Home Care Aide Council
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MENTAL HEALTH SUPPORTIVE HOME CARE AIDE: CURRICULUM OUTLINE

Health Care Workforce Transformation Planning Grant

Grantee
The Home Care Aide Council

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The Home Care Aide Council

The Home Care Aide Council (Council) is a non-profit trade association with over 150 members throughout Massachusetts committed to enhancing quality of care throughout the home care industry by focusing on the advancement of the home care aide workforce.

Home care aides are the heart of the Commonwealth's home care system, providing personalized and supportive services that enable our elders and disabled children and adults to remain at home. The Council works with state agencies, the Legislature, the media, and the general public, providing timely information and education on home care services and advocating for priority home care issues and initiatives.

Throughout our history, the Council has brought together providers from certified home health, homemaker, and private pay agencies to ensure that quality home care aide services are delivered throughout Massachusetts. The Council has been the leader in setting standards for home care aides and is proud to serve as the question and referral source for standards of practice.

Table of Contents

Section 1. Introduction

The purpose of the Home Care Aide Council's planning grant activities was to develop a detailed outline of a new Mental Health Supportive Home Care Aide training curriculum, which is presented in this report. The basis of this curriculum outline comes from reviewing current best practices for mental health trainings and gaining important insights from home care aides, agency supervisors, and key industry stakeholders. Results from these efforts are detailed in this report as well.

Our expert consultants from Jewish Family and Children's Services led the task of reviewing existing best practices of mental health training curricula. In addition, a total of 10 focus groups were conducted across the state in the following cities and towns: Greenfield, Framingham, Worcester, Boston, Marion, Lawrence and Brockton. Five focus groups were conducted with home health aides (n=49), 3 focus groups with supervisors (n=20) and 2 with stakeholders (n=15). Participants were recruited via email and paper flyers and self-selected into the sample (i.e., participation was voluntary). Home health aides were compensated for their time. Next, 5 key informant interviews were conducted with individuals viewed as experts in the areas of mental health, aging, and home care in the state of Massachusetts. These interviews provided important context to the development of the mental and behavioral health training outline for home care workers. Focus groups and interviews were completed between May 7th and July 25th, 2014. By utilizing qualitative methods to execute in-depth semi-structured interviews and focus groups, the Council was able to design a curriculum outline that incorporates not only accepted best practices, but also the important input of staff that are most familiar with the needs of those living in the community with mental and behavioral health needs.

Results from all 3 sources of data (review of existing trainings, focus groups, and interviews) were triangulated to draft the outline of the new Mental Health Supportive Home Care Aide training curriculum. Primary findings from these efforts include 1) the identification of the most common and prevailing mental or behavioral health conditions that home care aides face (depression, hoarding, substance abuse, anxiety and general psychosis); 2) the importance for the training curriculum to focus on the recognition and response to *behavior* (as opposed to the diagnosis) as well as drawing on adult-learning styles; and 3) to incorporate broader personal and professional development skills into the training.

Section 2. Curriculum Review

To determine the best practices currently used in mental and behavioral health training for healthcare workers, eighteen curriculums were reviewed (see **Table 1**). The curriculums were identified from a variety of sources. The project advisory board, stakeholders, and key informants all made recommendations of trainings they had either attended or heard about related to mental health. Additionally, trainings that either the Home Care Aide Council or Jewish Family and Children's Services were familiar with or aware of were also included. Each training was reviewed and evaluated for three standards: topical, content, or methodological material that should be considered for inclusion in the new curriculum. **Tables 2 through 19** outline each curriculum and the findings on the three areas of interest.

Table 1. Curriculum Reviewed

Author/Source	**Title**
Alzheimer's Association MA/NH	Caring for People with Alzheimer's Disease (2012)
Boston University School of Social Work: Center for Aging and Disability Research	Review of On-line Certificate Programs
Elder Services of the Merrimack Valley (Kim Flowers)	Supportive Homemaker In-Service Training Modules
Hazelden	How to Talk to an Older Person Who has a Problem with Alcohol or Medications (pamphlet)
Hoarding Best Practice Committee	Hoarding: Best Practices Guide (2012)
Home Care Aide Council	Supportive Home Care Aide Curriculum (1996)
Jewish Community Housing for the Elderly (JCHE) and Jewish Family & Children's Service (JF&CS)	Tips and Techniques for Supporting Residents with Mental Illness: A Guide for Staff in Housing for Older Adults (2012)
JF&CS	You Can Save A Life. Detecting Depression and Preventing Suicide. Workshop curriculum for home care aides (2010)
MA Association of Older Americans, Inc. (MAOA)	Eliminating Barriers to Mental Health Treatment. A Guide for Massachusetts Elders, Families and Caregivers (2008)
MA Department of Mental Health	The Core DMH Curriculum, Volume X. The Unique Mental Health Needs of the Elderly (1997)
MA Department of Public Health	Alcohol and Medication Issues Among Older Adults. Home Care Aide Update. Fact Sheet
MA Executive Office of Health & Human Services	ABCs for Direct Care Workers (2013) - curriculum

Mass Housing and the Statewide Steering Committee on Hoarding	Massachusetts Hoarding Resource Directory (2014)
Relias Academy	Geriatric Mental Health Certificate (online)
U.S. Department of Health and Human Services, SAMSI-IA, National Council on Aging	Get Connected: Linking Older Adults with Medication, Alcohol, and Mental Health Resources (2003)
U.S. Department of Health and Human Services, SAMSHA	Substance Abuse Among Older Adults (rev. 2010)
U.S. Department of Health and Human Services, SAMSHA	Promoting Mental Health and Preventing Suicide: A Toolkit for Senior Living Communities (2012)
Unknown	Self-Care Tips Sheet Mental Health Fact Sheets

Table 2. Caring for People with Alzheimer's Disease: A Habilitation Training Curriculum

Author/Source: Alzheimer's Association; MA/NH Chapter

Topic Ideas/Suggested Times

- 12 hour training: 8 modules with an extra 1 hour "Understanding and Working with Families

Content Ideas

- Uncover and dispel any culturally imbedded myths about aging or AD that are potential barriers to learning
- Rules of good communication (general relevance not just for habilitation approach)

Methodology Ideas

- Learning formats: Discussion activities, lecture, demonstration, role-play, group work
- Adult learning strategies up front in facilitator guide
- Test after each module
- Potential Pitfalls to Avoid
- Reinforcing throughout that reporting their observations and concerns are especially critical to maintaining the health and safety of the clients

Table 3. BU CADER On-Line Certificate Program Outlines

Author/Source: BU CADER Website

Topic Ideas/Suggested Times

- Compulsive Hoarding in Older Adults- 4 hours (required as part of Mental Health in Aging certificate)
- Mental Health and Aging Issues- 4 hours
- Suicide Prevention Among Older Adults- 4 hours
- Substance Abuse Among Older Adults – 4 hours

Content Ideas

- For home health aides, a general understanding hoarding behavior but they have to be part of a team
- Overview of research on hoarding in older adults and implications for practice
- Understanding intervention options and treatment approaches, ethical concerns, vulnerability of older adults, and family and community perspectives
- Prevalence of many coexisting medical conditions, greater use of multiple prescribed medications, and stereotypes about aging are among the many issues that make mental health concerns of the older individual complex and challenging
- Recognize suicide risk among clients
- Understand how personal attitudes about suicide can affect the care of older people in their practice
- Effective suicide-prevention activities
- Importance of being culturally aware
- Good listening and questioning techniques
- Re Substance abuse- provides opportunities for participants to explore their own attitudes about substance abuse in this population
- Understanding of the older adult's ability to accept help; of one's own attitudes toward substance abuse; of the older adult's right to dignity and self-determination
    - Relationship between substance abuse and the physical and mental status
    - Effects on family as well as individuals

Methodology Ideas

- Learning formats: Discussion activities, lecture, demonstration, role-play, group work
- Adult learning strategies up front in facilitator guide
- Test after each module
- Potential Pitfalls to Avoid
- Reinforcing throughout that reporting their observations and concerns are especially critical to maintaining the health and safety of the clients

Table 4. Elder Services of Merrimack Valley

Author/Source: K. Flowers, MAO & DMH Mass Aging and MH Coalition 2006

Topic Ideas/Suggested Times

- Great Power Point Presentations
- Boundaries
- Working with folks with Borderline PO- what makes them "difficult"
- Hoarding vs. Clutter-great differentiation
- Elders and loss
- Good outline of QPR- Suicide as topic
- Alcohol
- Communicating with difficult family members

Content Ideas

- Self-care tips sheet
- Chart of changes in BPD symptoms over Life course
- Tips for working with elder with BPD
- Tips for HC worker in preventing elder depression
- List of types of items that folks clutter
    - Rating scales with photos
    - Impact of clutter
    - How to help
- Explaining Erikson's state of late life-integrity vs. despair
    - Working with end of life
- Suicide myths and facts
- Why addiction is a problem for older adults
- Treatment info- role of caregiver
- Resolving conflict tips

Methodology Ideas

- Tips for homemaker re termination when client dies and managing their reactions

Table 5. Elder Services of Merrimack Valley Training Notes

Author/Source: Elder Services of Merrimack Valley

Topic Ideas/Suggested Times

- Review of services available through ASAP network in order to make suggestions to client re additional assistance available
- Addiction
- Personality disorders

Content Ideas

- Language seems too high for some of the aides - needs to be simplified

Methodology Ideas

- Use of case study
- "Care tips" specific to diagnosis very useful

Table 6. Hoarding: Best Practice Guide

Author/Source: Laurie Grant and Committee

Topic Ideas/Suggested Times

- Excellent overview of the extent of hoarding problems in the community and the implications for clients

Content Ideas

- Hoarding Intervention Decision Tree
- 92% of people with hoarding condition also have another co-occurring MH disorder
- Ways of engaging the client-"finding an opening"-(useful for other diagnoses as well)
- Identifying challenges to working with hoarders (applicable to other diagnoses?)
- Self-care suggestions

Methodology Ideas

- "A plan for each visit"
- Use of pictures (we should consider use of short videos for different diagnoses)

Table 7. Supportive Home Care Aide Curriculum 1996

Author/Source: Home Care Aide Council

Topic Ideas/Suggested Times

- Role of the supportive home care aide
- Documentation and reporting Communication- including silence (?)
- Addictions- including dual dx- substance abuse
- Is Elder Abuse/Neglect a necessary part of this or is it covered in the general training?
- Suicide
- Self-care/burnout
- Culture issues-biases- racial discrimination and how to deal with it
- Loss, grief, death and dying

Content Ideas

- Ethical issues-confidentiality
- Treatment options
- Definitions of terms related to addiction (page 83)
- Myths related to suicide
- Signs of burnout- role of the aide and agency in addressing this

Methodology Ideas

- Using different instructors for different sections (rationale not provided for this)
- Objectives spelled out for each session
- "What should the Home Care Aide do?"- use with different scenarios presented
- Provide job description for Aide position
- Test questions at the end of each session
- Role plays- group discussions
- Brief case examples interspersed
- Therapeutic and non-therapeutic communication techniques with concrete examples
- Do's and don'ts of working with addiction problems
- Role plays around client not taking meds, sexual advances, etc. helpful

Table 8. Tips and Techniques for Supporting Residents with Mental Illness: A Guide for Staff in Housing for Older Adults

Author/Source: JCHE, JF&CS

Topic Ideas/Suggested Times

- Hoarding
- Depression
- Anxiety
- Depression or Dementia?
- Personality Disorder
- Delirium
- Bipolar Disorder
- Substance Abuse
- Psychosis: Paranoia, fixed delusions, schizophrenia

Content Ideas

- Working with families
- Being part of a team/collaboration
- De-escalation
- Boundaries, expectations

Methodology Ideas

- Case studies
- Tips and techniques
- Suggested Language

Table 9. You Can Save A Life. Recognizing Depression and Preventing Suicide in Home Care Clients (2010)

Author/Source: JF&CS

Topic Ideas/Suggested Times

- 1 hour workshop

Content Ideas

- Depression is not a normal part of aging- 'Truths" about depression.
- 12 Clues (client behaviors) for Recognizing Depression in Seniors
- Helpful things to say
- When to call your supervisor

Methodology Ideas

- Quick Reference Cards in English, Spanish, Portuguese, Vietnamese, Chinese and Russian
- Facilitators guide, PowerPoint with facilitator notes
- Pre and Post Tests (validated)

Table 10. Eliminating Barriers to Mental Health Treatment

Author/Source: MAOA & DMH Mass Aging and MH Coalition 2006

Topic Ideas/Suggested Times

- Normal Aging vs. Mental Illness
- Challenging Behaviors and how to address them
- Stigma

Content Ideas

- Myths and realities of mental illness

Methodology Ideas

- Case examples with possible reactions to address stigma issues

Table 11. DMHE Core Curriculum, 1997: The Unique Mental Health Needs of the Elderly

Author/Source: Office of Clinical and Professional Services, The Training Program

Topic Ideas/Suggested Times

- This curriculum is a general overview on aging issues that was used as part of a larger DMH curriculum

Content Ideas

- Included content on hearing loss. Curious if this is dealt with in the ABC PHCAST curriculum

Methodology Ideas

- Case vignettes on depression, dual diagnosis, dementia, delusional disorder, reversible dementia
- Provides a list of organizations/contacts who can provide speakers (e.g. Alcoholics Anonymous, Samaritans)

