment complex after living in her community for more than 30 years. The disruption to her social world was traumatic. More than 2,000 older adults in Detroit may be displaced from their housing as it is converted to market rate privately-owned apartments over the next decade.

The mural created by Change AGENTS during the 2014 Change AGENTS Conference in Philadelphia

In Los Angeles' Skid Row neighborhood, older women experiencing homelessness are disproportionately likely to use emergency health

care services, despite eligibility for Medicaid. Emergency Department care is fragmented, uncoordinated, and costly—and notoriously poor at delivering quality care for chronic disease. The stress of daily life without a home, as well as health problems, leads homeless older adults to a life expectancy only in the low 60s (Culhane, 2010). In Salt Lake City, overburdened caretakers of older family members or friends pushed through their exhaustion alone, even though the state of Utah had relief programs in place. Many caretakers did not identify as such—they were only doing what was needed for their family or loved one. The Utah Caregiver Support Program was able to provide a respite stipend to only 400 caregivers last fiscal year, out of 336,000 caregivers in Utah—less than .001 percent—due to resource constraints.

These three cases illustrate the state of communities before Change AGENT projects in each locality launched to improve the lives of older adults. To support local change, The John A. Hartford Foundation (JAHF) partnered with the Gerontological Society of America (GSA) in 2013 to implement the Change AGENTS Initiative. The John A. Hartford Foundation Change AGENTS Action Awards are one-year grants made available to interprofessional teams for the purpose of achieving meaningful change to practice or policy that will improve the health and wellbeing of older adults and/or their families.

Change AGENTS received a variety of types of support, including mentorship, skill-building, and the use of planning exercises through conferences and Policy and Communications Institutes. Professional and organizational development opportunities were integral components of the Action Award grants. Opportunities for skill-building have helped Change AGENTS develop their capacity to deliver change as more effective advocates. For example, participants at the 2016 Policy Institute learned how to navigate the legislative and regulatory processes that affect the policy context for projects. Change AGENTS learned skills in coalition-building and issue framing. At the 2016 Communications Institute, Action Award recipients left with a draft communications plan including action steps for implementation. Support also came more informally, through free-form idea sharing with a group of bright, motivated individuals in the field. Ongoing supportive relationships, and a sense of community, were welcome and intentional by-products. Having the dedicated time and space to explore project approaches was an additional, less tangible benefit.

Three case studies will explore the value of the Change AGENTS skill-building opportunities in expanding skillsets, and helping projects make a greater impact.

### **Relocation Amidst Revitalization: Recreating Social Worlds for Older Adults**

In 2014, approximately 100 older adults in a senior building in downtown Detroit were expelled from their Section 8 senior housing in favor of market-rate luxury apartments (Perry, 2014). Some displaced seniors had been living in the senior building community for decades and experienced emotional, health, and financial repercussions. “These people experienced grieving for their lost homes, friends, and places of memories,” said Kathleen

Carsten, MSN, RN, Faith Community Nurse at St. Aloysius Catholic Church in downtown Detroit.

A coalition was quickly born, coalescing around the displaced seniors. The Senior Housing Preservation of Detroit (SHP-D) is a coalition of 17 member entities, including Tam Perry, Ph.D., M.S.S.W., Assistant Professor at Wayne State University, and local service organizations, faith organizations, and advocates, formed to advocate for the preservation of senior housing and provide supportive services for those displaced in the Detroit area.

Perry, as an Action Award recipient and Change AGENT, gathered evidence for policymakers about the impact of redevelopment through interviews and post-traumatic stress disorder measures with those displaced from their homes. This advocacy project demonstrates the need to balance a changing downtown Detroit with the needs of older adults living in the community.

### **Partnering and Value Propositions**

SHP-D engages a broad coalition of community stakeholders, from St. Aloysius Parish to the Detroit Area Agency on Aging. One of Perry's early challenges in undertaking her Change AGENTS Action Award was to understand the value of membership for her diverse partner organizations. The 2014 Change AGENTS Policy Institute presented an interactive workshop on value propositions. Value propositions are "clear, simple statement[s] of the benefits, both tangible and intangible, along with the approximate price it will charge each customer segment for those benefits" (Lanning & Michaels, 1988). When she returned home, Perry and Ruth took the exercise to the next coalition meeting. "It was informative because it helped us realize what's at stake for each organization we work with," said Perry. The value proposition exercise came at an optimal time, as SHP-D was asked to present before the Detroit Mayor's Office shortly thereafter.

