A New Paradigm of Care

for Managing Behavioral Disturbances in Adult Day Dementia Programs

Circle of Harmony Workbook

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Funded by the Department of Health and Senior Services, Division of Aging and Community Services,
Adult Day Services Program for Persons with Alzheimer's Disease and Related Disorders.

Introduction

The Circle of Harmony *concept and the related techniques and approaches described in this workbook, and the accompanying video, are based on the work and practice of the staff at the COPSA Day Program, COPSA Institute for Alzheimer's Disease and Related Disorders at UBHC/UMDNJ.*

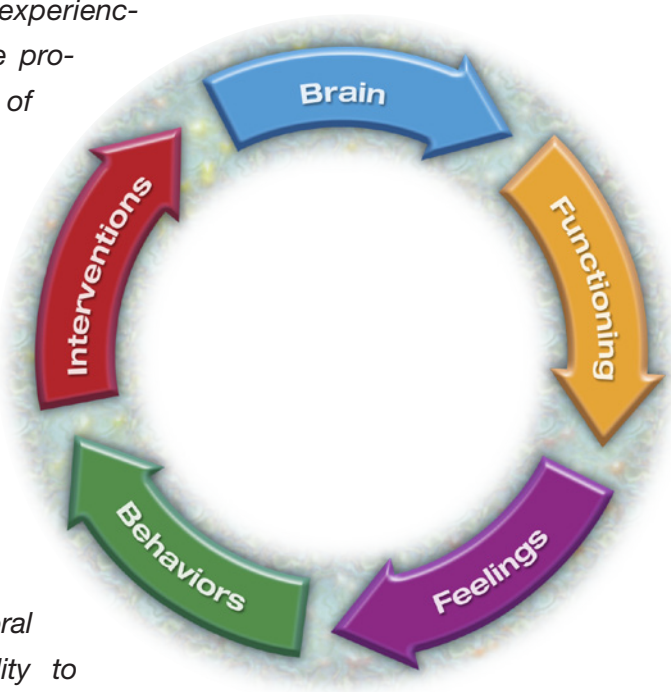
Opened in 1982, The COPSA Day Program was the first specialized, dementia day care program in the state. As a university-based program, we have had the mandate and advantage of incorporating the latest research into practice in our daily work.

The COPSA Day Program practices are rooted in some fundamental beliefs about our clients and their families. We believe that every human being, no matter how impaired, has the ability to love and be loved. We believe that every person has an enduring sense of self and a need to be in harmony with his or her environment, and we believe that our work with caregivers is as important as our work with clients.

Circle of Harmony

The Circle of Harmony is a new paradigm of care for people with dementia. It consists of five inter-related components: ***Brain,*** ***Functioning,*** ***Feelings,*** ***Behaviors,*** *and* ***Interventions.*** *These five components must be kept in balance in order to achieve and sustain harmony. Harmony, as it applies in this context, is a state in which a client, his or her caregivers, and fellow clients are in a supportive state of well-being.*

People with dementia are constantly experiencing distressing change. As the disease progresses, it robs them of a wide range of abilities, often replacing them with a frightening, distorted perception of reality. A behavioral disturbance is the result of a person struggling to adapt and achieve balance in the midst of a world that, to them, has become chaotic and unpredictable.



We who care for those with dementia must be sensitive to their profound struggle. We must do our best to reduce their stress and their behavioral problems while maximizing their ability to function. The Circle of Harmony paradigm offers us the tools to address these issues and effectively support our friends on their journey.

How to Use this Workbook

"We have no time for training." *is the one message we have heard loud and clear from daycare staff throughout the state. We understand that it is difficult for staff to go out for an all-day workshop. Even a half-day is more than most of you can spare. So we decided to create a training program that had the flexibility to meet your needs.*

This workbook is designed to accompany the video "Circle of Harmony". The video can be viewed in its entirety or in smaller segments. The same is true of the exercises in this workbook. You can work on this training together or individually at your own pace.

Since daycare staff members usually have different levels of education and experience, some sections of this workbook contain supplemental information and exercises for those who would like to learn more.

About the Reflection and Exercise Boxes

The Reflection Boxes *contain questions to think about based on your* ***experience.*** *They are intended to generate insights about each topic.*

The Exercise Boxes *contain suggested* ***activities and related questions.*** *Fill in the answers in the spaces provided. Should you need more space, use the reverse side of the page.*

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continued

S E C T I O N S

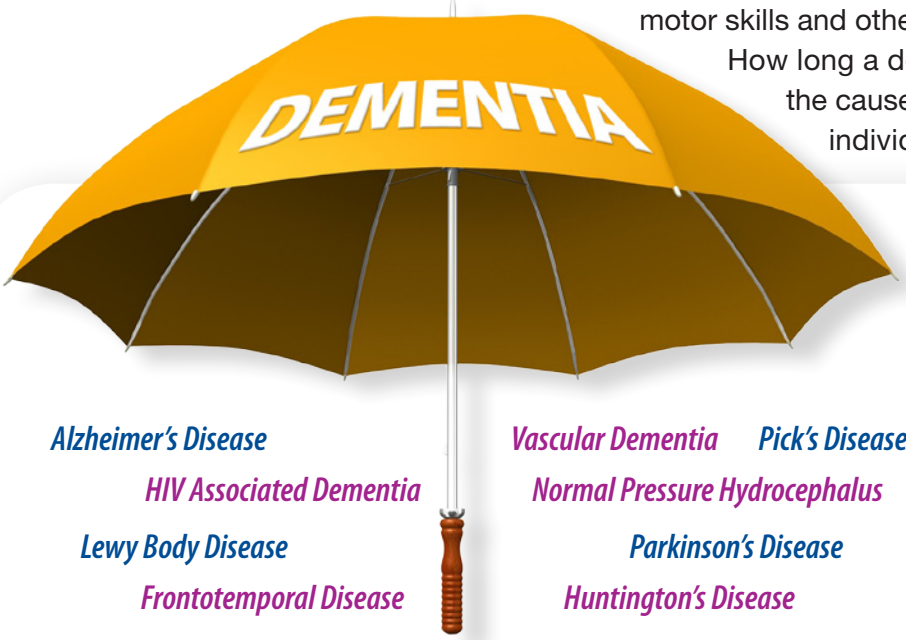
Are you an Instrument of Harmony?

How do you think of your role as a day program professional?

How do you relate to the metaphor of yourself as an Instrument of Harmony?

In the video, we talk about helping a friend open a locked door. Are there other images that come to mind when you think about your role in the day program?

Dementia is a syndrome characterized by impairment in various areas of cognitive (brain) functioning. These areas include: memory, language, visual-spatial skills, executive function, calculation, and recognition. Dementia can be caused by a number of conditions and illnesses. Some have a sudden onset while others are gradual. Many dementias are progressive and eventually impair motor skills and other areas of physical functioning. How long a dementia lasts depends on the cause and often the health of the individual patient.



There are many different kinds of dementia.

REFLECTION

All of the changes that we see when someone has a dementia are due to damage that occurs in the brain.

- What other people besides those with dementia suffer from some kind of brain damage?
- Think of someone you know or have heard about who has suffered brain damage. How were they different from other people?
- Did they look or act the same as other people?
- How might it be harder for family members, friends, or strangers if the person who has brain damage looks the same as before he or she became ill?

EXERCISE

Think about your day program clients.

- What kinds of dementia do they have?

- On your intake form, do you list a specific type of dementia?

- When you talk to family members, what do they say is the cause of their loved one's disease?