Table 12. Alcohol and Medication Issues Among Older Adults- Home Care Aide Update

Author/Source: MA DPH, Produced by MA Healthy Promotion Clearinghouse, The Medical Foundation; www.maclearinghouse.com

Topic Ideas/Suggested Times

- Alcohol and medication

Content Ideas

- Provides information directed to home care aides on:
    - What you need to know (e.g. signs of a problem
    - What you can do to help

Methodology Ideas

- Fact Sheet- 2 sided

Table 13. ABC's for Direct Care Workers, 2013

Author/Source: Mass Personal and Home Care Aide State Training Program, EOHHS

Topic Ideas/Suggested Times

- This curriculum addresses communication, culture/diversity and abuse/exploitation
  - Can they be skipped in specialized training?
- Learning outcomes for each section
- Understanding the aging process
- Professional and personal boundaries
- Confidentiality
- Hoarding

Content Ideas

- Communication specifically with people with mental illness should be included in the new curriculum-this is a good overview of the topic that maybe should be reviewed- open and closed end questions
- Working with family members of the consumer- different role of family members vs. worker
- Listing of trigger points- "when emotions get in the way of listening" (page 21)
- EARS approach to working with consumers-empathize, accept, respect, support (page 159)

Methodology Ideas

- Adult learner-centered training based on building on the participants past experiences or knowledge
- Demonstration role plays and practice role plays
- Small-group work with specific tasks and roles assigned
- Have participants describes clients who might fit the profile of needing a supportive home health aide because of mental illness
- Consumer profiles
- Demonstrate by asking trainee series of first closed end questions and then open ended
- Trigger points- pulling back
- Listing "observe and report" signs/symptoms
- Listing tips from other aides
- Using situation with question on what aide would do or say

(MF idea- demonstrate hearing voices by someone whispering in your ear while you are trying to carryon a conversation with someone else about something practical)

Table 14. Geriatric Mental Health Certificate (online)

Author/Source: Relias Academy https:l/mha-nyc.academy.reliaslearning.com/Geriatric-Mentai-Health-Certificate.aspx

Topic Ideas/Suggested Times

- 11 total hours
  - Alzheimer's Disease (2.25)
  - Anxiety Disorders Among Older Adults (1)
  - Depression in late Life (1)
  - Diagnosing Substance Use Issues in Older Adults (2.5)
  - Managing Challenging Behaviors of Older Adults with Dementia (1.5), Mental Issues in Older Adults (2)
  - Supporting Family Caregivers of Older Adults with Behavioral Health Needs (1.5)

Content Ideas

- Anxiety- Most prevalent; identify most common types and hallmark symptoms
- Substance abuse- Identify risk factors, signs, and symptoms; describe central aspects of comorbid, physical and psychiatric problems
- Mental health issues- Increase understanding of the role of both formal informal supports for older adults with behavioral health disorders, including family caregivers

Methodology Ideas

Table 15: Get Connected: Linking Older Adults with Medication, Alcohol, and Mental Health Resources

Author/Source: HHS-AOA & SAMSHA, NCOA (2009)

Topic Ideas/Suggested Times

- Provides useful information for the topics- Substance Abuse, Harmful Interactions of ETOH & Medication
    - Focus group participants were interested in learning more about medication effects

Content Ideas

- General issues on Aging:
    - Challenges people face as they grow older (e.g. retirement, loss of spouse, friend, isolation, more health problems, loss of independence)
    - How people cope with challenges, both positive and negative ways

Methodology Ideas

- Fact Sheets/Program Support Materials very clear in describing prescription and over-the-counter medications and older adults
- VIDEO: It Can Happen to Anyone: Problems with alcohol and medications among older adults
- Format: Warning signs/behaviors; What you Can Do Screening tool: "10 Important Questions for Those Over 65" Check Your Mood- Screening Tool
- Myths and Realities approach to learning about realities of alcohol, medications, and mental health issues in older adults

Table 16. Substance Abuse Among Older Adults: A Guide for Social Service Provider

Author/Source: U.S. Department of Health and Human Services, SAMSHA (2012)

Topic Ideas/Suggested Times

Content Ideas

- Focus on older adults useful in terms of specific barriers and challenges
- First Chapter provides good overview of the "Invisible Epidemic"
- Chapters 2 and 3 provide useful key topics around alcohol and substance abuse
- "Substance abuse disorders, if not diagnosed and treated, may ruin the last stage of life for countless Americans"
- Screening information (including Michigan Alcoholism Screening Test-Geriatric Version) provides valuable indicators of potential abuse

Methodology Ideas

Table 17. Promoting Mental Health and Preventing Suicide: A Tool Kit for Senior Living Communities

Author/Source: SAMSHA (2011)

Topic Ideas/Suggested Times

- Written for administrators and managers of departments of nursing, social work, pastoral care, wellness, and staff development in senior living communities
- Prevention

Content Ideas

- Suicide Prevention:
  - Whole population approach- Strategies to promote the e emotional health of all residents
  - At-Risk approach- How to identify and assist residents who are at a particularly high risk for suicide and related emotional health problems
  - Crisis response approach- What to do after suicide deaths and attempts
- Limiting access to methods of self-harm
- Covers substance abuse as a risk factor for suicide
- Depression in Alzheimer's Disease and Other Dementias

Methodology Ideas

- Tools (Facts)

Table 18. Mental Health Fact Sheets

Author/Source: Bill McGrory, LICSW

Topic Ideas/Suggested Times

- Quick information on various diagnoses- Bipolar, depression, schizophrenia, and suicide

Content Ideas

Methodology Ideas

- Short quiz on schizophrenia
- Suggestions on what to do if someone is exhibiting warning signs for suicide

Table 19. Self-Care Tips (One-Page Fact Sheet)

Author/Source: Unknown

Topic Ideas/Suggested Times

- Self-care

Content Ideas

- Ways to identify and manage stress; stress reduction
- Important component to the new curriculum

Methodology Ideas

- Information from this one-page fact sheet could be incorporated into the new curriculum (Not as a handout)

Section 3. Focus Groups with Home Care Aides

To create a training for home care aides, it is critical to hear directly from aides about their experiences working with clients in the community. Five focus groups were conducted with aides from across the state to determine the challenges that they face when providing care to clients with mental and behavioral health diagnoses. Three focus groups consisted of aides who had not yet received the mental health supportive home care aide training and two focus groups had participants who had received the training. In total, 49 home care aides attended the focus groups; 15 were supportive home care aides, 30 were home health aides, and 4 were personal care homemakers, homemakers, or personal care attendants (see **Table 20**). 96% of the aides were female and their years of experience in the field ranged from less than one year to forty years, with a mean of 9.3 years.

Table 20. Descriptive Results-Home Care Aides (N=49)

	M(range)	N=
Job Title		
Supportive Home Care Aide (SHCA)		15*
Dementia		2
Mental Health		3
Both		8
Home Health Aide		30
Home Health Aide Only (HHA)		16
Home Health Aide & Certified Nursing Aide (CNA)		10
Hospice Home Health Aide		4
Personal Care Homemaker/homemaker		2
Personal Care Assistant (PCA)		2
Female		47
Years of Experience	9.3 (<1-40)	

* The specialization of 2 SHCAs is unknown.

Hoarding was mentioned most often by home care aides as a condition that their clients experience (see **Table 21**). Second to hoarding, aides stated that their clients often have substance abuse issues and present signs of depression. Frequently, home care aides were unaware of a specific mental health diagnosis either because these diagnoses had never been made or the information about the diagnosis had not been provided to the aide. Other conditions home care aides often encounter with clients they care for include: schizophrenia, dual diagnosis of a mental health condition and dementia, bipolar, or suicidal ideation.

Table 21. Frequency of mental and behavioral health conditions specified by aides.

Condition	n=
Hoarding	19
Substance abuse	13
Depression	10
Other*	7
Schizophrenia	6
Dual Diagnoses (mental health and dementia)	4
Bipolar	3
Suicide Ideation	2

*Other diagnoses include: autism, multiple sclerosis, dementia or unspecified emotional/mental health condition.

Home care aides struggle to provide care to clients with mental and behavioral health challenges, particularly when accompanying behaviors limit their ability to perform their job. Aides reported feeling scared and unsure of how to respond when clients exhibit aggressive behavior towards them or display paranoia or delusional symptoms. A major barrier to assisting clients with mental illness is when their behaviors limit the home care aide's ability to provide personal care or to meet the other requirements of their job (see **Table 22**). The experiences shared by aides point to a need for further training and guidance on how to manage challenging behaviors in a way that keep the aide safe while also meeting the needs of the consumer.

Table 22. Behaviors associated with mental health diagnoses posed challenges for aides.

	Commentary
Aides struggle with how to respond when clients exhibit aggression towards them or others.	"There's been times where …I see him balling up his fist. His face is turning red and he's bigger than me. I don't want him to hit me. So I just say listen. I gotta go. I see him three times a week" "She does swear – I remembered when I came back last weekend, I forgot I had a sippy cup with me and I forgot to take it with me. And I came back and I rang the doorbell. And she swore at me and …she called me something." "But again, sometimes you'd say the wrong thing and she would be a maniac. Literally, a maniac. She got up in my face one day and screamed. I mean her face was like nothing I'd never seen." "I mean she's thrown things at people -- scream and yell and it's been bad -- locked people out. "
Clients often exhibit behavior that disrupts the aide's ability to provide care.	"She just was not a happy person and she would pretend to be. I mean, you thought she was on the surface. She'd always want to know, and I saw her twice a week, so what's new with you this week? And I couldn't say anything normal. Oh I just went shopping and, you know I brought my kids here. That's not -- she wanted to hear something exciting every single time I saw her. So I got to the point where I just started making things up." "So she slept in the sofa bed in the living room. She [would] pee in there …naked. She does not want to wear clothes and then I have to give [her] a shower. …she said no. And then …she got something to hit me." "So my hands are tied. …All I can do is every time I go in there is suggest to her, "Don't get mad. You wash up. Do you want help with the shower? If you want to take a shower, I'm here." I tried every avenue with her. I tried to get her to wash up. Nothing works. She doesn't mind me doing housekeeping. But as far as personal care? No. She's adamant about that."

Aides report that clients exhibit other psychotic symptoms that limit their ability to complete their job.	"She thought everybody was out to get her and her kids never called her because … they didn't want to deal with that. So she kept saying 'I know my kids don't bother with me because they're trying to kill me'. And every time he would give her a tea or coffee she said there's poison in it so I'm not going to drink it. So if I came in and gave it to her it would be okay…but anybody else…in the family, she wouldn't take anything. She was paranoid that he was trying to kill her." "I had this client who…wouldn't let anyone into her home. And she [thought] everyone was after her. It got to the point…she was urinating and yelling just in the main room. Like she opened the door and I got the smell of urine…, the poor woman … said she couldn't go to the bathroom because that was how they were coming into her now was if she went to the bathroom they were going to get her there." "I mean you have to be very careful that, you know, everything's in its place and that if the patient is already paranoid and saying stuff's missing? You know, I had one guy who said the hippies were coming and stealing his sugar. That was kind of silly, so people know, but people have valuable things and if it's just moved, then it's gone. If it's just out of sight, then it's gone."

Though many aides noted that they had never received any training on how to work with clients with mental illness, often they developed skills on the job or used their intuition to respond to the challenging behaviors exhibited by these individuals. Home care aides report using various communication strategies to de-escalate a situation or to build a relationship with consumers. Aides gave examples of using negotiation skills, active listening, voicing empathy, or joining their client's world if they are experiencing delusions or hallucinations. Part of communicating with clients, is building a strong relationship based on trust and mutual respect. Home care aides spoke about the ways that they develop relationships with their clients and how by doing so, they are able to not only empathize with them but also know their triggers and learn how to better manage their difficult behavior. Beyond communication and relationship building, aides are frequently put into situations where they are forced to take action. For instance, when their safety is at risk they must choose to leave the client's home to protect themselves or call their supervisor for further support (see **Table 23**). Aides have learned, often on the job, strategies to manage consumer's difficult behavior and successfully get their job done.

Table 23. Aides develop strategies for managing client's behavior related to mental health.

	Commentary
Aides have developed communication techniques to manage difficult client behaviors.	"I tried to understand her. I'd repeat back what I thought she was trying to tell me. What she was trying to get across…what she wanted to do. But again, sometimes you'd say the wrong thing and she would be a maniac."
	"Try to be patient and I would just answer her if she kept saying, hey you there? You there? Actually yeah, I'm here. Everything's safe. You're okay. Try to get some rest. You need some rest."
	"But [if] that person's yelling? …when you're quiet they realize they're arguing with themselves. And then they realize they can hear themselves. And then they end up apologizing."
	"I guess the client I have now…she will be talking with someone. And then I'll come in the living room and I'll say, "Will you introduce me?" And she'll say, "To who?" And I'll go, "Well you're talking to someone. They're here? I'd like to say hello." Because to her, they're real. You gotta make them feel like it's still important. What they do is important. It's important."
	"Usually I try to calmly tell them that they're hallucinating. You know, it's the middle of the night and you're supposed to be asleep and you were dreaming …and sit with them until they fall back asleep ...You identify yourself. I've never had anybody react badly."
	"One of the things that I do is ...to be there to listen as I'm doing my job. A lot of them need to vent. Also with the hoarders…I was confronted with a situation where…my client …they get anxiety. They get anxious and they need to know where everything is. So …just asking them…'where would you like me to start?' Just having that communication is good."