### **Advocacy and Emotion**

The meeting with the Mayor's Office helped raise the profile of older adults at risk of future displacement and opened an ongoing conversation. "The Mayor's Office, the Planning Committee—those are the gatekeepers who make decisions about building use. What does it mean to have a healthy mixture of seniors and young people in downtown Detroit?" said Carsten.

Through Change AGENTS skill-building opportunities, Perry and her partners planned their communications in recognition of the power of story. In addition to presenting her research findings to policymakers, an accompanying documentary film will add a memorable emotional component to her advocacy efforts. "We needed to put a human face on the issue for briefing legislative aides and to be able to tell the story to developers and city officials. We needed a vehicle to address the emotion and trauma of the victims of displacement,"

said Dennis Archambault, Vice President, Public Affairs with AuthorityHealth and the coalition's co-communications director.

Now, SHP-D will publicize the documentary to spread important messages about the experiences of displaced older adults. The 2016 Communications Institute allowed the two communications co-directors to collaborate in a disciplined way to develop a communications plan—an intensive period of time to place total focus on this work. Strategic Communications and Planning (SCP) led teams in a consultancy exercise, where small, facilitated groups gave feedback on communications challenges through brainstorming. The exercises helped strengthen SHP-D's messaging approach.

### ***Home Health Connect: Improving the Health of Aging Homeless Individuals through the Coordinated Entry System and the Affordable Care Act***

Amy Turk, LCSW, Chief Program Officer of the Downtown Women's Center (DWC) in Los Angeles launched the Health Home Connect Project after noting opportunities, made possible through the Affordable Care Act (ACA), for innovative work between community-based organizations and traditional health care systems to improve the coordination of care for older adults experiencing homelessness. Under an initiative of the United States Department of Housing and Urban Development (HUD), federally-funded entities must now create a Coordinated Entry System (CES) to prioritize individuals for housing (Turk, 2015). Seizing on the opportunity to use CES as a vehicle to enroll individuals eligible for health care under Medicaid, the Downtown Women's Center created the Home Health Connect program. An individual placed on the CES for housing is also prioritized to receive medical care, which may include connection to a primary care physician; benefits education; patient navigation; transportation; and advocacy for specialty care (Turk, 2015).

“HUD requires streamlining in how people experiencing homelessness enter housing, which is great, but what's missed is an opportunity. On intake, we ask many questions about health care, but there's no requirement to actually streamline healthcare delivery. We have seen much headway with Home Health Connect,” said Turk.

### **Working with Policy-Makers**

Turk attended the 2015 Policy Institute to support her Home Health Connect Action Award and learned how to be of more value to elected officials, up to the point of writing legislative language for the state health care department—which was implemented verbatim later. She was surprised to learn how much support and information elected officials and their staffs were eager to take and use, from talking points to legislative language.

“It was incredible to have so much support [from Policy Institute faculty] before meeting with elected officials and getting thrown into Capitol Hill. We had tremendous experts. In my case, my elected officials had known about Medicaid and addressing homelessness, but didn't fully understand it. And since then, I've had many conversations with their staffs.

The Policy Institute launched an ongoing relationship,” said Turk. Through legislative advocacy, Turk shaped the dialogue about the relationship between homelessness and health care, and explained these intertwined concepts to policymakers. Turk has met with representatives locally and in D.C. to advocate for legislation to direct the Centers for Medicare and Medicaid Services to advance the 1115 Waiver program to meet the needs of homeless Medicaid beneficiaries (Turk, 2015).

### **Communicating with Confidence**

The 2014 Communications Institute instantly launched Turk into refining her elevator speech for her small group. She left feeling competent and able to further her research with the expertise she was developing. “I was able to go out and have more confidence in speaking to the media,” said Turk. She also became more comfortable speaking about herself, her work, and her project in a direct, to-the-point style, which she has found to be invaluable in garnering respect for her work in making inroads in her community.