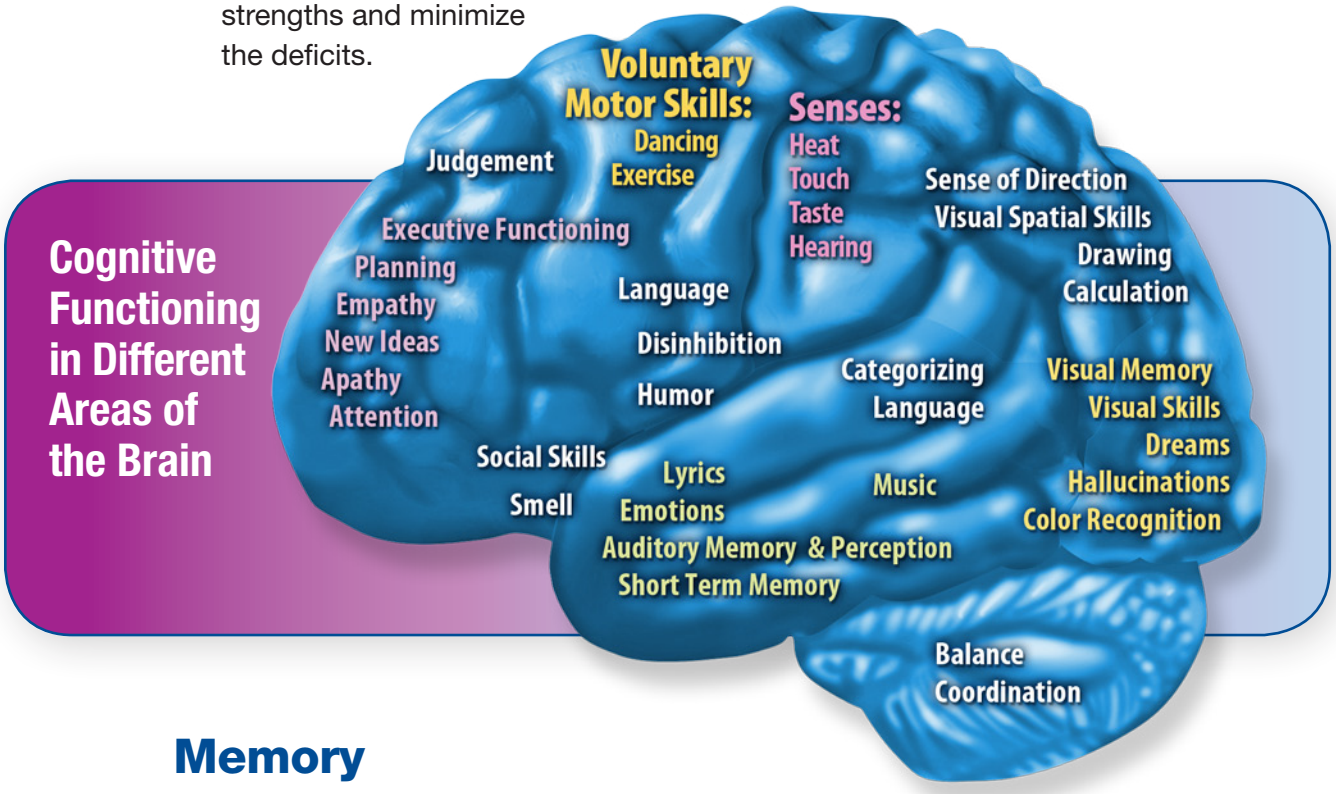
- Do they use the broad term dementia or do they name a specific kind of dementia?

- What would be the advantage of knowing what kind of dementia a person has?

- What other common terms have been used to describe dementia?

Cognition: the Work of the Brain

There are many different areas of cognitive functioning. It would be impossible for us to review them all. For now, we would like to focus on some of the cognitive strengths and deficits of people with dementia. It's important that you understand both because we design activities that will both maximize the strengths and minimize the deficits.



Memory

Being able to remember seems like such a simple, natural ability that we usually take it for granted. But memories are actually the product of a complicated process that our brain usually performs automatically. There are different types of memories including: long and short-term, memories of music, of language and procedures. Each type of memory is processed and stored in a different area of the brain. When there is damage in that area, that type of memory will be impaired.

Often, those suffering from dementia first have trouble with short-term or recent memory because that part of the brain is damaged earlier in the illness. The areas that handle long-term memory or memories of songs and music are preserved longer. You have no doubt noticed that many of your clients will not be able to recall what they did last weekend, but can tell you all about their third grade teacher. Many of them know all the lyrics to songs from the 40's and 50s. They

can easily recall words and phrases that have been "over learned" such as prayers, famous quotes or sayings.

While clients with dementia have trouble learning new information, they are able to learn new routines. This is one of the reasons they derive the most benefit from attending daycare at least two days a week. Once clients learn a routine, it's best to stick to it as much as possible. Changes can cause anxiety, confusion and catastrophic reactions.

REFLECTION

- What are some of the dangerous consequences of having poor short term memory?
- How might having this problem impact the person with dementia?
- How might it impact their caregiver?
- How do people act when they can't remember something?
- What feelings do the following comments convey?
  - "They have very selective memory problems."
  - "Why can they remember things that happened a long time ago but can't remember things that just happened?"
  - "Why is it that sometimes their short-term memory is fine and at other times it's terrible?"
  - "I think they forget things when it's convenient."
- Have you ever heard professional caregivers make similar remarks?

EXERCISE

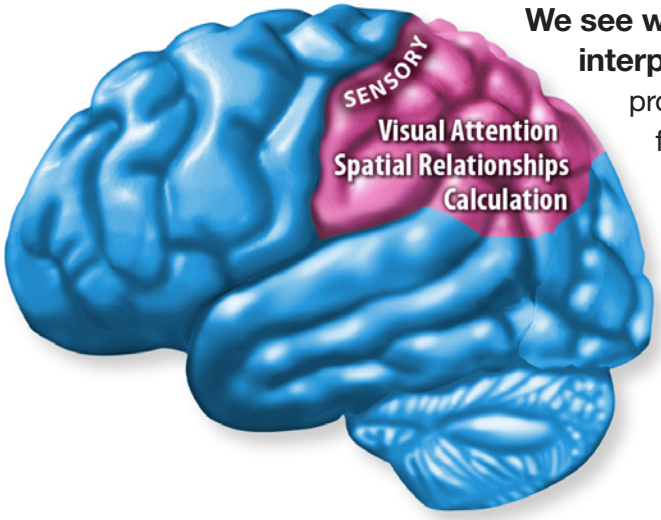
List some examples of short-term memory problems exhibited by clients with dementia in your program.

➤ How does your program use memory strengths to engage clients in activities?

➤ What comments do dementia patients make about their memory?

➤ Do you think that clients understand how bad their memory is?

Visual-Spatial Skills



We see with our eyes but our brains must process and interpret that information correctly. When someone has problems with visual-spatial skills they may try to pick the flowers off of wall paper or think the characters on TV are in the room with them. People with poor visual-spatial skills may get lost easily when driving or even going from one part of their home to another. The mental map that normally guides them is not working properly.

REFLECTION

- If you did not know where the bathroom or bedroom was in your home, what would help you?
- Think about the example in the video where Danielle is trying to pick the grapes off the table cloth. Would it help to tell her that there are no grapes?
- How will she feel if she is seeing grapes and someone tells her they are only a drawing? How might she react?
- What would be the best way to support Danielle in this situation?
- Have any caregivers ever mentioned situations where their loved ones were displaying problems with visual-spatial skills?

EXERCISE

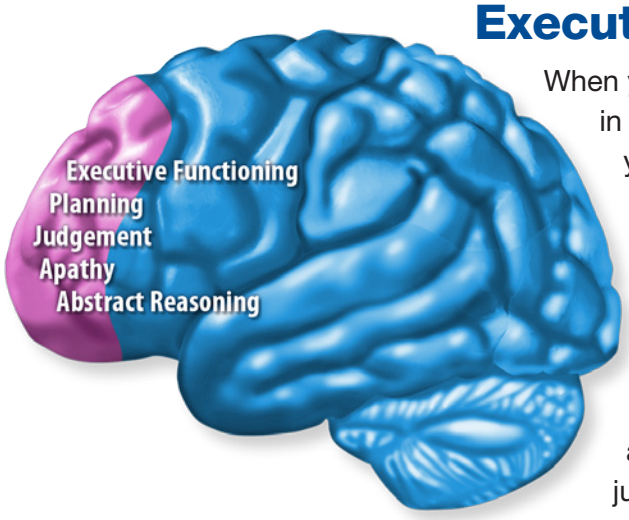
- Can you think of a recent example when you saw evidence that a client has visual-spatial impairment? What did you see?

- Client Name_____
  I know they have visual-spatial impairment because…

(Did they have difficulty sitting in a chair, a hard time finding the faucets to wash their hands? Did they have difficulty locating food on their plate? Did they paint the tablecloth instead of the birdhouse? Did they miss the door handle when they went to reach for the door or walk into the wall with their walker?)

- What do you do, or not do, in your day program that helps support people with visual-spatial deficits?

