A Better End: Supporting Our Communities around Death & Dying

Cinthia Vega Gabriele, MSW (she, her, hers)
Edekira Liberato (she, her, hers)
Duysal Karakus, LMSW (she, her, hers)
Community Access expands opportunities for people living with mental health concerns to recover from trauma and discrimination through affordable housing, training, advocacy and healing-focused services. We are built upon the simple truth that people are experts in their own lives.
Community Access, Inc.

THEN:
- Founded in 1974
- Friends, families, activists came together to rent, renovate and run housing on the Lower East Side in NYC

NOW:
- Low-threshold, supportive housing throughout the Bronx, Manhattan & Brooklyn
- Howie the Harp Advocacy Center
- Peer-Operated Respite Center
- Mobile Teams
- Art Collective
- Self-Direction program
- Supported Education program & more
Death & Dying at Our Community

• Shortened life expectancy of participants

• Low-threshold housing serving as NORC’s

• Current crises of death related to overdose and COVID
Challenges & Barriers
Challenges & Barriers

• Lack of knowledge of systems and how to navigate
• Lack of knowledge of advance planning rights
• Challenges in engaging participants in conversations about death & dying
• Lack of support/resources for staff and communities
• Workers with little to no experience around death, newly facing concerns around loss, mortality, etc.
• Workers with a great deal of experience with death, loss, experiencing re-traumatization and overload
• A health system not providing adequate supports for those with serious medical concerns and therefore supportive housing workers are left filling in some gaps
Our Death & Dying Workgroup

- Incident Review Committee

- Gaps identified:
  - Advanced Planning - knowledge, skills, and support to complete
  - Memorial/Legacy Planning
  - Support for the community (participants and staff) around loss
  - Overall – Comfort/ability in the community to raise topic of death & dying
Our D&D Workgroup Structure

- Project Manager(s) to oversee the committee
- Inclusion of those within the programs
- Zoom meetings/participation (even before COVID-19)
- Subgroups/Project Groups
- Each D&D meeting begins with an icebreaker
Icebreaker Questions - Sample

• Share a movie you like about death and dying
• Would you like to know when/how you would die? Why/Why not?
• What is the number one item on your bucket list?
• What would be the color of death for you? Why?
• What is one thing you would like to bury with & why?
• Talk about a celebrity or famous person’s death that deeply affected you?
• What would you do if you found out you only had one month to live?
• What is one song you would want played or one food you would want served at your memorial/funeral service?
• What would be the ideal scenario for your death?
Things we’ve done

• Discussion/viewing of *Being Mortal*, with Atul Gawande
• Day of the Dead & other program events as conversation starters
• Memorial prep packages for Managers/programs
• Monthly Support Groups (Not a therapy group)
Things we’ve done

• Advance planning workshops through community organizations with expertise
• Guidance document explaining various advance planning rights & tools
• Developing & uploading training in LMS
• Reviewing/updating policies in collaboration with Senior Administration
Things in process

- “Learning on the Fly” events when it is safer again to gather
- *Re-imagine NYC*
- Drop-in Sessions for Advanced Directives
- Gatherings - D&D Poems, Writing for Grief, D&D Playlist
- D & D group as pollinators
What if?

D&D Committee is not an option....

What is possible?
Things to Consider

• Values and/or Personal Experiences
• Comfort Level
• Knowledge
• Meeting/Group Facilitation Skills
• Planning and Implementation within your Program/Organization
Some examples/ideas

• Starting the conversation with folks who already have shared an interest
• Organizing a gathering at your program (e.g. movie screening)
• Inviting other agency programs to join your events
• Inviting organizations to talk about Advanced Directives
• Organizing a gathering outside of your programs
• Memorials/Celebration of Life/Obituaries
“I loved my friend
He went away from me
There's nothing more to say
The poem ends,
Soft as it began-
I loved my friend.”

-Langston Hughes
Resources

• The Conversation Project - https://theconversationproject.org/
• Reimagine https://letsreimagine.org/nyc
• The Compassionate Friends - https://www.compassionatefriends.org/
• Pet Loss support group - https://www.amcny.org/pet-loss-support-program
• Get Palliative Care https://getpalliativecare.org/
• Caring Info https://www.caringinfo.org/
• Respecting Choices https://respectingchoices.org/
• Death Café - https://deathcafe.com/
• Cake - https://www.joincake.com/company/