	"You've gotta break the cycle. So if she keeps going up and down the stairs I'll say, 'oh are you hungry? Do you want to have a snack with me? Want some tea?' So hopefully she'll forget about it – …Because if you don't break the cycle she'll keep doing it until she wears herself out. And then if she falls then that's going to…be on me because I didn't try to stop her…"
	"I always ask her to follow me and ask her where to put things. 'Where do you want to put this?' And I let her pick a place. And she feels really good the next time I see her she said, "See. I had the house re-organized for you" …every time she keep it like that, I give her praises. She tried, you know?"
	"…but that was a big deal to just be able to talk to her on a level where you weren't better than her or you were literally on her level …I just found it easier to deal with her like that. Because people that were coming in were like, ewww. This is gross."
Interpersonal relationship building is a critical way that aides are able to manage behaviors and provide homemaking and personal care to clients with mental illness.	"I do care and I've been doing this for 17 years, like I said. And it's been good. And when they die I sometimes smile. I say I know I give a good care. They go happy. And they know I love them but I don't have to be there because this is professional. …it doesn't matter how much I love them. I don't have to be there like their family was there. They are not my family. I do care…we have to, you know, separate one thing from the other."
	"Make them like you. ...You walk into their house and you know, you don't see the mess. You just be like hey. How are you? Let's go take a shower. And then like sit with her. And then if she brings it up, then you might say something. But not just be like 'oh hey. Your house is dirty. Let's clean up.' No. They have feelings. They're human. They're just like us."
	"… we…were sharing …and then while we were sharing I was cleaning up and asking her, "You want me to do this here?" And you know, I- I didn't even really give her… suggestions… she was doing all the work...every now and then I said," Well I think this would be better here." And then she was like, "Oh that works out nice." And so we cleared like two rooms."
	"you walk in blind literally not knowing how this person is, what they like and- But once you start asking questions and say hey, do you like this? Do you want to do this? It's just a different, different experience....If you find a commonality with them it makes it so much easier. You know, to communicate and have something to talk about."
	"That's the thing and I – it took a while for me to build up that trust.…if you work that way with them you start to gain their trust a little more...and eventually you might be able to get a little more done. The first thing you have to do is you have to gain their trust."
	"… You have to really, really talk to them and unwrap them like a gift, slowly. You know what I mean? And to find out more about them before you start cleaning up. And that's what I did. I just talked to her, and listened to her mostly, and she did all the talking about how she got that way. And, you know, and doing so we got rid of a lot of stuff."

	"Well I heard you threw your homemaker out." "That's right. And you're out too," [she said.] I said, "Well let me tell you, after you threw your homemaker out you called in two weeks later and wanted her back." I said, "You'll only throw me out once – and I won't be back." "Well, what will I do?" [she said.] I said, "I don't know. Maybe they'll send somebody else." "Oh," she says, "I just got used to you showering me."
When clients exhibit difficult behavior, aides are often forced to take action to either protect themselves or to get help.	"She still has emotional issues, but if you can redirect the person and maybe get them interested in doing something like playing cards, or watching a movie, or talking about certain subjects that they like to talk about. That really does help." "…I just went "okay. I think it's time for me to go now." Very calmly. And I just walked out the door and called my manager." "What I find helpful to do sometimes when I find clients that are sort of difficult to be with sometimes? Is if they give me such a hard time, I'll leave them alone and I'll step back. And then tell them I'll go do this and I'll be back and then try to re-direct it in a different sort of way." "If you're not safe and you have to leave then that patient's not safe because you're not there. So what's the plan? You know? It's 911 right now. That's all there is, 911, which is sad." "It's hard because sometimes I'd go into a house and I couldn't get my client to wake up because she was passed out [from drugs]. And I'd have to call the office and then, you know, watch her breathing. Call a family member that was like on a contact list. And eventually she passed away from that. And she was only in her 50's. Near my age."

Home care aides report both positive and negative experiences working with their direct supervisor and the larger agency. Their relationship and overall interpretation of the level of support they receive from their supervisor and agency strongly shape their broader work experience on the job. For those who voiced having a positive experience, they spoke of the support they receive and how they feel that they are part of the larger team. This often centered on receiving adequate information to feel prepared for each consumer and to successfully complete their job. Those aides who did not have that experience voiced concerns about the lack of support that they receive, particularly feeling like the supervisor and others within the agency did not understand the realities of the home care aide's job and the challenges that they face. Additionally, not having anyone to call for help or receiving appropriate or correct information about clients was brought up as a major frustration that often left aides feeling isolated (see **Table 24**). Inclusion of the emergency contact structure as well as supervisory visits and communication would be critical to informing the home care aides upfront about the support that will be provided to them. It also is important to engage the larger agency, and in particular the supervisors, in discussions and further training to encourage better support of home care aides who are providing care to individuals with mental and behavioral health challenges.

Table 24. Overall agency and supervisory involvement shaped the aide's work experience.

	Commentary
Positive Connotation	
Aides report feeling adequately supported by their agency and supervisors.	"We have a good support system at work. And we have a counselor that is head of support of aides. He is used to mental health issues and someone to vent with. Plus we used to have the weekly meeting for support of aides where the counselor would let us talk about Parkinson's with, you know, her about what's going on…it's changed… the meetings. I think they're four times a year." "I'm blessed because I have the support of a team and any issue I have I can go to whatever. You know, if it's the uh, nurse or if it's the social worker I can go and deal with that. I can also report something that I see happening in the family or with that patient. And they are very skilled at going in and seeing what's happening and not using my name, and not saying Mary said and they back me up. And I've done all those other jobs. And I can't do those other jobs anymore because you don't have the support. And I think that's a huge issue."
Aides have various approaches to receiving the information they need in order to provide care to clients.	"… if they call and say, you know, oh we need you to go here. Well who, what, where, when, why I want. I'm like gee you're asking us all these damned questions. I'm like well I've been thrown in the fire a number of times. They will try [to give me the information I need to know]." "We have little electronic devices. You know it's what we [use to] clock in and clock out -- it signs your name. And it gives you kind of like, you know, a run-down of their diagnostics, you know, and what type of medicine they're on. And depending on who, you know, does the format with bringing it in, you know, with the computer system to where it goes to everyone's phone whoever has, you know, certain clients. I mean it kind of gives you like a run-down whether, you know, they have been, you know, abusive, or you know they're very verbal and stuff like that."

Negative Connotation	
Many aides voiced a general lack of support from their direct supervisor and from the larger agency.	"They will send you but they have no idea… where you're going into. All they think about is the hours. 'You're going to get 60 hours. It's good pay.'… I don't care about the 60 hours. I want to be comfortable." "I question sometimes with the agency, and with the coordinator and the nurse. I'll be like you don't know what they hell we're going through. Like why don't you come out one day out of your office and see what we go through." "… it got so bad that sometime I couldn't go. I didn't know what to do. I'm like, you know, nobody's hearing me. You know, I'm not in charge of the company. … I love the company I work for. I'm not faulting them, but … what do you do in this situation?" "[with my former supervisors]everything was black and white. …you couldn't talk to them [supervisors]. You know, they didn't want to give you any information either, or help. Because it just seemed more like a business like they didn't really care." "A lady [client] took a knife on me and I called the agency right away. And they kept [me with] the client after that like about a month. And I didn't feel comfortable after that happened. And I feel like I was forgotten by the company."
Aides did not feel like they received enough information to perform their job successfully and when passing information on to the agency, did not think it was taken seriously.	"And then he was getting depressed. He started losing a lot of weight. And I informed my agency… At first I wasn't saying anything. I was trying to take care of it myself. But I said you have to go." "… she lie on the sofa. I call [to] her. She didn't open her eyes. She looked like she had passed away. And then I say okay, let me call [the agency]… there's nobody in the office. So …I call 911. Then after that they [client] call. They don't want me anymore." "I just walked out the door and called my manager and said, "I think you're going to be getting a phone call." And that's when I found out oh yeah she's got all these issues and she's fired us before. And I said, "Oh my God. Why didn't you tell me that?" Because it was a very stressful visit. If I had some background when I was going in to it I think I could have been more successful." "I'm not told that this person has mental illness. I mean I've walked into some client's houses that I've known half of the stuff that I really wish that I had known ahead of time." "And the problem too is… many times I've turned down a case …so that it would be passed to someone else. And the *more* it's passed, the *more* the case manager has to pay attention to it and it becomes a priority."

Home care aides struggle to cope emotionally with the demands of providing care to clients with mental and behavioral health diagnoses. Facing difficult behaviors, like aggression and resistance to care, pushed many aides to state that they had to walk away from working with clients or even from the job entirely. Fear, frustration, and concern were also voiced as emotions aides face when trying to manage the demands of the job while also dealing with their own personal life circumstances. Often home care aides were so distraught with the situation, they would blur boundaries moving from professional relationship into personal. Going above and beyond to meet the client's needs felt necessary to the aides who lacked support and training to know where to draw the line. Aides reported feeling personally responsible for the behaviors and actions of their clients and often experienced stress and burnout from the job. Though many aides voiced concerns about the high demands and limited support, some were able to identify successes and realize the positive impact they were making in people's lives. Often the successes were small, but the home care aides could feel accomplishment in building a relationship with the client, bringing them joy, or assisting them with needed tasks (see **Table 25**). This highlights the need for self-care tips within the new curriculum, as well as strategies for building and maintaining strong boundaries with clients. Stress management and coping with the emotional response to challenging situations are critical to keeping aides long-term in their job. Additionally, teaching home care aides how to appreciate the small successes is also important, particularly when working with clients with mental illness.

Table 25. Aides personally and emotionally struggle to cope with the demands of clients with mental health diagnoses.

	Commentary
Coping with their own emotional response to clients behavior is a major challenge for aides.	"…I mean he was drinking. I'd go there at ten o'clock in the morning and he'd be drinking- I don't know what do you call them—those big gallon things of vodka? Straight. And then when I knew he was like that I just – I'd have to call emergency. I can't stay here. I couldn't, I mean, I was like, you know what? I gotta go. And I finally said to him, "I'm not coming back here. You scare me. I'm afraid…And he could barely even walk. I mean, he was just, like riddled with arthritis but he was very violent and scary."
	"…And I think it got so bad that sometimes I couldn't go. I'm not even going to lie to you. I didn't know what to do. I'm like, you know, nobody's hearing me. You know, I'm not in charge of the company. And I'm not, you know, I love the company I work for. I'm not faulting them, but I'm just like oh what do you do in this situation? You know, I'm like praying for him. You know, I'd go home and I'd pray, Lord please!"
	"Because when we went to the bathroom she was like, "Don't touch me. You're ugly." And then, you know, I had a phone call and I was talking in Spanish. And she would curse me out because I was Spanish. And it was very uncomfortable"

Aides have issues establishing and maintaining boundaries with clients.	"That's what I believe, just by her house and it's oh man it was horrible. So I come in to take care of him. I did personal care, two hours. But his surroundings were horrible. Like it was, I was getting depressed. You know, 'cause I'm trying. You know, I'm like, okay I'm just here for this. I'm not here to clean, you know, but it needs cleaning. So I would do stuff that is not even really my job. You know, I would make this bed, clean up. And his clothes would get dirty and I don't, and I'm like okay. Well what am I going to leave him naked? He don't have no clothes. So one time I went out and I – Christmas time was there, and I didn't make that for an excuse and I brought all these clothes." "Okay, my question is for you. How is it you – how is it able for you to be with a person seven days a week and not get attached to them? You're with them at the supermarket. You're with them every day. You're with them when they're sick. You shower them. You have a personal relationship. Okay so you're not going to tell them hey I'm married. I've been five years married. I have kids. No. You're there taking care of them. They see that. They're human. You get feelings. And then, I was on this for four years. You know, it's not like hey I come in and you know. It's not that I want a relationship with you. It's just that I'm at your house every day." "…I just take care of her daughter. I'm still with her. I've been with her for about two years. When I first went out there her daughter's hair was a mess. She was dirty. Her fingernails were long with everything under them. Her toenails were long and she was lying in a playpen And she would never get out of the playpen. I threw the playpen away and I made her walk. I made her come to me, take a few steps. She started learning how to stand and watching TV. Eventually she started walking in her crib by herself." "So, you're essentially her mother." "There's been situations where I wanted to quit. But it's like if I quit what's going to happen to this little girl. That's all I think about."
Some aides are able to feel a sense of accomplishment from small successes.	"I have a hoarder. It was very challenging because getting her to throw things away was very difficult...But that was my huge thing was trying to figure out how can I get her to throw these newspapers away from 1984? So I would take like on day a week and say, "Listen. Let's just go through them. If it's something you don't want? If you want it we'll save it. If you want to get rid of it, we'll throw it out." And I managed probably to get rid of maybe like 35 recycling bins of newspapers. There's still 35,000 more, but that was a big deal for her…" "Sometimes, there's been times when I wanted to quit. And XXX was like, "No. You can't quit." And I'm like, "Maybe I'm in the wrong field." Maybe I think, you know, this is not for me. But the more I stay, the more I say that to myself- Like one time I was really negative and I went to see a client and I put on this smile. And I was doing something and the client just encouraged me all day. And I was just like, "I needed that." "I cleaned a bad house like that. I got paid extra because it was like so filthy. Like they, like I even shampooed the rugs. I was like scrubbing the walls and stuff for like two day, six hours a day. It was just like grease everywhere. I guess he's been there five years and hasn't cleaned it. So it was just a lot of buildup. And after I did it like you can actually see white, is was actually kind of cool."