Executive Functioning



When you balance your check book, follow a recipe, or get up in the morning and plan your day, you are using what is called your "executive functioning" cognitive abilities. **These abilities help you focus, plan and carry out decisions, and come up with new ideas.**

Apathy, or lack of initiative, is a common result of problems with executive functioning. Individual with this problem may not only be unable to plan their day, they may be unable to decide to get up out of a chair. People who suffer from apathy don't make trouble. They may have the reputation of just being quiet, so this symptom often goes unrecognized.

REFLECTION

- How do caregivers describe problems with executive functioning?
- How do they describe apathy in their loved ones?
- Apathy has been called the number one behavioral disturbance of people with dementia. Do you think this is true?

EXERCISE

- Can you think of ways that clients in your day program demonstrated problems with executive function skills? What did you see?

_____

_____

_____

- Client Name: _____
  I know they have executive function problems because:

_____

_____

_____

EXERCISE continued

- How can you tailor your program to help people who have problems with executive functioning?

- What symptoms do you see when someone is suffering from apathy?

- How does your program try to engage people with apathy?

- What kind of activities would work best with someone like this?

Language

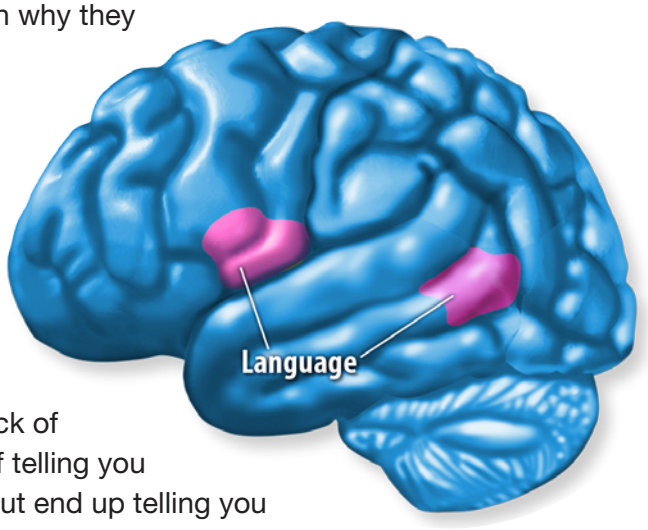
Language seems essential to understanding and navigating our world.

Below is a list of some of the common language problems caused by dementia:

Word Finding – Trouble recalling the correct word to the extent that it noticeably interferes with the ability to communicate.

Echolalia – People with echolalia will automatically repeat what other people say.

Confabulatory speech – People with this condition may make up stories when asked a question or asked to explain why they did something.



Receptive Aphasia – Difficulty understanding speech.

Expressive Aphasia – Difficulty speaking.

Perseverative Speech – Repeating the same questions, stories, or statements over and over again.

Tangential Speech – Getting off the track of the conversation. The person may start off telling you what they ate for breakfast that morning but end up telling you about going to vote.

REFLECTION

In the video Janet has a problem with expressive aphasia, yet she is able to read fluently. What do you think of that?

- How would you feel if the words that came out of your mouth seemed right to you but the people around you couldn't understand what you were saying?
- What do you do when someone is trying to tell you something but it's not making any sense?
- Do you think it's good to try to finish sentences for people?

EXERCISE

Beyond speech, what other forms of communication do you and your staff use?

- What methods do you find most effective?

- Are there certain methods that work with one person but not another?

- What activities does your day program use to compensate for language problems?

- Look at the image of the brain on page 11. Are there other areas that are intact that you can utilize for communication?

Apraxia

Apraxia is characterized by loss of the ability to carry out a learned movement. Getting in and out of a car, brushing your teeth and hair, sitting in a chair, getting dressed… all of these are simple tasks that you've been doing all your life, and that you probably first learned as a child. Dementia patients often have trouble with these tasks because of apraxia.

REFLECTION

Dementia patients often say they have bathed when they haven't.

- Do you think that some may be suffering from apraxia and have trouble bathing?
- What excuses do they provide when asked about bathing?
- Have you heard clients with dementia say they don't know how to do something they should know how to do?
- Do you think they have insight into their own abilities?

EXERCISE

Name three other behaviors that patients with dementia have trouble with, due to apraxia.

_____

_____

_____

- What did you see?

_____

_____

_____

- Client Name: _____
- I know they have problems with apraxia because:

_____

_____

_____

Recognition

People with dementia may have trouble recognizing their surroundings or familiar people. Sometimes they may even have trouble recognizing themselves. They may argue with their reflection in the mirror because they do not recognize the face looking back at them. They may walk to the end of the driveway to pick up the mail, turn around and not recognize their home.

REFLECTION

- What would it be like to wake up surrounded by strangers in a place you have never seen?
- How would you feel if a strange face looked back at you in the mirror?
- What would reassure you that things were OK?
- What do caregivers say works in these situations?

EXERCISE

- How is this behavior demonstrated in your day program?

_____

_____

- How might you compensate for this deficit?

_____

_____

- Client Name: _____
- I know they have problems with recognition because:

_____

_____

_____

Orientation

When someone has trouble with orientation they may not know what day it is, what time it is or what year it is. They may be confused about the season and about where they are.

REFLECTION

- How does not knowing what day or year it is affect your clients on an everyday basis?
- How does not knowing where they are affect them?

EXERCISE

- Who in your program is most disoriented?
- What activities do you provide that helps reorient your clients?
- How do you do this on a one-on-one basis?
- How do you orient people without correcting them?
- Do clients ever become upset when their beliefs are corrected?

Disinhibition

People with dementia will sometimes become disinhibited. **They may be socially or sexually inappropriate.** This is often one of the first symptoms families notice when someone has Frontotemporal Dementia or Pick's Disease. It is also one of the most distressing.

REFLECTION

- How are the consequences of this behavior different from others?
- What do family caregivers say about this?
- What if this behavior is not recognized as a symptom of dementia?

EXERCISE

Some examples of disinhibition are: talking to everyone when shopping, grabbing to hug and kiss small children when they pass them on the street, commenting loudly on another's appearance, cursing during normal conversation, etc.

- What is your experience regarding clients with disinhibition?

- From your client contact, give an example of disinhibited behavior. (Yelling out responses, inappropriate social comments, inappropriate touching of peers/staff, etc.).

EXERCISE continued

- Name of client: _____
- Disinhibited behavior or speech I witnessed or family member told me about:

_____

_____

- Do other day program clients ever take offense at this behavior in other program participants?

_____

_____

- How do you as a staff member handle that?
(Please give specific examples)

_____

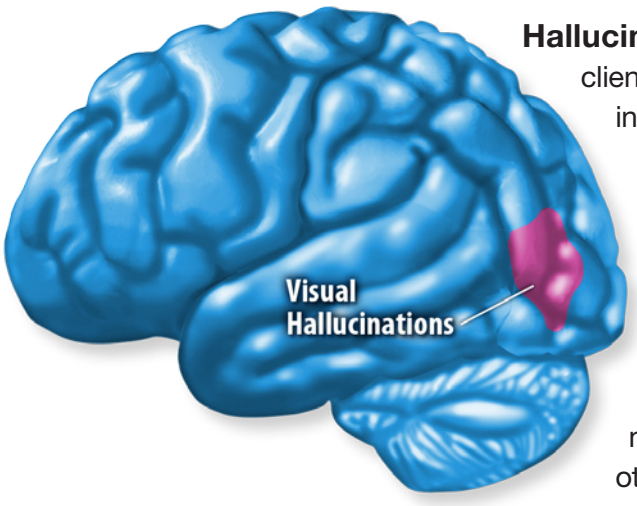
_____

- What is your experience regarding clients with disinhibition?

_____

_____

Hallucinations and Delusions



Hallucinations involve the senses. They are something a client sees, hears, smells, tastes or touches which is not based in reality. **Delusions are thoughts not based in reality.** Some delusions are very common in certain forms of dementia. Alzheimer's Disease patients often see children or small animals. They may believe their spouse is unfaithful (delusions of infidelity), or that someone is stealing their things, or that a family member is not really their loved one but an imposter (Capgras syndrome). When someone has Lewy Body Disease, they may have more complex paranoid delusions involving conspiracies or other departures from reality.

REFLECTION

- If your client says that someone is stealing her things, do you believe them?
- How do you know the difference between a delusion and the truth?
- What do families typically think and do when in these situations?