At the 2016 Communications Institute in Chicago, participants learned how to create a strategic communications plan for their change efforts. They also shared experiences and insights with each other in a supportive, engaging environment. Ann-Sophie Morrissette, Director of Communications and Policy at the Downtown Women’s Center, attended and was grateful for the time and space to strategize during the mid-point of program execution—rather than at the end. “It was so helpful to strategize ahead of time. We had clear tools we could walk away with and put into action immediately,” said Morrissette. Morrissette also found the pairing of a communications staffer with a programmatic staffer to be illuminating. “I thought it was smart to invite additional staff, not just the principal researcher. The Change AGENTS Initiative is dedicated to building the skills of a whole organization,” she added. Morrissette took away tangible tools, such as the communications workbook, and has found others in her organization can use them as templates.

In the future, DWC is well-positioned to build on the work of their Action Award with a full advocacy portfolio and expanded programming, including an evidence-based diabetes care program for homeless older women. DWC has leveraged its Change AGENTS Action Award to become a “pacesetter community,” with support from the Robert Wood Johnson Foundation to accelerate improvement in health for a target population. “The Change AGENTS Initiative launched us into this effort,” said Turk.

### ***Early Intervention for Informal Caregivers: Using High Fidelity Simulation via Community-Based Participatory Ethnodrama***

The majority of long-term care needs for older adults are provided by family caregivers at a value of billions of dollars annually (Utah Commission on Aging, 2014). State-level support for caregivers exists in Utah, but caregivers, especially those just beginning to give care, may be unaware of them. Support reduces burnout and increases caregiver well-being while

allowing older adults to remain in their homes and communities. Jackie Eaton, Ph.D., Research Assistant Professor at the University of Utah, led an interdisciplinary team from the University of Utah College of Nursing, the Utah Caregiver Support Program, and a professional theatre group, Walk Ons, Inc., to create an ethnodrama targeting early caregivers. Ethnodrama is the process of turning verbatim nonfictionalized personal accounts into a performance with the goal of making research findings accessible to the general public.

The team collaborated with 22 caregivers, who cross-interviewed each other about caregiver needs. A blend of more experienced and new caregivers was recruited to give a range of perspectives. Identified themes were used to create the ethnodrama script, with the result a play entitled Portrait of a Caregiver. The primary goal of Portrait of a Caregiver was to promote awareness of caregiving resources, caregiver needs, and to train early caregivers before they became over-burdened. Post-performance discussion and evaluation has yielded additional data. Originally, the team planned to host four performances for early caregivers, with timing to attract the attention of state lawmakers.

### **Messaging and Recruitment**

The first challenge for Eaton was to recruit caregivers for interviews, especially before they reached the point where they became over-burdened, and direct them to resources available from the state of Utah. The team brought this challenge to the 2015 Action Award Institute, and left with a lengthy list of action items and a new strategy for volunteer recruitment. The team learned that caregivers didn't necessarily identify with the term "caregiver," and so changed its message. Recruitment was much more successful thereafter. "You get in your own little silo, and at these Institutes people have such great ideas. It helped us think beyond what we already had planned, and go further together," said Eaton. Bringing problems to the group of like-minded Action Award recipients helped hone the team's messaging, and ultimately, its success in participant recruitment.

### **The Power of Story**

Nancy Madsen, MS, Program Manager of the Utah Caregiver Support Program and Change AGENT, knew something special was afoot at the first ethnodrama performance. The first showing was privately hosted for the caregivers who had collaborated on the script. "I watched how caregivers felt so validated. They knew that other caregivers were in the same boat, with little or no information," said Madsen, a former caregiver herself.

Opportunities for marketing emerged after additional ethnodrama performances. Eaton presented to the Utah Commission on Aging, and it agreed to help provide funding to promote the performances because of shared goals and values. The team leveraged early marketing support and offers of assistance to expand the number of people who heard about and attended the ethnodrama performances. Working with an advertising agency, the team created a website and other marketing tools to publicize its effort.