In addition to work demands, aides often struggle with personal life factors that impact their job.	"Eighteen years I need money to make education for my two kids. That's why I still there. Sometime the people don't know you got education too because they treat you bad. I don't care." "I work seven days a week. I used to work 60 hours. I don't work 60 hours anymore because of my kids. But I work 32 hours now and what we did is we divide so there's another agency that comes in." "He, he didn't always have schizophrenia. He was perfectly normal growing up. He got diagnosed when he was in his early 20's. He's now 26. He's not like- He doesn't like talk to people. But he's the type of person he'll walk up and down in the city and he'll laugh to himself. And nobody will really know why, but you can tell like there's a problem." "Is this a client?" "This is my brother actually."
Though aides try to cope with the challenges of working with clients with mental illness, often they fall short and face negative consequences.	"I was always able to find, to help do anything for my client, but at times when I felt like I was going to burnout, like I was too overstress, when I got depressed? When my client died, because I had one client for 11 years and I saw her every day. When she died I had to take like a year and a half off because I could just not look at anybody in that age group without breaking down and crying. And there was no support at all." "She used to be a drug addict. Like she was a recovering addict. So I was just like, I said, I think she's relapsed and I was just like -- kind of broken hearted. I was just like, oh man. You know, and sometimes I feel responsible. Because you know what I mean? You don't know what triggered it. You don't know. So I always take full responsibility for all my clients – for their bad days. That's just me. I don't know why but that was challenging" "The frustrating part is you go in there and you do the best you can for them. And you clean up and make it safe for them to walk and stuff and you go back the following week and it's worse…and you feel like you're being taken advantage of, really" "And I think that we need that kind of thing too being out there because what is the support? Where do you go to if- I know they have an elder at risk and, you know, what are the capabilities out there to get help for ourselves or for the patient?"

Families add to the challenges faced by aides for a number of reasons. First, family members, often due to their own mental or behavioral health diagnoses, can complicate the ability of the aide to execute care or they can engage in abusive behavior. Home care aides state these can be their most difficult clients of all. Clients with mental or behavioral health challenges often have difficult family dynamics, either with families not being involved in their lives or having tenuous internal family relationships. Aides often feel stuck in the middle when clients do not have the family support that they would expect. Managing the client's behavior in addition to the family members can put a great deal of stress on home care aides. Abusive situations can also be present within households, forcing aides to determine how to manage the situation and when and who to call to report it (see **Table 26**). Working with families is not necessarily a part of a home care aide's job description, but it becomes a reality of their day-to-day experience, particularly when there are difficult family dynamics or mental illness is present. Preparing home care aides in the training on how to work with family members, including communication strategies and when to seek support and help from their supervisor, will be important components to incorporate.

Table 26. Families moderate the ability of aides to successfully provide care.

	Commentary
Client's Families are often plagued with difficult dynamics.	"Some of them have no family support. We found that they've pretty much been disowned from family. So we're basically the only ones that they have coming in there." "I've had experience of families being fragmented. There's this one the lives far away. Somebody's taking somebody's money. And somebody's taking somebody's drugs. And, you know, there's fighting between siblings over property or whatever."
Family addiction and abusive behavior can present major challenges for aides when trying to care for their client.	"The daughter's being neglectful. Not only is she neglecting herself, but the daughter is neglecting her because they're not forcing the situation or getting involved." "I walked into the house with him abusing her. It was really not pretty. I just let her know that I was there. Hi. I'm here. It's XXX. He's still screaming at her, swearing at her, telling her she's filthy. Get out of bed. You know, I'm sick of this. Screaming at the top – and he finally would just walk away from it. But I mean I walked into the situation hoping he would calm down because she was so upset. But she just protected him after. Oh my poor son. You know, he's the best. He's the smartest one. It was really not good." "I had this woman [family member] get in my face before, threaten to kill me, [and] threaten to like hit my patient. And I'm like, no. Not this. I'm done. I'm done dealing with it. Like there are some, like the rest of the family was really good but there was just this one woman." "I had to call the cops on a family member, have them physically removed from the property, and issued a stay away order. Because they would continuously show up to my patient's house at like 2:00 or 3:00 in the morning, paranoid out of their mind, drugged out of their mind and drunk off her butt and my patient could not deal with this trash. She had a heart condition. She had all kinds of other conditions, stress. Her doctor said any elevation in stress could potentially kill her like that and this was just ridiculous."

	"But the son, the son was like, we think he had a drug problem too. And he's been in and out of jail and he lived in her cellar."
Aide's use various strategies to try to interact successfully with families.	"But I've even had family members give the information to the office and it's nothing like what they say because maybe they haven't seen them in a while. Maybe they only see them at the time of the day, you know, I don't know." "Trying to get them [family] more involved in the care has to be challenging because they expect the PCA or the CNA or whatever to do everything. And we can't always be there. Just like they can't always be there, we can't always be there. And just having them come visit for an hour can like help that person's emotional health so much." "I had the opposite experience because a lot of times family members will look to me like the expert and I'm not. So that's interesting." "Well I would give my opinion and make sure that they knew it was my opinion but, you know, it's not my area of expertise."

Most aides within the focus groups reported never having received any training on mental illness or behavioral health. This lack of training leads aides to feeling unprepared to manage the behaviors presented by clients with mental illness. Those who have received training state that the majority of the training content focuses on diagnoses instead of giving practical information on how to best respond to difficult behaviors. Training is also presented in a variety of ways, some more successful than others. Aides note that when they 'stand in the shoes' of individuals with mental illness they increase their understanding and empathy. Additionally, trainings led by experts who had experience, either personally or professionally, were highlighted as being most desirable. Trainings that were not in-person, such as aides who reported being sent information about mental illness in the form of pamphlets and fact sheets, were described as not being overly useful. Currently trained Mental Health Supportive Home Care Aides (SHCA) were the exception, with most stating that the training they have received was both effective and helpful in preparing them to work with clients with mental and behavioral health conditions. In addition to the initial training the SHCAs received, the regularly scheduled meetings required under the SHCA service were found to be an important avenue for continued training and on-going support for the SHCAs (see **Table 27**). The extreme difference found between the non-trained home care aides and the current SHCAs illustrated how critical initial and on-going training and support is for aides who work with clients with mental illness.

Table 27. Gaps in current training led to aide's feeling unprepared to work with clients who have mental illness.

	Commentary
Current training for aides is limited to information about mental health conditions.	"Yeah because you can't really mentally prepare yourself to deal with any issues that might arise if you have no idea of what you're walking into, you know? And then it's just kind of all slammed on you. And you're like okay. How am I going to deal with this again? And there's no real formal training of any kind that says how you should potentially deal with this other caretaker and what steps you should do to like help that behavior. Like there's no training really that I've seen." "But, they never actually said like how you shouldn't maybe react or, you know, teach us how to actually handle the situation, which I though was kind of weird."
The format of trainings is reported to affect its efficacy.	"The part where they, you got to be pretty much in that persona of the person with schizophrenia. It was very helpful just to really understand that this is what is going on in their head….Basically they were videos- the movie was like a video tape from the perspective of being at the person's face. And then you can hear all the voices in the background, what they experienced. So that was, that was huge." "[I was trained] on hoarding though, but it was—they sent me like a sheet of paper with information and then a test with it. You read it and you fill out the answers and that's it. I mean it's good to go into detail like they're saying, you know, have somebody that's really dealt with it, really been in there. And share, you know, stories and situations. I think that would be more helpful than just reading, you know, the paper and answer questions."

	"We talked about alcoholism, which kinda related to the fact that I was working with them at the time. And then we had a speaker that came into our company and spoke on different topics and it really helped get through that a lot of schizophrenia and there was a while listing of psychological, different methods and things that they talked about. So it was really a help when you really went into this."
Current supportive home care aides are better equipped to work with clients with mental illness.	"What I remember- because it was quite a while ago that I went through the training. What I remember, what was good was we had things defined for us. For example, I walked into this not knowing what the difference was between schizophrenic and multiple personality. And these things were defined for us so that we knew. Most of the time we didn't know where we were going or what was wrong with the person we were seeing, but at least we had a toolbox." "When I took the course I felt like I learned a lot because I learned so much about mental illnesses and what makes a mental illness. What is pathological and what is not, for example, depression may be, may be not, depending you know, you've just had a terrible thing happen in your life. It's normal to be depressed. But for the person who's always depressed and can't get out of it, that's pathological." "We had for a long time, we had, twice a month, supportive meetings where we exchange information and everything. Now we're down to every few months, but we still get together and do that. A lot of times it just disintegrates into war stories and sometimes we can't work our way through those. But most of the time we learn things."

Home care aides desire more training to give them the skills and the tools to better perform their job. In particular, aides identify attributes of the adult learning principles and format as important for an effective and useful training. Hearing directly from experts in the field, role plays, case studies, and on-going training were all suggested as components for the future training. Learning how to maintain compassion, be patient, build boundaries, and not take client behavior personally were also highlighted as areas of training need for home care aides who are providing care to individuals with mental and behavioral health conditions. Tools and resources to bring with them on the job, like checklists or fact sheets, were thought to be an additional training device that could remind them of what they had learned. Trainings offer home care aides not only the skills they need to do their job, but also offer an opportunity for peer support. Providing adequate time to share experiences and provide advice and insights is as important as the training and learning (see **Table 28**). The adult learning principles endorse the inclusion of many of the techniques and components identified by the home care aides who participated in the focus groups. It is recommended that the new mental health training for supportive home care aides be designed using this method.

Table 28. Aides suggest that future mental health training focus on practical information for use in their daily work.

	Commentary
Adult-learner format identified as being most useful for training of aides.	"A psychiatrist that deals with bi-polar and depression and stuff like that- and behavioral issues speaking and telling us things about how best to deal with that situation, who we can call if it gets out of hand, stuff like that. That would be nice to see. And perhaps like she said, some kind of doctor that can explain how some medications can do this, and some medications can do that. That would be nice to see. Some training that involved those." "Some real professional in the field that have a lot of experience with it that can like give us helpful tips, and tricks, or whatever to like- so we're not going in blind, you know? So that we have some kind of fall back information that we can use to help" "I think the training should be a little bit more- like they should come and do it every six months, the training. They should do at least a month of training. And then if after you do a month, put you into a client's house that has mental [health issues] and you see how it goes. And then have maybe a month of like, okay how was it? How did it go? Like you know, are you okay with the case? Do you feel comfortable with it? Do you have any, you know, any concerns about it or anything?" "It's like with just the role playing. And then if somebody came in who is an expert on it, watched us interact, then get the feedback of what could you do differently in this situation? How would you handle that better, or differently? Would it work? Why wouldn't it work? I really think that's more helpful than any information that can be given to us."

Aides identify the need for training on maintaining personal composure.	"Something to learn about being more compassionate. And seeing these people as people with a history, and not just someone with bi-polar, or someone that hits and swings at you and calls you names all the time. But they were someone who was healthy just like you, probably when they were your age and that they need you to explain things to them and not rush them all the time." "Sure it's patience too I think plays a part in that. But you, you definitely have to have like, not so much the gift. But you have to have the compassion to care for someone in order to, you know, do this type of stuff." "[Training on] not to take it personally because, you know, a lot of times their anger is- you get the brunt of the anger, but it's really directed to somebody else. You know, it's about something that happened to them probably before you got there. So it's like you must learn to not take it personally and a lot of people have trouble with that." "Definitely boundaries. What are the alternatives? What are the tools that are out there for you to use? Like once you've established those boundaries, how else can you deal with this situation so that you don't become the all and all?"
Development of handy resources to be used in the field seen as an important addition.	"Look for like unsanitary things that could like really cause harm to someone, like eating bad food that is like bad, bad meat, you know? They should teach us how to like handle that situation too. Because if something happened to them on your watch then you could still get in trouble for that, you know?" "Maybe something that would point out, red flag something you should be looking for to identify a situation or a problem." "My thing is like you need a Bachelor's degree to be a counselor for people with Schizophrenia. They're sending us in with health aide degrees. It's just as important for us to be prepared and protected, if not more, than somebody that's counseling them once a week. So I think like extensive training, the company should pay for. And you should be able to get more than a certificate. I mean if that's what they want us to deal with? People are staying at home. People aren't going to nursing homes now and we're being pushed. I mean it's just going to be so prevalent with people with mental illness but it can be very dangerous at times. Very dangerous."
Aides identify the need for support as a critical component of the training.	"When we have classes it's always funny how I'm always going through something right then and there. And we'll have a class that- and I'm like I'm just going through this. Whey this always happens to me I don't know, but it's so helpful. So I just think that we should have support groups because sometimes I think I'm the only one going through it. And then when we have a class and everybody's raising their hand and telling their story, I'm like whoa. Now I don't feel like answer that. You are not equipped for this. You might as well quit."

Specific conditions were identified that home care aides felt needed to be included in the mental health training. One unique topical area was the aides' interest in learning more about medication side effects and symptoms of medication non-adherence. Additionally, there was an interest in learning about those clients who are diagnosed with multiple mental illnesses, have mental illness in addition to chronic conditions, or who have dementia coupled with a mental illness. The other conditions suggested by home care aides for inclusion in the training are listed in **Table 29**.

Table 29. Several conditions specifically identified to be included in future mental health training.