EXERCISE

People experiencing hallucinations or delusions may see bugs on their furniture or clothes, they may hear people talking to them and telling them to do things, they may see a stranger at the foot of their bed, or think that someone is trying to steal all their jewelry, they may see sticky notes on the wall with messages or think that someone is out to hurt them, they may smell garbage, etc.

- Do you have any clients who experience hallucinations or delusions?

_____

_____

- Can you state what they have reported seeing or hearing?

_____

_____

- Has the family ever reported hallucinations or delusions? If you don't know, ask your supervisor.

_____

_____

- Name of Client: _____
- Description of hallucination, delusion or paranoia:

_____

_____

Functioning

When a person experiences brain changes, it negatively impacts their ability to function independently.

A person may have difficulty with cooking, finances, bathing, using the bathroom, dressing, brushing their teeth, shaving, keeping appointments, making a bed, walking in the neighborhood without getting lost, taking medications, going to the grocery store, driving, turning on the TV, making coffee or putting away the dishes.

EXERCISE

Pick one person from your day program. Are you aware of any difficulties they have with functioning? Maybe you have witnessed these difficulties or heard their families talk about them. List five ways that they have had difficulty with functioning:

- Client Name: _____
  1. _____
  2. _____
  3. _____
  4. _____
  5. _____
- Have caregivers ever complained to you about all the things their loved one can't do for themselves anymore? What did you hear them say?

_____

_____

- How do family members feel about these changes?

_____

_____

- How do they react?

_____

_____

Feelings

How would you feel if you realized you were in a strange place and didn't remember how you got there? If you didn't know how you were going to get home? If you couldn't find your mother or father and the people next to you were telling you they were dead?

What if you thought someone was taking all your money or you couldn't find your purse? What if you woke up in the middle of the night in a strange house? If you were hungry but couldn't find the bread to make a sandwich? If someone had to help you take a bath or use the toilet?

These situations might make you feel scared, sad, angry, ashamed, afraid, vulnerable, worried, anxious, threatened, isolated, irritable, exposed, depressed, panicked, worthless, disoriented or trapped.

REFLECTION

- Think of a recent example when you needed help from someone because you couldn't do something for yourself. How did it make you feel?

EXERCISE

- Have you ever heard your clients discuss how they feel not being able to do things for themselves anymore? What did they say? How did it make them feel? Think of an example and describe it below:

- Have you ever witnessed a client having difficulty with a task while at the day program?

- How do you think it made them feel even if they did not articulate the feeling?

EXERCISE continued

- How could you tell how they felt? Describe below:
  (Example: Anna stands to participate in the ring toss game. The first ring she throws doesn't come anywhere near the target. She shakes her head, her shoulders drop, she frowns and she turns away from game, states she wants to go back to her seat and doesn't want to play anymore. She appeared to be feeling very bad about her performance and hopeless about her chances of success. She may have been embarrassed about failure and ashamed.)

- What would you do if you had these intense feelings but could not articulate them or really explain to yourself why you were feeling them?

- From the list on the previous page, pick one of the feelings that you may have experienced recently.

- How did others react to you when you expressed that feeling?

- How did you want them to interact with you?

REFLECTION

Attitudes about race, religion, ethnicity, disability and sexual orientation have changed since many day care program clients were young.

- How do you think these issues may affect the feelings of some of your clients?
- What does your program do to make people of diverse backgrounds feel welcome and comfortable?

Behaviors

Some behavior changes that clients may experience include:

Irritability, Anxiety, Agitation

Motor Restlessness – frequent rising from chair, roaming the hallways, pacing the room, fidgeting with feet

Confabulatory Speech – making up stories when asked a question or asked to explain why they did something because they really don't remember

Perseverative Speech – asking the same question over and over again or repeatedly telling the same story

Rigid Demands of Others – insisting peers sit in certain seats or that their juice cup is always filled, or that they must always go first

Social Withdrawal – not initiating any conversations, social interactions or activity

Hoarding – taking all the tissues, stuffing plastic utensils in their shirts and pants pockets, putting handfuls of toilet paper or paper towels down shirt or up their sleeve

Sundowning – sudden increase in anxiety, agitation, confusion, disorientation, wandering and motor restlessness usually around late afternoon when the sun is decreasing and the night is approaching

Adjustment Difficulties to Day Programming – wanting to go home, refusing to participate in activities, fixation on bus or coat

Resistance to Assistance with ADLs – not wanting help in changing soiled clothes or incontinency pads, not accepting contact assistance when walking

Obsessive/Compulsive Behaviors – picking at clothes or specks on the carpet, sweeping, spitting

Pathological Laughing or Crying – uncontrollable laughing or crying not congruent with situation

Catastrophic Reaction – behavior that is severe, intense and extended in duration, it may involve yelling, screaming, crying, aggression, violent outbursts or fleeing with the level of emotion expressed not in keeping with the situation

Disinhibited Comments – saying inappropriate things about appearance, making sexual comments, blurting out prejudicial comments

EXERCISE

Review the list of behavioral changes below. If you can think of a client in your program who exhibits each behavior, fill in his or her name.

- irritability, anxiety, agitation: _____
- motor restlessness: _____
- confabulatory speech: _____
- perseverative speech: _____
- rigid demands of others: _____
- social withdrawal: _____
- hoarding: _____
- sundowning: _____
- adjustment difficulties to day programming: _____
- resistance to assistance with ADLs: _____
- obsessive/compulsive behaviors: _____
- pathological laughing or crying: _____
- catastrophic reaction: _____
- disinhibited comments: _____

Behavioral Change vs. Behavioral Disturbance

What may be disturbing to one caregiver may not bother another caregiver. Recall in the video the example of Barbara being upset by the hallucination of children jumping on the furniture. Remember how her husband yelled at the imaginary children? Also recall the story of the spouse who was upset by her husband not putting on his pajamas vs. the spouse who let his wife sleep in her clothes and instead had her change her clothes in the morning.

EXERCISE A

➤ Can you think of a time when you found a client's behavior irritating and that same behavior did not seem to bother your colleagues? Or was there a time when you noticed a colleague becoming upset with a client's behavior which you did not find disturbing? Describe what you remember:

_____

_____

_____

_____

Behavioral Disturbance

A Behavioral Disturbance produces clinically significant levels of anxiety, agitation or disturbance that is:

- Frequent or severe
- Disturbing to caregivers/peers
- Disruptive to group process
- Threatening to others

EXERCISE B

Below is a list of some common behaviors that we may see in day programs.

➤ Review the list and check those you encounter frequently in your work.

- ❑ wanting to leave the program early
- ❑ not participating in sessions
- ❑ refusing to use the bathroom
- ❑ arguing with peers
- ❑ irritable comments
- ❑ inappropriate sexual behavior or comments
- ❑ wandering in the hallways
- ❑ asking questions repeatedly
- ❑ fixation on coat or purse
- ❑ worry about the bus
- ❑ insisting that a peer is their spouse
- ❑ yelling at staff or peers
- ❑ negative comments during sessions
- ❑ perseverative stories or comments
- ❑ laughing or crying
- ❑ catastrophic reactions
- ❑ other _____
- ❑ other _____

➤ Add any other behaviors you encounter to the list.

_____

➤ Circle those you find most disturbing.

Medical Conditions

With the sudden onset of behavioral disturbances it is necessary to evaluate medical conditions in order to rule out or treat the following:

- Urinary Tract Infections
- Constipation
- Physical Pain
- Undiagnosed Illness/Delirium
- Side Effects of Medications

Routine medical screening including updated blood work is helpful especially for the person who may not be able to clearly articulate how they are feeling physically due to language and comprehension impairment.

Changes in Routine

We should also inquire about changes in routine.

- Is there a new caregiver in the morning, or a longer bus ride?
- Are there household changes such as construction in the home, or any overnight guests or other changes?
- Is there a sick pet or family member?

EXERCISE

➤ Can you think of a time when a client was more agitated or confused while in the day program because of an underlying medical condition, or because of changes with their routine or in the home? What happened? Explain:
(For example, Louise suddenly becomes very restless and will not stay seated for activities. It is later discovered that she has a urinary tract Infection. Once the infection is treated, the motor restlessness subsides. Or consider Charles who is typically very alert and engaged during verbal sessions. One day he is very sleepy and lethargic, unable to engage in sessions on a level consistent with recent weeks' participation. A phone call to the daughter reveals that she has been giving him over-the-counter cough medicine which contains a sleep ingredient.)