After subsequent performances, new potential partners, such as the Utah Chapter of the Alzheimer's Association and the Utah AARP emerged, moved by the story being told. "That was the beginning of a groundswell," said Madsen. Partners began to request additional performances of the ethnodrama for their constituencies. The Utah Alzheimer's Association provided funding for a fifth performance and post-performance evaluation, increasing the impact of the work.

### Partnering to Increase Impact

The team wanted to solidify partnerships with interested organizations. Through the Change AGENTS Initiative, Eaton had learned important lessons in partnering; approaching a potential partner once is not enough. Repetition is key. Madsen put her lessons learned to work in developing a strong partnership with AARP Utah. "I followed the format from the Communications Institute to negotiate the progression of an important meeting with AARP. I knew we needed a specific ask at the end. We see a long-term partnership with AARP," said Madsen.

Now, AARP Utah is working to improve policies related to family caregiving in conjunction with the Change AGENTS team. They have enthusiastically supported the project by publicizing performances and recruitment needs on their blog and other social media outlets. AARP Utah sponsored a performance at their September 2016 volunteer training for increased publicity. "We are working with them to lobby the Utah State Legislature now, and we have much more to do," said Madsen. "I think they will be our strongest partner." Change AGENTS seek increased dedicated yearly funding in recognition of caregiving as valued and supported by the Utah State Legislature. The Legislature has made year funding increases, but the Utah Caregiver Support Program would like to see those yearly increases made permanent.

As the Action Award project has blossomed, the team credits the training for its success. "It's been a process for our learning, with increasing our confidence and stepping out. Change is happening, and it's above and beyond what we could have imagined," said Eaton.

### Summary

The Change AGENTS Initiative is catalyzing practice change and transforming the way health care is delivered to our aging society. Although the Action Award cases are widely divergent in their paths to achieving their role as community catalysts, they share similar tactics in developing their organizations and bringing about change. All three Change AGENT projects have the need to establish partnerships; to build relationships in the community; to plan ahead; and to communicate effectively.

- **Partnerships:** Partnering with community organizations increased the capacity to deliver change. As Eaton explained, "establishing partnerships in communities is something the Change AGENTS Initiative really cares about—it's beyond just academic

research.” Change AGENTS emphasized that in many cases, relationships had to be built over a period of years in order to see a fruitful impact now. Thinking through the value proposition for each partner was an important exercise from the skill-building opportunities; this was a tool used again and again.

- **Community:** Being a part of the Change AGENTS community was motivating, and gave participants a sense of shared purpose and legitimacy as a force in their respective communities. “The energy I drew from being a part of a community of interest was phenomenal,” said Archambault. Joining colleagues informally, and traveling with teammates, also fostered trust. “We are proud of our coalition because we have high trust. I’m thankful for the support through Change AGENTS. We needed sustenance to keep us going, keep us inspired,” said Perry.
- **Mentorship and Networking:** Action Award teams strongly desire to keep in contact with their cohorts and mentor others in the field. “The mentorship of people doing this work, as a Change AGENT, was just exceptional. They are amazing cheerleaders. It was confidence-boosting, and expanded my network. To have these touchpoints across the nation is a privilege,” said Turk.
- **Planning:** Change AGENTS found that skill-building opportunities created the space and time to work with teammates to develop plans, including communications planning, stakeholder mapping, and advocacy plans. “Having concentrated time was invaluable—we are very busy with our respective organizations in the coalition, trying to achieve our own missions. And, the Institutes are disciplined. Not a moment is wasted,” said Archambault.
- **Communicating:** Trouble-shooting communications problems, both formally and informally at skill-building opportunities, was of great help. Articulating a communications plan and re-using communications planning tools also benefitted Change AGENTS. Said Eaton, “After each meeting we always have a huge to-do list. It helped give us foresight into our next steps, and created a new timeline, a new path forward for us.”

Overall, Change AGENTS expressed their appreciation of the support they have received as a member of this community. “The Institutes are supportive and wonderful. They’re hard work, but also designed to refresh and support you as a scholar and Change AGENTS community member,” said Perry. Highly engaged Change AGENTS want to mentor others in their advocacy and practice change work. Moreover, they want to engage with their communities, continuing to serve as change catalysts in the future. “Now we are Change AGENTS forever more!” said Eaton.