Condition
1.Schizophrenia (Split Personalities)
2. Discerning between being sad and being depressed
3. Symptoms of medication non-adherence
4. Medication side effects
5. Violence and/or aggression
6. Dementia
7. Substance abuse
8. Dual Diagnosis
9. Hoarding

Section 4. Focus Group with Home Care Aide Supervisors

When it comes to professional support and accessibility to training for home care aides, agency supervisors play a crucial role. For this reason, three focus groups were conducted with aide supervisors (n=20). A majority of participants identified themselves as nurses by training (55%) and reported a wide range of experience (see **Table 30**).

Table 30. Descriptive Results Supervisors (N=20)

	M(range)	N=
*Professional Credentials**		
Nurse		11
Social Worker		2
Home Health Aide		2
Female		18
Years of Experience	15.5 (1-30)	

* The credentials of 5 supervisors are unknown.

Substance abuse and hoarding were the most commonly specified mental or behavioral health conditions that supervisors named as posing challenges for themselves and aides (see **Table 31**). In addition, a variety of other conditions including personality disorders and general mental or emotional illness were described as being challenging and sometimes not even accompanying a clinical diagnosis. Depression and bipolar disorder were also mentioned as presenting regular challenges to aides and supervisors in providing safe and quality care to clients.

Table 31. Frequency of mental and behavioral conditions specified by supervisors.

Condition	n=
Substance abuse	8
Other*	8
Hoarding	6
Depression	4
Bipolar	4
Anxiety	3
Schizophrenia	2
Dual diagnoses	2

*Other diagnoses include: traumatic brain injury, personality disorders, or unspecified emotional/mental health condition

Among the most notable findings that surfaced from the supervisor focus groups is the notion that challenging client behavior is most disruptive to care provision, regardless of any specific mental or behavioral health diagnosis. For example, refusing care or being non-compliant with the care plan was highlighted as perhaps the biggest challenge that aides and their supervisors must overcome; and this type of behavior accompanies a variety of mental and behavioral health conditions (see **Table 32**). Supervisors also cite the inability of aides to personally cope with challenging behaviors as a major barrier to providing safe and quality care to aides. These findings point to the need for training to focus on the appropriate reaction to a variety of behaviors, as opposed to being condition-specific.

Table 32. Supervisors explain that many challenges for aides go beyond the mental or behavioral health diagnoses.

	Commentary
Client non-compliance is a major barrier to care for both aides and supervisors.	"I think medication compliance and attending counseling sessions are the two major things that we bump up against that are barriers to providing the care." "…clients can be resistant….A lot of refusals. You have to kind of build up a trust. So they need to know that they have to build up that rapport and trust first with the client in order for them to at least be able to accept them into their home and maybe allow them to start to do something with them. Just so long as the workers know when they go in that the client is the one in charge. You know, it's their home. " "One of the biggest issues is not home…They have a home. They're just not in it. They're not at home when you go to treat them…So it's really non-compliance. They're not compliant with the plan of care. They don't adhere." "…folks that isolate because of their mental illness and don't go out to get the care that they need. So they get- All home care providers and treatment can be challenging versus their ability to leave the house and go to [a]… program or something like that."
Aides struggle to personally cope with challenging client behaviors related to their mental/ behavioral health conditions.	"I think one of the hardest things for the aides is no matter how mentally disturbed the client is, when they have family who will have nothing to do with them [client].I think that's very hard for them because they see value in everybody or they wouldn't be doing this [work]." "…we're dealing with home care aides, a lot of them have psycho social things in their background. …if that aide has a little depression or a little something…and you go see the client and you pick up the same thing? Then you know this is just not going to work." "There's also the allegations a lot against the aides, that they're mentally ill. That they're refusing – this, well we just got the one yesterday – identity theft. And then trying to figure out what is actually going on. And trying to get into the home and them not wanting us to go in the home."

"If you spend a lot of time with people with mental illnesses, sometime you feel a little mental yourself. And I have to say that from experience…They're [aides] at high risk for depression I think. Because if you do this- Yeah. And you can do this for a long time, like I said you almost think, oh, that's okay. You get de-sensitized to what's going on. "

Managing and supporting aides who are working with clients that have mental or behavioral health conditions can be just as challenging to supervisors. Supervisors described a number of regulatory barriers to providing quality care to the clients and supporting the aide to the full extent that they need support (see **Table 33**). For example, the coordination across providers can be inconsistent and oftentimes leaves supervisors, and subsequently home health aides, without adequate information about the client and their mental or behavioral health symptoms. As described in-depth by the aides, these symptoms make care provision more challenging, time consuming and sometimes nearly impossible. Supervisors echo this sentiment and add that as the primary support system for aides, they too are often left without information or proper care coordination with other providers. Together, these challenges make it difficult to properly support the aides in providing care to clients with challenging behaviors.

Table 33. Supervisors face their own set of challenges in managing the care for clients with mental and behavioral health conditions.

	Commentary
Regulations can create barriers to care.	You know? So you know, it, it's not an easy thing. Again it goes back to the whole medication thing that you and I were talking about. They have lock boxes, many of them. Well who has the key? And what responsibility can the aide have, or should the aide have, or is allowed to have under the ASAP reg[ulation]s to say it's time for your medicine. I'm going to unlock the box for you. But then the client's supposed to take their meds and then the box gets locked again. Or can the aide not do that because that's considered a piece of administration. So you have all those, the rules and the reg[ulation] barrier, to med[ication] compliance and adherence. "What's the answer to that?" "There was no answer. Or the answer is, It's your agency policy." "It's gray area" "Well again, it's hard to support the aide. And again we can't go as far as the family because of the ASAP. And they're not our clients, per se, as opposed if it was your private pay there you could sit down with the family. Then it falls more on the case manager from the ASAP to help deal with the situation." "…we do have nurses that go out and place initially,… our nurses do this whether it's a homemaker or a CHHA. Not that we have to, we choose to, and I think for us that's been best practice ... Yes the care plan is given to us by the ASAP, but we still call the ASAP and say, this care plan looks great but you missed this. This is a problem, and update that care plan on admission to make sure we're meeting the needs of the client. So just because it's given by the ASAP doesn't mean it's right. I think that one of the keys if it's coming through and they're asking for a supportive aide you get a lot of information. It's the one's that aren't coming through with supportive aides that really should be, that that's kind of where there's no support."

Coordination with other providers can make information sharing difficult.	"No diagnosis? Oh all the time… A lot of times we don't get a diagnosis" "Well I think a big thing with the elderly too is that a lot of these diagnosis went unnoticed their whole life." "I have a conversation depending on the client obviously, but most of the time with the client and the aide so everybody's clear. And I say that the purpose is so you understand what she can do and you understand what she can do and we're all on the same page. And I will go back out more frequently and the frequency is dependent upon the behaviors. And I'll talk to that aide frequently, but under the ASAP umbrella that's not the reality" [Other participant] "And that's so true 'cause a lot of times the ASAP will not tell you any of that…Or they have no idea." "…and sometimes they're [client] in that financial bracket where they have like a dollar too much to qualify for things but no money to pay for anything…treatment can be challenging…" "…sometimes there's other agencies involved too and you've got to be careful that you can't, you know, you can't crossover. Sometimes we don't know who this other person might be, and you've got to watch what you say. And especially if we're not doing the transportation but somebody else is doing companion care. It's kind of like so that gets a little tricky when there's too many hands in the pot and then you, you know, you reach out to the case manager. And it's like well can you talk to the other agency because they're showing up the same time we're there and it's kinda causing some confusion. And oh yeah I'll take care of it and the aides going, "There they are again." So sometimes it's just like a little frustrating. Communication can be tough sometimes. And everybody's got a huge workload and, you know, you do the best that you can."
Supervision of aides can be a challenge when working with a mentally ill client.	"You know, if you have a client with behavioral health issues you really, there's certain aides who do really well with- There's certain nurses who don't even do well. So there's certain aides who do really well and there's certain ones that don't." "It's really selecting the appropriate aide and the approach. Like if you get the right match? The client is going to do so much better...And the aide will be happier too when it's not just a constant resistance and push/pull. " "Because every aides different and what works for one doesn't work for the other. They might not like the color of your hair or something. It's a puzzle sometimes. You have to fit the right person" "…aides don't tell you things. They think it's their job to fix whatever they come across. So unless you're out there on a very regular basis like weekly, twice a week or something, they're not just going to pour everything out to you. They only do that when you see them."

"And I will say that one of the stressors on the aides in that environment is, because I've had aides in similar environments where they don't report it because they're afraid to lose their job. And they figure that they've been with this client, you know, for two years on a live in, loves them like family. And now the son moves in, starts drinking, blah, blah, blah. And if the case ends then I lose my connection with the client and I lose my job."

"You can't support them enough. It's difficult to do this case, after case, after case, after case. That's what they do 40 hours. So that support is critical, you know. Sometimes they'll just call and say I've gotta talk. I say okay. You know, but if that's important or if they really feel, you know, that they need some help, sometimes I'll … go out and make a visit. Go out there and see, you know, because that? That's a good support for them too. To see it through her eyes and to say 'oh yeah."

"It's awful. You know, I mean if you have CHF we can give you diuretics, we can weigh you, we can make you feel better, but how do you make somebody with a psychiatric illness feel better if they won't adhere to their meds."

As was described by a number of the aides who participated in this project, supervisors recognize that aides often develop their own ways of working with individual clients with mental or behavioral conditions. Some of these strategies are described as successful by supervisors and the supervisors also describe how they themselves take action to provide care to the client and support the aide (see **Table 34**). Supervisors tell stories of aides who were able to build a healthy personal relationship with their client that allowed them to provide care without much difficulty. In addition, supervisors describe the importance of celebrating small successes with aides and recognizing them for a job well done when it comes to these difficult clients. Communication with the aide is deemed an integral aspect to aides being able to successfully provide care to clients with mental illness or behavioral conditions, and when necessary, supervisors take direct action to improve information exchange across providers.

Table 34. Supervisors recognize when aides are successful or unsuccessful in responding to client's behaviors and also employ their own methods of supporting aides.

	Commentary
Building a healthy relationship with the client is an important key to success for aides.	"Slow changes. Don't walk in there and like want to uproot their whole house. They really have to trust you and I think it's slow changes. That's taking baby steps in their homes." "…And uh, what happened was this girl was from a culture that was very respectful. And when the person asks you a question, you answer it. She ended up giving her name, her telephone number, her address to this person who ended up calling her, writing her letters [and] writing letters to politicians in the city. And it became to the point where, you know, we had to, of course, notify the caseworker and pull her off the case. And eventually she had to change her number. So the workers need to know that when you're dealing with someone with schizophrenia, there's boundaries that need to be set." "But I think then, you know, for a safe hoarding environment it's just about instructing the aide that you're not going to change this. That's not what you're there for. You're not there to change their behavior, because for most people that are hoarders, they hoard to fill a void. I mean that's typically there's been some sort of trauma, or a loss, or something that's happened. And that's how they really hide from it, but that's what their coping mechanism is. And you can't, you can't just expect that you're going to go in there and because we have the funding, or you have the aide, we're going to fix it and take it away. We kinda, you have to work around it." "And they have to know that sometimes you have a success. That you can throw one thing away and when you go back there's ten more things. And you have to really be mindful that that's okay. It's okay. You just have to approach it with, it's okay. So we'll work on it a little more. And, you know, if you go back and it's undone, its okay. And I think the more you do that, the more they tend to trust and accept you. And the more they accept you, the more they kind of want you to help them."

Supervisors highlight a number of ways they support the aide when it comes to clients with mental health conditions.	"And if something happens they call me and I'm in touch with the Social Worker. And they kind of address it from a different area so that she still feels trust in us. Like that it's not really coming from us. Like she wanted our aide to transport her to XXX and she used to have some drug contacts there so that, you know, they called me. And I said, "Tell her I was the bad guy there. We don't transport her out of XXX County. We can't do that." "We have a nurse that will place initially. So the nurse will go out. They'll go over the care plan and assess any issues and do education with the aide right then and there. So if there's behavioral issues and the nurse recognizes that? That would be a part of the care plan and they add that to the care plan for the aide to follow moving forward. And then we, all of our, you know, supervisions after that are done by nurses as well." "I think one of the things that works is the aide having access. Now when I say the aide having access I mean someone who's going to answer that phone on the other end. Not that they're going to get an answering service. Not that they're gonna get a voicemail. That's what's worked for me with aides is that they know they can call me 24 hours a day and I'm going to pick that phone up, it's not going to be, oh I have to wait to hear from them until tomorrow, because by tomorrow, it's already over." "So I try to make sure that I keep that calendar updated and that I talk to them at least once a week. They're more apt to unburden themselves if I'm calling them then if they have to call me. You know, when they call me they know they're calling me with a specific problem. But when I call them it's open for anything they want to talk about. It makes a difference that I'm approaching them. Like "what's going on?" "How's it going?" You know, "Any problems?" "Well we have, the supportive aides in XXX I've been with them now for three years. I did the training and they're strictly mental health. So I meet with them every single month. And that's when you find out a lot of information too."
Supervisors also take action to support the client with mental health conditions.	"There's one caseworker here who's excellent. I don't care, anytime I get her she follows through. She let me know and that, that probably, her clients are probably serviced better than others. She's on top of things. She lets us know. If I call with a problem she'll come back and say yeah this is what we're going to do. Blah, blah, blah, blah. So that's great to have that information, because that allows me to let that aide know so that she can service the client much better." "Yes the care plan is given to us by the ASAP, but we still call the ASAP and say, this care plan looks great but you missed this. This is a problem, and update that care plan on admission to make sure we're meeting the needs of the client. So just because it's given by the ASAP doesn't mean it's right."