Pharmacological Interventions

Behavioral disturbances that are severe and do not respond solely to behavioral interventions may require medication. Some of these behaviors include:

- Delusions
- Hallucinations
- Paranoia
- Mood Irritability
- Combativeness

Below we have listed the brand names of some of the most common medications that doctors prescribe to treat dementia patients. Some are used to slow down the course of the disease, others target specific symptoms. Once a medication is approved by the FDA doctors can use that medication off-label. For example a medication designed to treat depression may also be used for anxiety.

Medications used to slow down the progression of dementia:

- Aricept (donepezil)
- Reminyl or Razadyner (galantamine)
- Exelon (rivastigmine)
- Namenda (memantine)

Anti-anxiety medications used to lower anxiety and agitation:

- Xanex (lorazepam)
- Ativan (alprazolam)
- BuSpar (buspirone)

Anti-psychotics used to treat hallucinations and delusions:

- Risperdal (risperidone)
- Zyprexa (olanzapine)
- Seroquel (quetiapine)
- Abilify (aripiprazole)
- Thorazine (chlorpromazine)
- Haldol (haloperidol)

Medications used to treat depression:

(especially important for patients with dementia since depression can cause problems with attention and concentration, which interferes with memory)

- Paxil (paroxetine)
- Prozac (fluoxetine)
- Lexapro (escitalopram)
- Celexa (citalopram)
- Zoloft (sertraline)
- Pamelor (nortriptyline)
- Cymbalta (duloxetine)
- Remeron (mirtazapine)
- Wellbutrin (bupropion)
- Effexor (venlafaxine)

Mood Stabilizers often used to manage combativeness:

- Tegretol (carbamazepine)
- Depakote (valproic acid)

REFLECTION

- Do you think most caregivers understand the difference between those symptoms and behaviors that can be treated with medications and those that can't?

EXERCISE

- Do you know if any of your clients take psychiatric medications? If you don't know, ask your supervisor or bring it up at your next staff meeting. Choose a person who is taking such a medication and discuss how long that person has been taking it.

- How often does that person follow up with the doctor regarding that medication?

- Do you think the medication is effective?

Interventions as an Art Form

Successful interventions need to be creative. Remember…

- There's no one solution
- Behaviors are unique and ever-changing
- Interventions vary with individual personalities
- It's a group effort

EXERCISE A

- Can you recall some creative strategies you have used in the past to reassure and redirect clients?
  (fake phone calls, memos with information on ride home, etc.) Describe below:

- Recall an event when it took creative teamwork to redirect a client. Describe below:

EXERCISE B

Evaluate your team:

- Rate your staff's ability to work together as a team when dealing with disturbing behaviors. Circle your answer:

  Excellent Very Good Good Fair Poor

EXERCISE C

- Do you have any ideas about how your staff could improve their ability to work together as a team? Describe them below:

Plan on sharing these ideas individually with your supervisor or bring them up at your next staff meeting.

Fundamentals of Interventions

How to approach an intervention:

- Access Deficits
- Focus on Strengths
- Address Expressed/ Unexpressed Needs

REFLECTION

- Recall the example from the video about the client with pathological laughing during toileting. The staff was successful in reducing her laughing (her deficit) when they engaged her in singing (her strength).
- Can you think of a similar example from your time with clients when you focused on a strength to compensate for a weakness?

EXERCISE

Think about a client in your program who currently is exhibiting a behavioral disturbance and plan for a new intervention based on the fundamentals of interventions.

- What is the name of the client? _____
- What is the behavior? _____
- What is a deficit for this client? _____
- What is a strength for this client? _____
- What do you think the client may be feeling? _____

_____

- What activity might you try that minimizes their deficit, draws on a strength, and addresses their underlying feeling?

_____

_____

_____

The Client Profile

The Client Profile is a useful tool for gathering vital information that may improve our ability to design effective behavioral interventions. This tool is started at the time of admission and updated as new information is revealed. The information is shared with all staff members who may have contact with the client, empowering them to more fully act as "Instruments of Harmony".

EXERCISE

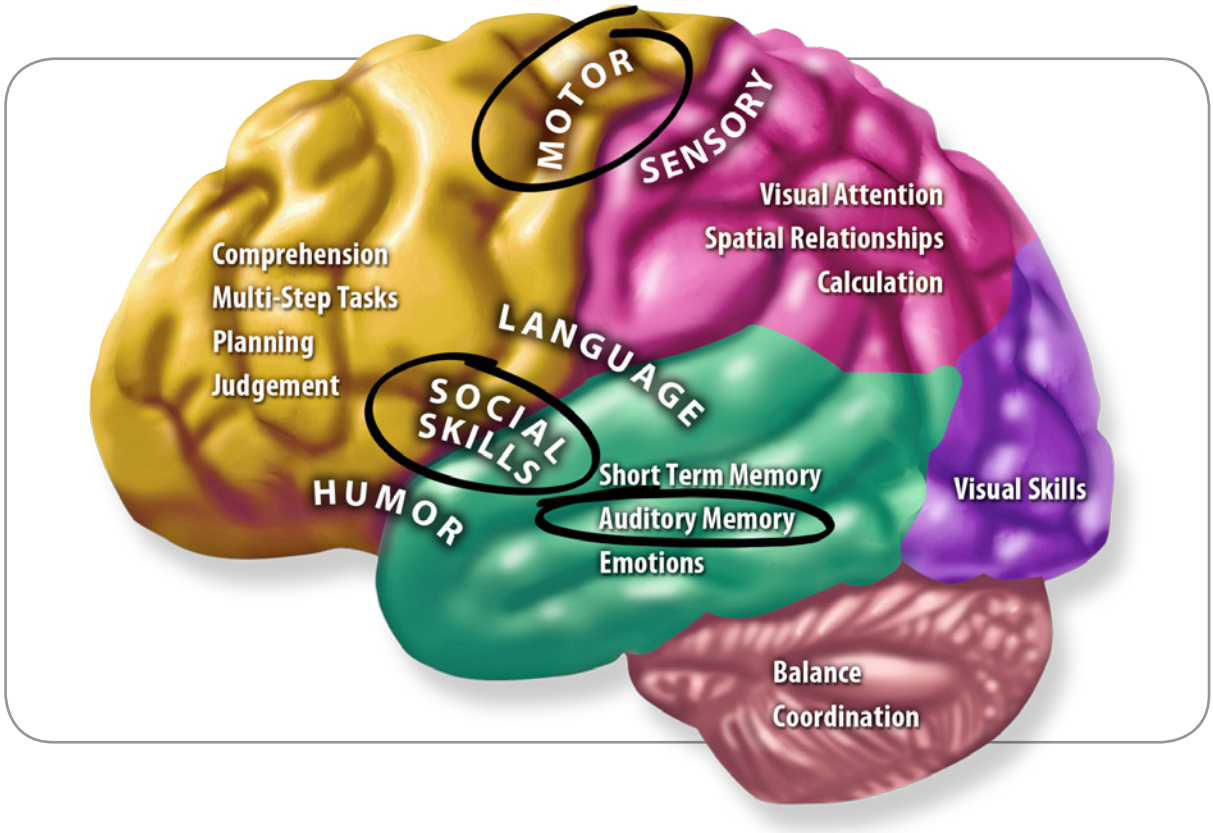
- On the next page you will find a sample of the Client Profile filled out for a fictitious client. Review this completed form.
- Next, pick a client from your program and complete one of the blank forms that follow. Ask your supervisor for access to intake paperwork that may assist you with this form. Ask your colleagues for any information they may have on the client. Review the form with your supervisor when you are done.
- Suggestion – You may complete this form by yourself and/or try doing one together in a small group, perhaps during a staff meeting.
- If you need further explanation, refer to pages 37-43 for more information on each section of the Client Profile.

CLIENT PROFILE

Client Name _____ Date _____

MMSE 10 Diagnosis Alzheimer's Disease

Circle the client's areas of **strength** on the brain diagram below:



Deficits:	Triggers:	Soothers:
Language Comprehension Calculation Short Term Memory	multi-step Tasks Verbal Activities	Singing Dancing Music

Birthday June 14th, 1924 Children Peter - Age 61, Claire - Age 59

Anniversary Date April 2, 1947 Favorite Foods ice cream

Role in Family housewife

(helper, provider, handyman, cook, housekeeper, etc.)

Socializing History played bridge, liked small groups of close friends

(likes large groups, life of the party, reserved, shy, not a joiner, etc.)

Civic Organizations voter registration

(Girl or Boy Scouts, Elks, American Legion, Rosary Society, local politics, etc.)

Military History husband served in World War II

Religion Roman Catholic

(Currently attending, any role in church, favorite hymns, past involvement, etc.)

Physical Stressors hearing impairment in right ear, arthritis in knees

(Pain when walking, pain when sitting, arthritis, hearing impairment, vision impairment)

Strengths very social non-verbally

(Relates on an emotional level, responds to visual cues, etc.)

Places He/She has Lived Brooklyn, Hartford, CT, New Brunswick, NJ

Travel Experience Spain, Ireland, Italy, Germany, Canada

Work History retail at JC Penny

Special Talents crochet, knitting, sewing

Hobbies bridge club, bowling

Favorite Music swing, jazz, Frank Sinatra

Proudest Moments/Achievements/Validating Stories

Sewing clothes for all of her children, winning Worker of the Year Award at JC Penny, her grandson graduating from medical school.

Triggers at Home noise when all grand children visit, being alone when it is dark

Soothers at Home folding clothes, drying dishes, looking at family photos

Triggers in the Program when her ride is late, complicated craft projects

Soothers in the Program singing, stretching sessions, one on one conversations with staff

Environmental Modifications sit close to staff, sit with female peers at lunch

Positive Past Responses to listening to music at dismissal time, helping clean up at the end of the day

If additional space is needed, please attach an extra sheet.

Completed by *(signature)* Lisa Barbaig **Date** _____

Updated *(signature)* _____ **Date** _____

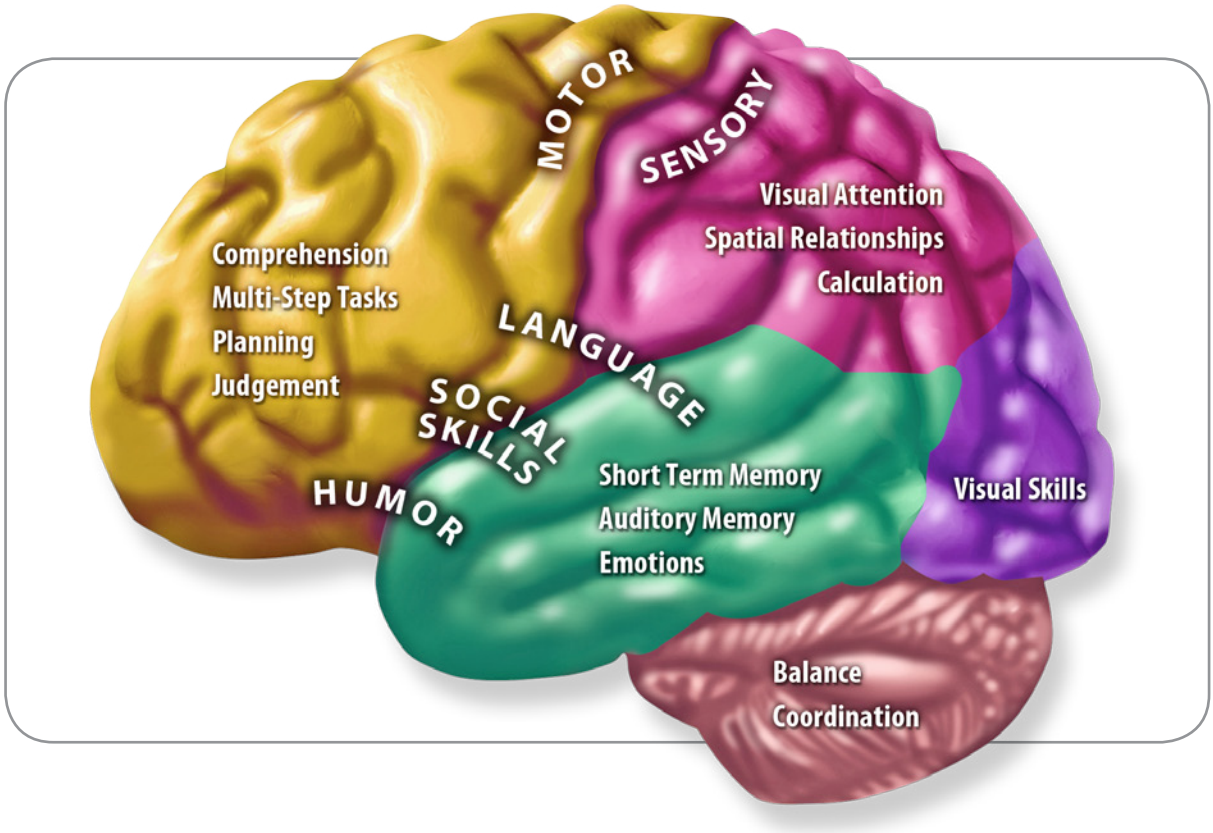
Updated *(signature)* _____ **Date** _____

CLIENT PROFILE

Client Name _____ **Date** _____

MMSE _____ **Diagnosis** _____

Circle the client's areas of strength on the brain diagram below:



Deficits:	Triggers:	Soothers:

Birthday _____ **Children** _____

Anniversary Date _____ **Favorite Foods** _____

Role in Family _____
(helper, provider, handyman, cook, housekeeper, etc.)

Socializing History _____
(likes large groups, life of the party, reserved, shy, not a joiner, etc.)

Civic Organizations _____
(Girl or Boy Scouts, Elks, American Legion, Rosary Society, local politics, etc.)

Military History _____

Religion _____
(Currently attending, any role in church, favorite hymns, past involvement, etc.)

Physical Stressors _____
(Pain when walking, pain when sitting, arthritis, hearing impairment, vision impairment)

Strengths _____
(Relates on an emotional level, responds to visual cues, etc.)

Places He/She has Lived _____

Travel Experience _____

Work History _____

Special Talents _____

Hobbies _____

Favorite Music _____

Proudest Moments/Achievements/Validating Stories

Triggers at Home _____

Soothers at Home _____

Triggers in the Program _____

Soothers in the Program _____

Environmental Modifications _____

Positive Past Responses to _____

If additional space is needed, please attach an extra sheet.

Completed by *(signature)* _____ **Date** _____

Updated *(signature)* _____ **Date** _____

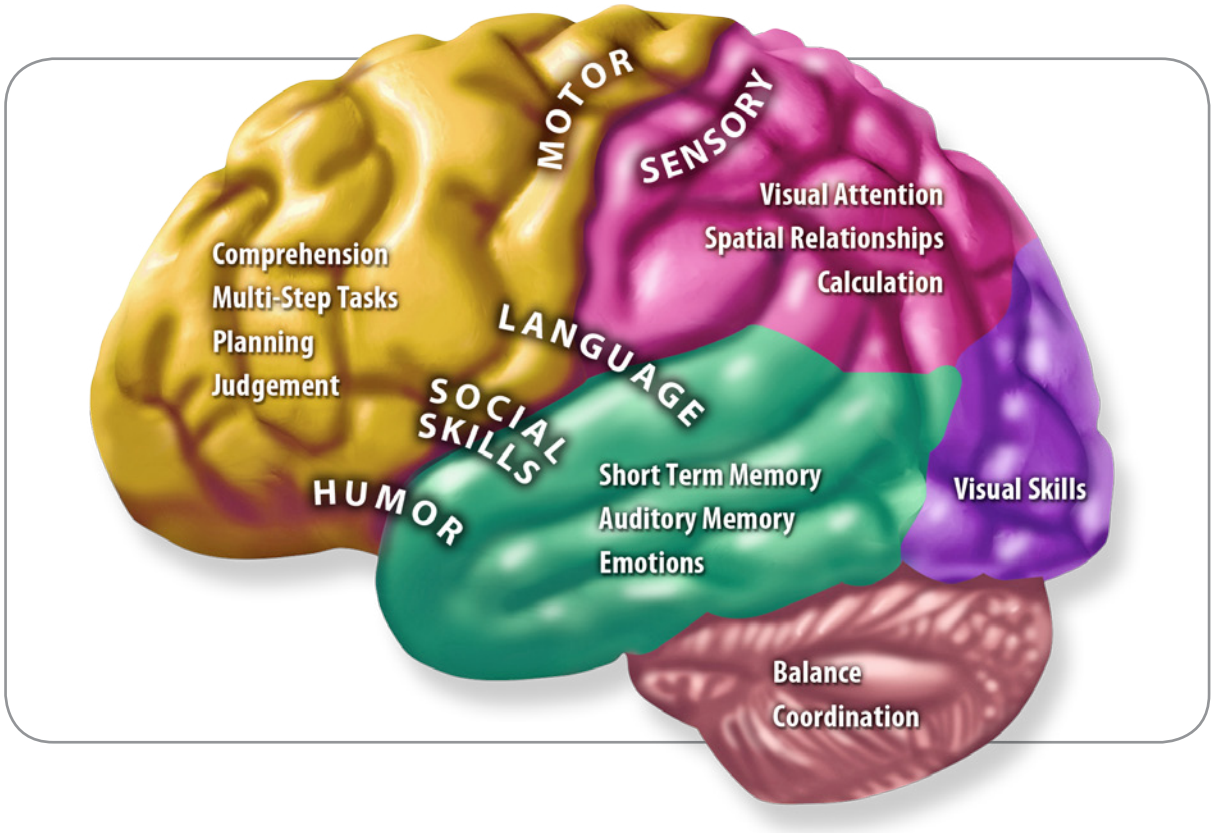
Updated *(signature)* _____ **Date** _____