When it comes to working with families, supervisors mostly suggest tactics that may be useful to incorporate into a training (see **Table 35**). Getting the family involved in the care plan and being sure that the supervisor can directly communicate with one family contact person have proven to be effective ways to both satisfy the family but also be sure that the aide is being supported in sometimes very complex situations.

Table 35. Working successfully with families can be tough for both aides and supervisors, but some tactics have proven to be helpful for the supervisors and the aides.

	Commentary
Supervisors cite success stories when aides were able to get the families involved in care of their loved one with mental or behavioral health conditions.	"And so she had him join them eating. She was a live-in aide. And she said, well you know, I'm cooking dinner. Why don't you join us? You know, I'm going to feed your mom and then you and I can just sit down." "…she's [aide] just noticing that the daughter's having behavioral stuff. And she's like 'what do I do? I'm here for him [client], not for her, but I know there's something definitely going on here.' … the son actually lives upstairs and he's very supportive. So she happened to just see the son … she's like, "I don't want to say anything, but I just want to make sure that your sister's okay." So she was level headed enough to be able to approach, you know, the brother. So he's like, "Yeah. I know. She's off her meds."
Sometimes, supervisors must step in and communicate directly with families in order to support aide in providing care.	"One thing that I find that's helpful in those complex situations when there's multiple children with multiple disorders, is that you say there's going to be one contact. And that if the other contacts try to draw the aide in, she says to them, you have to go to the supervisor. There's just one contact and then that person's responsible for talking to the rest of the people. Because otherwise, you know, your entire day will be consumed with one patient." "I just had a situation where a daughter who um, in general many providers feel doesn't care, is trying to keep them money, is long distance, and doesn't really get involved. But I actually met her one-on-one. And the first thing I did was acknowledge how difficult the situation she's in. And she just started to cry. She said, "You're the first person that's ever said how hard this is." "We had another case with the same scenario, where the son was an alcoholic living there and we, and then he became threatening to the caregiver. So we had to, you know, contract with him to, if he came to the house we were out of there. You know, that we would not- you know, we actually had written contracts that if this behavior takes place or if he arrives then we leave and you, the family, becomes responsible."

It can be very difficult for supervisors to support aide who is faced with a challenging client family dynamic.	"…And the daughter came home and moved in, but she had a mental illness. So we had to then get the attorneys involved in counseling for her and then get them to move her out because she was interrupting the mentally handicapped son that lived there. She would escalate him and then he would have behaviors that he never had before. Is it was just a very complex situation." "Sometimes with some of these elders that have some mental health issues; sometimes their children will be exploiting them for money. And, you know. There such a hold there for them to have somebody in their live that they allow that to happen. And I think when there's mental illness and depression it's even worse because, you know, they're being manipulated by these people who, by their children, by the brother, the whoever, that they're afraid won't come back. So my aides have told me, you know, the daughter is in there. And the daughter is eating the food. She's taking money from the mother. She doesn't have that much. So we report that right away to Elder Services."

Current training opportunities for supervisors were described as being useful but they confirm that there are not enough training opportunities for aides who are working with clients that have mental and behavioral health conditions (see **Table 36**). They emphasize that future training on these issues should focus on recognizing warning signs and reacting to challenging behaviors (i.e., knowing who to contact and when) as opposed to training on specific diagnoses or symptoms of each condition. In addition, they cite the need for some training on personal composure including how to recognize manipulation and maintain boundaries with clients.

Table 36. Training provided to supervisors is helpful, but supervisors emphasize the need for more training for non SHCA aides.

	Commentary
Little or no training is available to aides.	"And it's harder to train the trainer too, right? That's why it's a train-the-trainer. You teach us, or you know, then we go back and because you can't get your aides in. So, it's hard to get them in once a month at your own office." "I think that's part of the problem is that we're [supervisors] offered so many in-services. And we go to things for our CEU's for our nursing and social work. So, you know, I ran a symposium on hoarding. You know what I mean? But it was all us [supervisors] in the audience. You know, not necessarily like the direct care staff." "I think a training component for, listening skills and in validating people's feelings. I always tell my staff the first thing you do is you validate what they're saying. Yes, you're right. That is happening. You know, whether they're right or wrong, they're right. Because they're the client. So, you know, you validate what they're saying and listen to them, and make them part of the solution."
Supervisors highlight the importance of training on personal composure when working with clients with challenging behaviors.	"I think that's part of the training that a lot of the aides need is to know the boundaries of what they are supposed to put up with as far as the treatment. And to know that it's okay for them to say stop. And I'm going to report this. And I'm not going to be able to, you know, handle this case for you right now, or I need to leave." "Another part of the training is them recognizing manipulation, because you gotta remember that they're caregivers and their educational level is here. And so they're easily manipulated into doing things that they fall into that behavior and become, you know, co-dependent." "Aides need to know what to do to keep the client safe and themselves safe. Also, they need to know when to call the nurses and when to call 911. When they do call, they also need to be trained on what to report to the nurse or to the 911 operator." "And I think it's important too to teach caregivers signs and symptoms of crisis, because there are always warning signs. But because they aren't nurses and weren't trained in that or they're not social workers or psychiatrists, they don't see those warning signs. So if they had that then they would know, well what do I do when I see the warning signs. Who do I call? But that's an important thing they need."

Training should focus on recognizing warning signs or behaviors and not on diagnoses.	"I think, I mean if you look at what we see I would say education on disease processes and, you know, manipulative behaviors and how to handle those and I think the aides will probably agree with that piece of it." "And the solution for that would be to have the homecare providers of the caregivers a list of the resources that would be available, such as, you know, drug company applications for the medication that they need, you know, would be very helpful."

Finally, supervisors specifically named a number of focus areas for training. These are listed in **Table 37** and primarily address how to handle difficult behaviors and still manage to complete the work. One unique area that supervisors mentioned is how to provide care for adults who are members of cultures that have differing views on mental or behavioral conditions.

Table 37. Supervisors name specific topics to be included in future mental health training.

Condition
1. Nonviolent conflict resolution
2. De-escalation
3. Hoarding behavior
4. Traumatic Brain Injury (TBI)
5. Dual diagnoses (mental health + physical health)
6. Cultural competence related to mental illness

Section 5. Focus Groups with Community Stakeholders

In order to triangulate qualitative findings from home care aides and their supervisors, two focus groups were conducted with a number of stakeholder representatives (n=15). Over half (53%) of these stakeholders came from Aging Service Access Points (ASAPs) throughout the state; and nearly all of them were involved in the development and maintenance of contractual relationships with home care providers for their service population. In addition, representation from home care agencies, non-profit organizations as well as universities and state government participated in these focus groups (see **Table 38**).

Table 38. Descriptive Results-Key Stakeholders (N=15)

	M(range)	N=
Type of Affiliated Organization		
Aging Service Access Point (ASAP)		8
State or Local Government		1
University		1
Not for profit Organization		3
Homecare Agency		2
Female		13

Stakeholders identified common mental or behavioral health conditions within the context of the larger system of homecare. For example, the conditions that they referred to as being common were described as being a problem for the aide, the agency supervisor and ultimately came back to the stakeholder organization for additional action or support. Similar to both aides and supervisors, these stakeholders named depression, hoarding, and substance abuse as the top three conditions that their homecare partners face when serving clients with mental or behavioral health conditions (see **Table 39**). They also identified paranoia as a condition that often creates challenges for home care aides, the agency supervisors, and subsequently their own stakeholder organizations to provide safe and quality care.

Table 39. Frequency of mental and behavioral conditions specified by stakeholders.

Condition	n=
Depression	7
Hoarding	6
Substance Abuse	5
Paranoia	5
Dual Diagnoses	3
Undiagnosed	3
Personality Disorders	3
Other*	3
Suicide Ideation	2
Bipolar	2
Anxiety	2
Schizophrenia	2

*Other diagnoses include: ADHD, dementia or unspecified emotional/mental health condition

Perhaps the most interesting finding that emerged from the stakeholder focus groups was the clear linkage between the challenging behaviors of clients with mental or behavioral health conditions and worker turnover and burnout (see **Table 40**). The stakeholders provided a systemic view of the homecare landscape in Massachusetts and thus the description of mental and behavioral health training was described within the context of how the mental and behavioral health needs of adult's impacts the larger homecare system. Challenging behaviors associated with mental and behavioral health conditions coupled with the lack of adequate training for aides to respond to these behaviors was described as a clear pathway to employee turnover and, in some cases, the inability of the agency or ASAP to provide homecare to particularly challenging clients. For those aides who provided care to clients with mental or behavioral health conditions, these stakeholders speculated that those aides experienced great burden. This burden was aggravated by the difficult family situations that came along with clients who suffer from mental illness or substance abuse.

Table 40. Stakeholders link client's with mental and behavioral health conditions to aide turnover and burnout.

	Commentary
Challenging family dynamics can add to the burden placed on aides.	"… you get a lot of… angry families … [who say] You're not good. You're scum. …workers and the supervisors, they can come to me, there's weekly supervision so they have people they can go to and say this is hard. And you keep them longer, you know? I mean, that's true."
	"The one other thing that I would add is… anger in terms of families because I think people really do, can get scared. …not scared of violence so much, but … that demanding daughter or that difficult son…I'm going to get in trouble because they're angry."
	"…a mother and a daughter had a shared psychosis. And the daughter would have to taste the mother's pills and, you know, and that took- a lot of work. I mean so, you know, I was the clinician but I was thinking about and, you know, it took me a while to understand what the heck is this about? And we're getting consultation, trying to understand. But I was thinking if there was a home health aide, and I don't know if they would allow one in, you know. …I mean I didn't talk to the home health aide. Where is the communication? …It would have been probably very helpful if there was a home health aide for me to talk to that person and say listen, you know, this is what you're seeing."
	"You know, families are so complicated like you said. I mean again I remember working in places where, you know, somebody would say that daughter is the worst person in the world. It isn't easy. Those are very challenging I think. I think that patient's rights would be important to inform health aides and case managers…You know, I think my mother should have this or that. Or, you know, and one of the things we always explain to families – and I explain this to the family all the time – is that your parent has the right to live like this if they can make that decision."

Behaviors associated with mental and behavioral health proved to be a major contributor to aid turnover and burden.	"And it's kind of just a process of managing their relationships. … you know, because sometimes the clients will say something that's really inappropriate and [the aide] says, "I'm not going back."… so it's really, it's intensive case management. Yeah, just trying to get that service in [the home]."
	"One minute they're [the client] 'oh could you do my shopping?' and the next minute they're berating them [the aides], they're almost abusing them. And you need very thick skin to deal with that. And a lot of the aides are like that, but, or they fire them all the time. You know, this one called me the wrong name. My name is Susan, not Sue. You know, or I don't like her name. I don't like Chrissy. So …Get rid of them. And then you're running through so many [aides]"
	"I think the …borderline personality is the really lethal, bitchy, angry client and for some reason they don't come to me …Until it's getting to the point where the provider's starting to worry that they can't find anyone else. They've been through all of their best people. We try to prepare the homemaker… but it's tough and we can't sustain them because the elder all have a bad day. And no matter how good the worker was, they're just so easy to vent on. And they're in there for a period of time too. You know, the case manager or the nurse is in there for a visit and they leave. The worker's there for two hours, three hours or a couple of times a week. And they, you know, that's a tough burden on them [aide]."
	"Another situation we see are the folks that blame the homemakers or the supportive aides for everything. You know, this is missing and part of it can be a reality. It's part of the problem. But it's when the, it's the plastic flowers on top of the fridge. Or, you know, things like that -- that paranoia that's involved. That's really tough for a worker to deal with. We change the worker. For the worker's sake too, you know, I mean we'll log it. We have the provider investigate. You know, we kind of weigh it – jewelry versus plastic flowers. Is it, you know, but they also, they've been talking about me in the building and that paranoia is…, it's really tough on the workers. And you know some of them avoid to be short term, but then you run out of workers. You know, we only have a couple of vendors that do supportive home care aides. And I'm really glad the mental health aspect is being looked at because I don't know if the OEA heard us when we said it's the majority of supportive aides that are used in mental health situations and behavioral situations versus Alzheimer's, you know."
Lack of training and support for the aides working with a mental or behavioral health client was described as also being a part of high turnover and burden for the aides.	"And then you're going to send a worker in that has no idea, maybe they've just started. They're a fill in for the day just to get service in and then they say, "I don't like them. They were really upset. They were paranoid. They were aggressive. They were verbally abusive and then, no. They're not going to go back. Or they don't want those kinds of clients."
	"Our agency also does extensive training. We do in-services monthly. … but we have such turnover that I think we need to kind of re-hash pieces over, and over and over. And in general, I mean, I'm not sure how truly effective it is when you have someone that comes in for an hour and a half and, you know, they go do the presentation and the case managers return to their work."

"…it's different if you saw somebody with a stroke that can't… use their right side or left side. You know here, take these groceries up six flights. You wouldn't expect it. So you go in. You see somebody who looks perfectly normal and they've got this behavior that you don't understand…It's just, it's a lot. It's a lot. And then the young people [aides] wants to do a good job, very proud of working and wants to be in the field, or whatever, takes time to learn. That takes a lot of – and if you don't feel very confident, and then you don't feel very validated by your client or your agency, and you have no success, why would you want to stay in that field?"