CLIENT PROFILE

Client Name _____ **Date** _____

MMSE _____ **Diagnosis** _____

Circle the client's areas of strength on the brain diagram below:



Deficits:	Triggers:	Soothers:

Birthday _____ **Children** _____

Anniversary Date _____ **Favorite Foods** _____

Role in Family _____
(helper, provider, handyman, cook, housekeeper, etc.)

Socializing History _____
(likes large groups, life of the party, reserved, shy, not a joiner, etc.)

Civic Organizations _____
(Girl or Boy Scouts, Elks, American Legion, Rosary Society, local politics, etc.)

Military History _____

Religion _____
(Currently attending, any role in church, favorite hymns, past involvement, etc.)

Physical Stressors _____
(Pain when walking, pain when sitting, arthritis, hearing impairment, vision impairment)

Strengths _____
(Relates on an emotional level, responds to visual cues, etc.)

Places He/She has Lived _____

Travel Experience _____

Work History _____

Special Talents _____

Hobbies _____

Favorite Music _____

Proudest Moments/Achievements/Validating Stories

Triggers at Home _____

Soothers at Home _____

Triggers in the Program _____

Soothers in the Program _____

Environmental Modifications _____

Positive Past Responses to _____

If additional space is needed, please attach an extra sheet.

Completed by *(signature)* _____ **Date** _____

Updated *(signature)* _____ **Date** _____

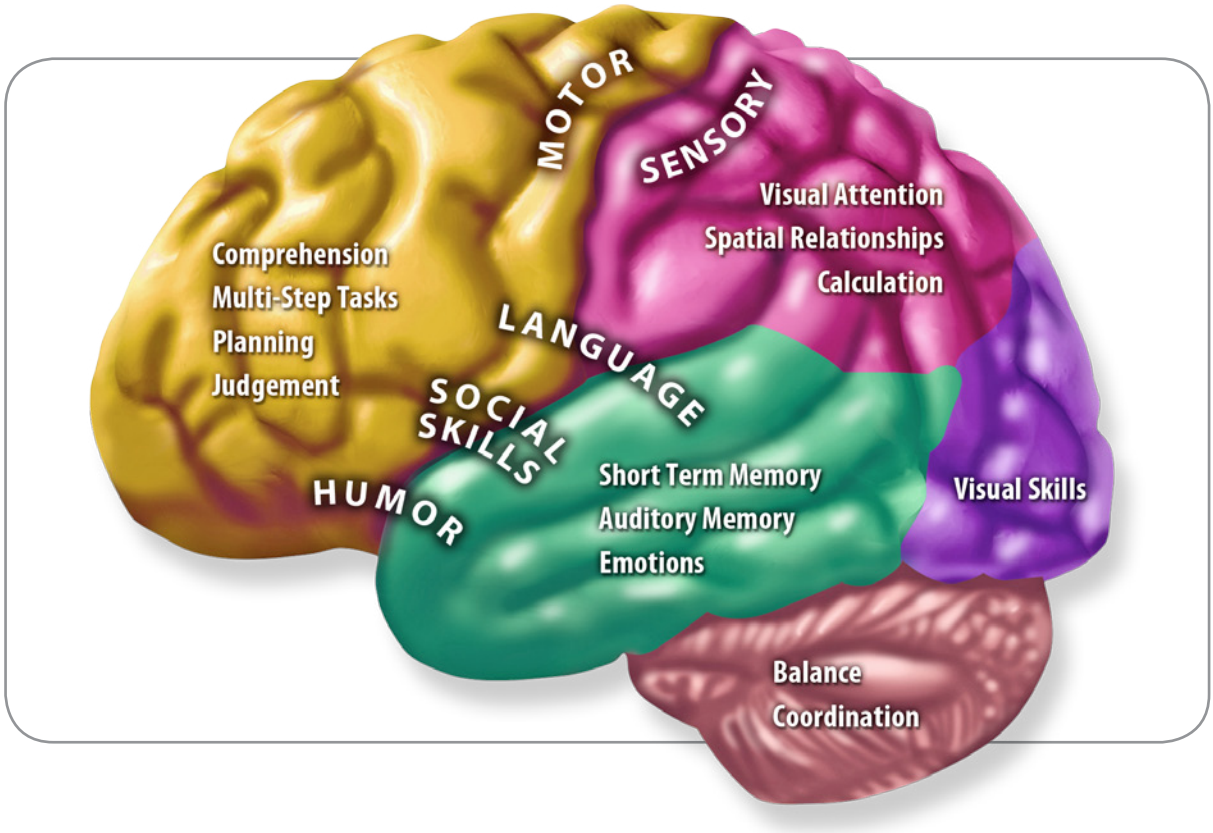
Updated *(signature)* _____ **Date** _____

CLIENT PROFILE

Client Name _____ **Date** _____

MMSE _____ **Diagnosis** _____

Circle the client's areas of strength on the brain diagram below:



Deficits:	Triggers:	Soothers:

Birthday _____ **Children** _____

Anniversary Date _____ **Favorite Foods** _____

Role in Family _____
(helper, provider, handyman, cook, housekeeper, etc.)

Socializing History _____
(likes large groups, life of the party, reserved, shy, not a joiner, etc.)

Civic Organizations _____
(Girl or Boy Scouts, Elks, American Legion, Rosary Society, local politics, etc.)

Military History _____

Religion _____
(Currently attending, any role in church, favorite hymns, past involvement, etc.)

Physical Stressors _____
(Pain when walking, pain when sitting, arthritis, hearing impairment, vision impairment)

Strengths _____
(Relates on an emotional level, responds to visual cues, etc.)

Places He/She has Lived _____

Travel Experience _____

Work History _____

Special Talents _____

Hobbies _____

Favorite Music _____

Proudest Moments/Achievements/Validating Stories

Triggers at Home _____

Soothers at Home _____

Triggers in the Program _____

Soothers in the Program _____

Environmental Modifications _____

Positive Past Responses to _____

If additional space is needed, please attach an extra sheet.

Completed by *(signature)* _____ **Date** _____

Updated *(signature)* _____ **Date** _____

Updated *(signature)* _____ **Date** _____

Mini Mental State Exam (MMSE)

The Mini Mental State Exam is a neuropsychiatric screening tool developed by Marshall Folstein et al. It is usually administered by a health care professional to quickly assess memory impairment. Medical professionals may routinely use this test to determine how quickly a dementia is progressing. In order for it to be effective, all staff must be sure to administer it the same way following the directions described in the test. Typically, a person with Alzheimer's Disease may drop a few points per year.

The exam includes 30 simple questions that test areas of brain functioning including: orientation, recall, calculation, visual-spatial skills, reading comprehension, naming, and the ability to follow multi-step commands.

Some of the questions include:

- What day is it?
- What is the season?
- What floor are you on?
- Subtract 7 from 100, 7 times?
- Take a piece of paper in your right hand, fold it in half and place it on the floor.
- Copy a design of intersecting pentagons.
- Write a sentence.