"And their [client's] counselor came while she [aide] was there. And they were like, you know, trying to introduce each other and work out a plan of care. But I mean, I feel like the training for her has been very limited and she's really out there. And the minute you get trained, like this week they virtually have no hours for her because his one died, that one died. She's doing a Hospice and supportive aide now. She has no hours. She's going to go to another agency this week to try to get more hours from another agency. So this is what happens. They bounce around from one agency to another to get the hours and the training is inconsistent where they're going next and how much training they've had."

Stakeholders also described how the demands of clients with serious mental or behavioral health needs bubble up to create challenges not only for the aide and their agency supervisor but also for the stakeholder organization as well. For example, the stakeholders mentioned that sharing information across the system regarding the demanding care needs of clients is important. However, is not a permanent solution to ensuring that the client is safe and receiving quality care and the aide is informed and supported in their daily work (see **Table 41**). In addition, overall changes within the client population and general limitations within the homecare system produce immense challenges for stakeholders to stay abreast with the care needs and available tools for serving this population as well as to advocate and support aides who do this difficult work. These larger systemic issues are often out of the control of stakeholders. Findings from these stakeholders suggest that, in order address and better prepare this workforce to safely serve adults with mental and behavioral health conditions, there must be action at the state policy level.

Table 41. Consequences of mental and behavioral health conditions remain challenging, even at the stakeholder level.

	Commentary
Changing client demographics create new challenges for stakeholders to serve clients with mental and behavioral health conditions.	"…with these younger elders that there's a lot of, I think, burnout for the case managers and for the staff that are going in there. And I mean, I have experienced with several cases that they're almost unserviceable at this point, because there's been so much turnover, so many agencies have been used. And you're talking about somebody who's 66 … they're going to be here for a long time." "And there's a whole other level now with the One Cares. That's where most of our mental health and behavioral health issues are right now…. the rapport is a very different thing ... So I can imagine it might be also for the aides going in -- much more skeptical …, much more, you know, retreating back into their privacy. …there's a different dynamic. They're younger and they're much more mobile. And they're much more demanding. You know, a lot of times when we're dealing with elders, they may be home bound. You know, so they're there for services. They're there for their meal. With the One Care population? They – I'm not there for my meal, bring it down. You know, or I want my record and I'm showing up at your door, which we're just not used to. And I think the workers are going to have a whole different level of issues with this population of them not being home, of dealing with- stronger, younger people with real behavior and substance abuse issues."
Sharing information about clients with mental and behavioral health conditions is key when it comes	"Is there some way you could have a case conference where you try to set limits – with the consumer in front of the aide. So the aide sees you're at least trying to make- I mean my take is that these things only work temporarily. " "And time, after time, after time the care manager who thought she was going to go and listen to, you know, a lot of meaningless stuff, heard the homemaker say well a storm was coming up so I made her a little casserole and brought it over. It's like wow you did that? I mean, sometimes they go way above and beyond."

to stakeholder involvement in their care.	"I mean generally when we see something [we] ask the provider to go out as well so there's a joint visit. And the nurse and the, you know, consumer go over this rhythmically how everything should be done. But … it doesn't last forever."
Broader aspects of the home care service system are identified as barriers for meeting the needs of clients with mental and behavioral health conditions.	"In the ASAP system, homemakers and care managers never talk. They both talk to the service coordinator. They both talk to the client, but they never talk directly to each other." "And they're [agency] not firing her because she's going. And they need to fill those hours. They had these two classes of homemakers. The ones that are new, so the new clients get the new homemakers and they're not very good. The longer you get services, the more likely you're going to graduate from a mature homemaker who knows her way around and doesn't fall into these cracks. But even if her days are full and there's, you know, until she loses her consumer, she doesn't have any availability. … in a way we're talking about the ones who've most earned a reprieve from the tough situations and they were going to throw you into the toughest of all. This is what you get for doing your job well." "We know there's a disconnect between workers who are paid ten and twelve dollars and hour going in and having to deal with mental health, behavioral health issues and have this high level of training. There's too much expected of them for the crummy wages they're making too in terms of being this life coach for people. Somewhere, you know, if the federal government really wants home care to work but there's a big issue here that has to be acknowledged. And that's that you cannot have people who cannot even live on their wages going in to do this kind of work." "Well with the caseloads they have. Yeah. And that's not really their job. I mean you're doing depression screenings and identifying suicide risks. You're doing a massive amount of work to accomplish a successful hoarding resolution. It's beyond, you know, you throw that, one of those at a case manager and they quit. At our point now, we've got case managers that have just said yeah. I'm giving my notice in three weeks to be out of here in five weeks. And that's after they've worked for us one month. It's just too much and there's nothing we can do that's going to resolve a whole big problem." "We [stakeholders] feel like we're under a mandate that we have to. We can't say to a client you're beyond our scope. Or, you know, you're not willing to play fair. We're not allowed to say that. So we're trying to. We're sending workers in. If a worker worked at McDonalds she wouldn't have to put up with the crap they have to put up with."

Having multiple stakeholders in the same room resulted in the sharing of existing formal and informal models and interventions for working with clients with mental or behavioral health condition (see **Table 42**). These interventions often include support for both the aide and client when it comes to tough situations like hoarding, wrongful accusations, or social isolation of mentally ill or disabled clients. Each stakeholder described a unique way of managing clients with mental or behavioral health conditions. This finding points to the complexity of the client population as well as the need for a more streamlined body of information and training on how aides and supervisors respond to these clients.

Table 42. Stakeholders shared existing approaches for responding and managing clients with mental or behavioral health conditions.

	Commentary
Existing interventions available within their organization to confront challenging clients.	"Well we had a support group for hoarders that's actually been successful. Our clinician runs it and it's purely voluntary. It's not anything you're made to come to. And there's, they have homework to do and they have all these things. And we've had a couple of people who have actually allowed clearing out of their homes in baby steps, but it's been very successful." "I have aides going in and I'm buying games and people are playing Chinese Checkers and they're playing cards with people. They say, you know, I'd like, I have nobody and I don't leave my house. So we're adding like an extra hour with the grant money to say, let's see how these interventions go. For some people who are legally blind who say "I can never get out." They're just, they're saying, "I'm lonely. I just sit here. My daughter calls me occasionally." So, we're having some of these aides take people out for walks…But so that's kind of what we're doing. And people, families and the elders seem really excited that they can have this."
As challenges arise, stakeholder devise their own personal response to the behavior of a client with a mental or behavioral health condition.	"Well you know I have another hoarder with safety. We just had a case conference and we let the client know we were going to pull out because he's got 18 cats and two more pregnant. The house, your eyes burn and, you know, it's not healthy for the workers to go in there. And he chooses when he eats food just to throw it on the floor. You know we just said you can't do this. We can't have our workers, you know, in a place like this. This is a disease for them." "Another situation we see are the folks that blame the homemakers or the supportive aides for everything. You know, this is missing and part of it can be a reality. It's part of the problem. But it's when the, it's the plastic flowers on top of the fridge. Or you know, things like that—that paranoia that's involved. That's really tough for a worker to deal with. [We deal with the situation] by changing the worker. For the worker's sake too, you know, I mean we'll log it. We have the provider investigate."

The participating stakeholders really illustrated a 'big picture' perspective on the issues of mental or behavioral health facing clients, families and aides. Thus, their suggestions for future training on these issues focused largely on the adult-learner format (i.e., drawing on practical experience and useful tools to use in the field) and the need for overall professional development training for aides (see **Table 43**). They highlight the importance of aides having a professional demeanor both to gain the respect of clients and families as well as to develop their own confidence in working with all clients, in particular those who have challenging mental or behavioral conditions. They also provided some unique suggestions for the administration of the training material, including shadowing, incorporating supervisors into the training and the blending of multi-media.

Table 43. Based on the stakeholder's experience with prior mental health training, they suggested that future trainings emphasize format and the professional development of aides.

	Commentary
Administration of training must draw on adult-learner methods.	"You know, it's finding a good person. It's finding a good speaker. Somebody that engages the audience, because anybody can put together a power point in a very dry, disorganized, and it's just kind of a boring thing. So it's somebody that has some practical [experience]." "I think role playing in that training session would be really helpful dealing with some behaviors and, you know, how would you approach it….But you know, when he's chasing you around the kitchen how do you redirect that, you know?" "Another good thing in a training I often like is if…if you have the person with the mental illness, with the depression or the anxiety talking about interactions that they've had with people that have felt good and have felt bad, and know you might not be able to- you know like panels of people with the disease that speak, or whatever…You may not be able to do that kind of thing, but you might be able to do videotaping of it. You know, so that maybe once again it kind of highlights what they're feeling since we're not in their shoes."
Stakeholders suggested some unique components of training.	"I don't know if it's necessarily a training, but when I was at XXX and I was a counselor, we did shadowing, which was nice because when you go into someone's house that is schizophrenic and extremely paranoid, and I mean obviously you pick the clients carefully, but a lot of these times they've built relationships. Even a case manager sometimes builds a relationship. The shadowing part was nice with difficult clients because you could see the direct interaction- how the worker responded, how the person responded. And doing that kind of, the new worker or the new individual isn't feeling kind of pressured. They're not in the spotlight, they're kind of an observer. They can see, you know, really what those types of interactions are. And I, when people used to come out with me it was a nice way to kind of bring them up to speed on, you know, how things can be." "…And also I think towards the middle there were at least two parts where supervisors were then invited in and there was a fair amount of discussion about the role of supervisors when you're supervising people where English is a second

	language. It was an excellent program. I think it, you know, people- it changed people that were in those positions." "So, but the program that I liked was our blended training that we just did at XXX on mental wellness and resilience among older immigrants and refugees where we had a face-to-face, and then online, and a face-to-face session. But if you did something like that with home health aides, you know people, but then maybe kept up, you know, a regular training?" "…But I really do think there should be more specialties around hoarders, around trying to manage substance abuse, trying to manage the dual diagnosis, trying to manage individuals that are schizophrenic. So I think the more education, the more you specialize the better off you can manage. I mean substance abuse and dual diagnosis is totally different than dealing with hoarding and going back and forth and trying to manage the symptoms of that, and trying to manage the lying, and the stealing around the potential pills or prescription meds and all that stuff, then going in and trying to manage hoarding? It's two different worlds and thinking differently. So I think that you really need to try to do more specialties as opposed to broad range."
Professional development of aides is an important aspect of future training in working with clients who have mental and behavioral health challenges.	"…To be mindful of the fact that good people want to stay where they are. If they're willing to try this then it means that there's some interest in commitment, or interest. So the education can only help to retain them in that position…and the support. And we're doing everyone a disservice if we don't do that, you know. So I mean, 12 hours sounds great, but I just think that ongoing support, ongoing training…you know is a way to kind of hold people in the position. You know, even as they work their way through nursing school or work their way through the next career. I mean it would be great for people to feel like I have a job, well even if it's something to hold me until I move onto my next one, you know." "But I think, you know, a lot of people, aides? People don't see them as professionals. Oh, you do that work. And I, you know, to sit and say, and maybe even having the lead aide who knows- I mean some aides are really good- to kind of promote them." "But I wonder about career ladders and compensation. I mean that, you know, should this be part of a- I mean ideally that organizations can change or can create. There can be change on an organizational level. So for instance, again one of the home health aides becomes an outreach worker."

When making suggestions for future training modules, stakeholders identified several condition specific topics (see **Table 44**). Interestingly, stakeholders highlighted the legal parameters surrounding marijuana now that it is legal in Massachusetts for medicinal purposes. Issues related to the safety of aides and the reporting of illegal activity quickly become muddled for agencies and stakeholders. In addition, stakeholders suggest that the training include some education for aides regarding how they fit into the larger home health system. The purpose of this is twofold. First, it is important for aides to understand how their work contributes to the work of other providers. Secondly, it could also help them in knowing how the lines of communication operate for their client and whom is best to contact in case of responding to challenging behaviors among clients.

Table 44. Stakeholders identified topics to be included in future mental health training.

Condition
1. Depression
2. Substance abuse (specifically highlighting marijuana)
3. Suicide
4. Hoarding
5. Responding to Behaviors
6. The aides role within the larger system

Section 6. Interviews with Key Informants

Hearing directly from those who are viewed as experts within the realm of mental health and home care was critical to gaining a full perspective into the training needs of home care aides providing care to individuals with mental illness. The key informants were selected with input from the grant advisory board and stakeholders within the community. The key informants were chosen because of their expertise in the area of mental health, home care, or the broader aging network. Five in-person interviews were conducted with six individuals from state agencies and non-profit organizations (see **Table 45**). The interview questions focused on key areas of interest for this grant with particular emphasis on the training needs of home care aides who are working with individuals with mental and behavioral health challenges.

The input shared by the six key informants overlapped in several instances, such as suggestions to focus the training on providing practical tips and information on how to successfully respond to difficult client behaviors. Chet Jakubiak (see **Table 46**), Kimberlie Flowers (see **Table 49**), Mary Beth Dowd and Carrie Sibilia (see **Table 50**) all highlighted the importance of preparing aides to use effective communication techniques when confronted with challenging behaviors. Sue Temper (see **Table 47**) particularly noted the need for additional training to arm home care aides with the tools to respond when difficult situations arise, such as when they are being accused of not performing tasks as they should, either wrongfully or appropriately, for instance if the consumer blames them for taking something from their home, for taking too long to complete a task, or for bringing home the incorrect grocery items.

Additionally, many of the key informants mentioned providing aides with training on how to maintain their own personal composure when they are confronted with demanding situations with clients. For instance, Chet Jakubiak, Mary DeRoo (see **Table 48**), Mary Beth Dowd and Carrie Sibilia stated that it was critical for home care aides to learn how to not take the behaviors client's exhibit personally, as they are likely caused by their disease and not by the aide's actions. Also stated was the importance of teaching home care aides how to build and maintain strong boundaries in their relationships with clients and families. This point was noted by Mary DeRoo, Kimberlie Flowers, Mary Beth Dowd and Carrie Sibilia.

The key informants' suggestions significantly aligned with the recommendations made by the home care aides, supervisors, and stakeholders within the focus groups. But unique to the key informants were suggestions about the inclusion of training on the broader aging network either within the education of the aides and to provide separate trainings to other healthcare workers. For instance, Mary DeRoo, Mary Beth Dowd, and Carrie Sibilia recommended that information on the aging network, including the relationship between the ASAP, the consumer, and the home care agency be included within the training. They each noted that aides are often not aware of the larger system that is there to support the client, and in effect, support the home care aide as well. Sue Temper and Kimberlie Flowers spoke of the need for an improved flow of information between the agencies and organizations serving consumers. Increasing communication would help to improve care for the client and boost the home care aide's status as a more integrated part of the larger team. Kimberlie Flowers took this a step further to suggest that an accompanying curriculum be developed to train ASAP case managers on the supportive home care aide service and to increase knowledge and understanding about the role of the home care aide within the larger system.

Table 45. Individuals selected to participate in key informant interviews

Name	Title	Agency/Organization
Chet Jakubiak	Executive Director	Massachusetts Association for Older Americans
Sue Temper	Assistant Secretary for Programs and Services	Executive Office of Elder Affairs
Mary DeRoo	Director, Home Care Program	Executive Office of Elder Affairs
Kimberlie Flowers	Clinical Outreach Social Worker	Elder Services of Merrimack Valley
Mary Beth Dowd	Client Services Director and Mental Health Program Director	Greater Springfield Senior Services
Carrie Sibilia	Geriatric Clinician	Behavioral Health Network

Table 46. Interview with Chet Jakubiak

Primary Topics of Discussion

Training Topics:
• How to successfully respond to behaviors
  o Using effective communication skills
• Maintaining personal composure
  o Not taking the behaviors personally
  o Maintaining patience
• Building strong relationships with clients
• Observing behavior change (observation and reporting)
• Staying safe in the client's home

Table 47. Interview with Sue Temper

Primary Topics of Discussion

Training Topics:
• Responding to wrongful accusations
• Focus on the behaviors and not the diagnoses
• Substance abuse and medication adherence
• Red flags/signs to look for:
  o Abuse and neglect
  o When to call protective services
 	
General Suggestions:
• Receive all of the information about the client upfront
  o Know a client's triggers and how to respond

Table 48. Interview with Mary DeRoo

Primary Topics of Discussion

Training Topics:
• Challenging diagnoses and behaviors, including:
  ○ Depression
  ○ Anxiety
  ○ Lack of initiative
  ○ Explosiveness
  ○ Repetitive health complaints
• Building strong relationships with clients
  ○ Clients need consistency and reassurance
• Maintaining personal composure
  ○ Not taking the behaviors personally
  ○ The aide may not know going into the home the diagnosis or behaviors
  ○ Maintaining strong boundaries with clients and families
• Appreciating small successes
• How to successfully respond to behaviors
• Using effective communication skills (motivational interviewing)
  ○ On-going training and support (support groups/meetings)
• Training on the Aging Network- ASAPS

Table 49. Interview with Kimberlie Flowers

Primary Topics of Discussion

Training Topics:

- Challenging diagnoses and behaviors, including:
    - Substance abuse (relapse)
    - Untreated mental health issues
    - Depression
    - Suicidal ideation
    - Grief and loss
    - Hoarding
    - Refusal of care
    - Paranoia
    - Delusions
- How to successfully respond to behaviors
    - Using effective communication skills
    - Awareness of community resources
- Building strong relationships with clients
- Maintaining personal composure
    - Maintaining strong boundaries with clients and families
- Understanding and appreciating the impact of culture
- Standing in the client's shoes
- Appreciating small successes
- Communicating with difficult family members
- Self-care (ex. stress reduction, managing grief and loss, etc)
- Red flags/signs to look for and how to respond:
    - Depression
    - Suicidal ideation

General Suggestions:

- Need for increased information and clear communication paths
    - Implement a team approach with information flowing from the supervisor, case manager (ASAP) and the aides
- Need for greater support through supervision and group meetings
    - Home care aides should feel that they are part of the larger team
- Create accompanying training for ASAP case managers

Table 50. Interview with Mary Beth Dowd and Carrie Sibilia

Primary Topics of Discussion

Training Topics:

- Challenging diagnoses and behaviors, including:
    - Substance abuse
    - Anxiety
    - Depression
    - Suicidal ideation
    - Bipolar
    - Hoarding
    - Sexual inappropriateness
    - Racism
    - Loneliness
- Building strong relationships with clients
- How to successfully respond to behaviors
    - Using effective communication skills
        - Negotiation
- Maintaining personal composure
    - Not taking the behaviors personally
    - Maintaining strong boundaries with clients and families
- Standing in the client's shoes
    - Sensitivity training
- Staying safe in the client's home
- Training on the Aging Network- ASAPS

General Suggestions:

- Need for increased information and clear communication paths
- Need for greater support through supervision and group meetings
- Provide home care aides with tools and resources
    - Referral list they can provide to clients and families

Section 7. Mental Health Supportive Home Care Aide Curriculum Outline

Overarching objectives:

- Assist consumers in remaining safely in their homes/community setting
- Ensure home care worker has the knowledge and tools to feel safe, comfortable and effective in providing this specialized care

I. Overview of Behavioral Health

a. What does behavioral health mean? What is meant by the various terms we hear: Behavioral health, mental health, mental illness, and substance abuse?
b. Continuums (i.e. mental health and mental illness; younger vs. older)
c. Myths and realities (stigma)
d. Personal values and experience
e. Assessing/decision making vs. diagnosing
f. Cultural competence
g. Empathy
h. Trauma informed – even if you don't know the client, many have trauma histories. What's the role of trauma?
i. What types of consumers will we be assigned to care for? (e.g. profiles to include dual diagnoses)
j. How will the training be organized?
    - Discussion of format: Getting the job done by 1) focusing on describing behaviors (red flags to identify a problem, signs/symptoms/what to look for; and 2) what to do; understanding and practicing appropriate communication/tips and techniques
    - Each module will include a focus on:
      Behaviors: What does it Look Like?
      What's being expressed? How does it feel?
      How do I Respond?
      Personal reactions; strategies for managing the consumer's mental health behavior including the kinds of verbal and non-verbal/body language to use; and when and how to get help (e.g. warning signs/symptoms of crisis)
    - Decision tree approach to know what to do and when to do it
    - Weaving culture and communication (e.g. verbal, non-verbal, open-end questions, EARS) in each of the modules

II. The Role of the Specialized Home Care Worker

- What are the duties of the specialized care worker?
- How is success measured? (i.e. notion of small successes; ameliorate vs. curing or "fixing")
- What gets in the way of being able to accomplish tasks? (i.e. barriers to providing care including behaviors, family dynamics and systemic challenges)
- Setting clear and realistic expectations for each client
- Working with limited information
- Role of the specialized home care worker in reporting changes and concerns (i.e. care plans are not necessarily static; things change)
- Team concept (i.e. who is the team? how can members work in concert?)

- Having a plan
- Working with families
- Resistance (i.e. refusing care, non-compliance)
- Building rapport and trust – a delicate balancing act
- Assessing changes (e.g. appearance, speech, physical, eye contact, mood thinking)

III. Working with Depressed and Suicidal Behaviors – "What's the point?"

What does it look like?

- Depression is not a normal part of aging – signs and symptoms
- Different expressions of depression including cultural (e.g. somatization)
- Continuums: grief and depression, dementia and depression
- Passive vs. active suicidal behavior

How do I respond?

- Assess changes in mood and behavior
- Communication: verbal and non-verbal interventions
- How and when do I get help?

IV. Working with Anxious Behaviors – "I can't decide what to do."

What does it look like?

- Interaction of depression and anxiety (include physical complaints)
- Obsessive and compulsive behaviors
- Difficulty making decisions
- How it affects what the aide is there to do
- Difference between helpful anxiety (i.e. positive aspects) and paralyzing anxiety (i.e. interferes with consumer's ability to function and manage everyday activities)

How do I respond?

- Break large tasks into small steps
- Importance of patience
- How and when do I get help?

V. Working with Hoarding Behavior – Trash or Treasures: Who Decides?

What does it look like?

- Show slides/video and assessment chart
- Exercise used at Minuteman Forum

How do I respond?

- Importance of self-determination/consumer involvement
- Use consumer's language regarding his/her possessions
- Small steps
- Team approach (i.e. home care worker as support/helper, not enforcer)
- What constitutes success?

VI. Working with Psychotic Behavior – "My neighbor is poisoning me."

What does it look like?

- Hallucinations, auditory, visual, tactile (cultural differences)
- Delusions
- Wrongful accusations

How do I Respond?

- Maintain calm
- Maintain boundaries
- Don't personalize
- Validate feeling but not the belief being expressed
- Anticipate triggers
- Give advance notice of change in normal routine
- Monitor medication adherence
- Alert supervisor to changes
- How and when to get help?

VII. Working with Substance Abuse. Excessive Alcohol and Drug Use

What does it look like?

- Difference between legal and illegal substances
- Physical symptoms, lifestyle signs, attitudes and language
- Distinction between early and late onset in terms of intervention strategies
- Interaction of chronic disease/medical conditions with substance abuse
- Interaction with family members

How do I Respond?

- What is my responsibility? How to avoid enabling
- What can I do that is helpful? (e.g. basic concepts of motivational interviewing)
- When is it an unsafe environment for the consumer or for me?
- How and when do I get help?

VIII. Working with Medications. How does medication affect my consumer?

What does it look like?

- Common classes of medications used in behavioral health
- Signs and symptoms of medication non-adherence
- Symptoms of medication interaction
- Side effects
- Delirium

How do I Respond?

- Communication: helpful and non-helpful responses
- Importance of reporting
- What is my responsibility?
- How and when do I get help?

IX. Dual Diagnoses. When it's more than one thing.

What does it look like?

- Dementia and psychotic behavior
- Substance abuse and depression or anxiety
- Stroke, Parkinson's, Traumatic Brain Injury (TBI), etc. (i.e. medical conditions) and depression or psychotic symptoms
- Autism and anxiety

How do I Respond?

- Importance of clear expectations of your role and how success will be measured
- How and when do I get help?

X. Setting Boundaries and Practicing Self-Care

- Applying what you know about setting boundaries and self-care to a challenging population (include splitting behavior of someone with a personality disorder in this section)
- De-escalation; non-violent conflict resolution
- Safety, back-up plan (when to call supervisor and when to call 911); what to report when you call
- Finding the balance between over-involvement and disengagement

Suggested training modalities:

- PowerPoint – didactic
- Role Play
- Video
- Discussion
- Subject-matter expert/professional speakers

Suggested allocation of time:

Modules I and II……..	3 hours
Modules III – IX……..	8 hours (based on focus group feedback, allocate more time on hoarding, substance abuse and depression)
Module X…….	1 hour

Section 8. Conclusion

This multi-level approach to data collection and analysis for the development of a training curriculum outline yielded three main findings: 1) the identification of the most common and prevailing mental or behavioral health conditions that home care aides face (depression, hoarding, substance abuse, anxiety and general psychosis); 2) the importance for the training curriculum to focus on the recognition and response to *behavior* (as opposed to the diagnosis) as well as drawing on adult-learning styles; and 3) the need to incorporate broader personal and professional development skills into the training.

In addition, communication across different providers, and between supervisors and aides themselves, were cited as key areas for improving care for clients with complex mental or behavioral health needs. Finally, one unexpected by-product of these focus groups with home health aides was the emphasis placed on peer-support. The opportunity to share stories and exchange strategies and techniques during these focus group conversations was identified as a valuable use of time and served as way of validating one another's struggles and successes with this population of clients. These contextual findings exemplify the need for continued training and professional development for this increasingly essential workforce.

Throughout all of our conversations with aides, supervisors, key stakeholder organizations and key informants across the Commonwealth, the sentiment that this workforce is compassionate and dedicated to the clients that they serve was reiterated. Despite home care aides' critical importance to the overall safety and quality of life for clients who choose to remain in their homes, we also heard from home health aides themselves that they feel unprepared to provide care to increasingly complex and frail individuals with complicated behavioral health diagnoses. These elders and disabled adults represent a growing percentage of those receiving care in the home and require highly trained caregivers who can manage not only the personal care responsibilities, but also the consumer's behaviors. These planning grant activities not only aided in the development of a new Mental Health Supportive Home Care Aide training curriculum outline; but they also served as a valuable opportunity for these workers to express their opinions and contribute their experiences to the development of a training curriculum that will assist them on a daily basis. The enthusiasm expressed by the participating aides illustrates that additional training on these important issues is desired and that any request for participation with regard to the implementation activities will be welcomed.

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