The highest score is a 30. The lowest score is a 0. Persons who score in the single digits are considered to have advanced dementia. They are probably unable to speak and display only passive participation during activities. Higher scores are found during the early stages of the disease. These clients may be the stars in your program. Many of your clients probably have mid-range scores from 10 to 16. They have noticeable deficits but still have enough strengths to benefit from therapeutic activities.

EXERCISE

Does your center ask for the MMSE from the primary doctor prior to admission? Does someone from your center routinely administer the MMSE? Do you know where you could find this information on the client's chart? Ask your supervisor for assistance.

If you have access to this information, pick 5 clients from your center and list their MMSE scores below (next page):

EXERCISE continued

Client Name	MMSE Score
1.	
2.	
3.	
4.	
5.	

➤ Can you draw any correlation between a client's MMSE and their level of functioning in your program?

Personal History and Validating Stories

This area of the Client Profile collects information on a client's past history including work, leisure, social groups, civic organizations, hobbies, church service, etc. It is vital to learn the validating stories for each person. What are the favorite stories that they keep telling over and over again? What makes them proud? What are their greatest accomplishments? Did they receive a medal in the war? Were they the first in their family to graduate from college? Did they receive a special honor upon retirement? Did they run a farm? Raise 9 children? Were they the regional leader for the girl scouts, or an umpire for little league? Did they make their own clothes?

Repeatedly telling a person's validating stories can help him or her feel better about him or herself and counteract any negative feelings that he or she may have about his or her current limitations.

Interventions
Part 2

EXERCISE A

From the video, recall the story of Scott using Navy language to overcome Bob's resistance to using the bathroom.

- Describe any similar success you have had with a client in your program using information from their personal history or validating stories:

EXERCISE B

Think about a client who has limited ability to speak.

- Think about how much you know about that client? Make a point to ask one of their family members about their proudest moments. Use that new information in an interaction with the client and note the results.

Triggers

A trigger is something that comes right before the disruptive behavior. When identifying triggers it may be helpful to ask the following questions:

- What happens right before the disruptive behavior begins?
- What time does the behavior usually occur?
- Is there a pattern?
- What else is occurring in the room?
  - Is there a lot of activity or is it very quiet?
  - Are there people entering or exiting the room?
  - Is there loud music?
  - Is there a lot of talking?
- Does it happen when the client is asked to do a certain kind of task?
- Does the behavior occur when the client is around a certain peer?
- Does the behavior occur when they face the window, when their back is to the door, when they see the clock or when they can't see the clock?

EXERCISE A

Recall the episodes illustrated in the video. Dannielle consistently becomes upset when her juice cup is not filled to the top. This is a trigger. The staff member successfully avoids the trigger by filling her juice cup to the top.

➤ Name some triggers that you have observed for your clients:

_____

_____

EXERCISE B

➤ Maybe family members have mentioned triggers for a client at home – what makes them upset or anxious? If they haven't, with your supervisor's permission, make it a point this week to ask a family member about a trigger for a client at home. Record the information here:

_____

_____

Soothers

Like triggers, we also need to collect information on soothers. We all have activities or objects that offer us peace and calm when we are feeling upset. Our job is to find those soothers for our clients and use them appropriately. The list is endless and unique for each individual. Some soothers may include:

Music, reading magazines or picture books, baking, having a snack or a cup of tea, singing, doing puzzles, setting the table for company, telling or listening to stories, looking at old photos, sorting through mail, working in the garden, taking a walk, stretching, painting, cleaning, yoga, etc.

We collect this information by talking with the family and finding out what works at home as well as through our observations at the day program. When we offer a wide variety of appropriately stimulating activities and carefully observe our client's level of engagement and response, we can remember this information and go back to these activities when the person is experiencing a behavioral disturbance. Furthermore, we can consistently use these activities to prevent behavioral disturbances.

REFLECTION

- Take a moment to think about yourself. When you are having a bad day, or feeling down, anxious or upset, what makes you feel better? What do you find soothing?

EXERCISE

- Think about soothers that you routinely use for particular clients? Describe below:

- Think of someone in your program who experiences anxiety or agitation on a regular basis. What soothers might you try with them this week?

Environmental Modifications

Attention to the environment can help us avoid triggers from ever occurring. It involves how the room is set up, where people sit, what they can see and the routine of the day. For instance:

- Does Norma always become upset if she doesn't sit next to Lila?
- Should Frank never sit with Ellis at lunch?
- Is it best if Tony sits next to staff so they can offer a reassuring touch on the arm or pat on the back when he gets anxious?
- Should Ruthie always have her back to the clock?
- Does Pete perseverate on his coat if the closet door is open?
- Does Beatrice become upset if she gets confused about distinguishing her purse from the others in the room?
- Does extra reassurance and ritual at departure time help decrease Jennie's anxiety about riding the bus?

EXERCISE A

Recall the example on the video about Dannielle and her anxiety about her purse. If Dannielle returned to the activity room after using the bathroom and saw several empty chairs with purses underneath them that belonged to peers who were also in the bathroom, she would become confused and upset about which purse was hers.

Disagreements and anxiety may occur. When the staff is aware of this trigger, they can think ahead and **modify the environment,** making sure that Dannielle never sees an unidentified purse under a chair. They unite Dannielle with her purse and avoid the trigger from occurring.

➤ Describe any similar success you have had in modifying the environment which helped to prevent a behavioral disturbance:

EXERCISE B

➤ Is there an environmental modification that you would like to try? Name it and pick a day to try it. Record the results here:

Evaluating the Quality of Your Activities

As Adult Day Program Professionals we have to ask ourselves:

- How engaging are the activities we offer?
- Are our activities so engaging that no one would think about going home?
- Are clients so fully engaged that they would never even think about wandering?
- Can we fully engage our highest functioning client while we fully engage our most impaired client?
- Are the activities multi-dimensional? Are there things to look at and touch?
- Are there things to listen to?
- Are there short bursts of movement and music if clients have been sitting and involved in more cognitive or fine motor tasks?
- Are those who cannot speak given ample opportunity to participate such as with the ringing of a bell, shaking musical instruments or setting up for lunch?

EXERCISE

Think back to one activity that you led this week. Recall the level of engagement of all clients in the room. Were some more engaged than others? Is there something you could do differently the next time that would more fully engage a larger number of clients? Was there someone who you were not reaching? What could you do differently to encourage more participation from the more passive clients? Could you add a picture for them to look at, an object to touch, a song to sing, a special job? Jot down your ideas below:

Make it a point to use some of your ideas the next time you lead this activity.

Discerning Underlying Feelings and Needs

Now that we have reviewed the importance of understanding the brain, use of personal history, identifying "triggers and soothers" and modifying the environment, let's return to one of the foundations of successful interventions . . . **discerning underlying feelings and needs.**

When an incident occurs, do you have an idea about what may be the clients' underlying feeling or need?

- Do they need to use the bathroom?
- Are they feeling lost or confused?
- Are they worried about not having enough money to take the bus home?
- Are they afraid they will be locked out because they can't find their key?
- Do they miss their deceased spouse?
- Do they feel left out and lonely?
- Are they frustrated with their limitations?
- Do they feel disempowered with not being able to drive?
- Are they tired of trying to understand what people are saying?

It is true, we may not exactly know how a person is feeling, but putting together what we know is part of the art of being an Adult Day Program Professional.

EXERCISE

The next time clients have a behavioral disturbance, find a way to ask them how they are feeling. If they cannot speak, think about how they might be feeling and ask them for confirmation. Example, "Selma, are you worried about your cat? Are you hungry? Do you want to take a walk?" Be a detective. Work hard at trying to uncover their need or feeling and then reflect on how this information affected your intervention:

Staff Log on Behavioral Interventions

The following form may be used to help you further evaluate isolated behavioral incidents. It provides an opportunity to analyze more closely the incident of a behavioral disturbance. It may be filled out individually or used as a tool to aid in a group discussion following a behavioral incident. It helps us integrate the components of the Circle of Harmony.

Staff Log on Behavioral Intervention

Client Name _____ **Date** _____

Location of incident _____ **Time of day** _____

What was going on in room at time of incident?
(motor session, cognitive verbal sessions, social session, structured or unstructured, quiet, noisy, note any distractions, motor participation requested, verbal participation requested, peers entering/exiting room, etc.)

How had client been participating?

What behaviors did client display?
(anxiety, irritability, motor restlessness, arguing, yelling, trying to leave building, crying, refusal to eat, etc.)

How did staff react?

What was successful?

What was unsuccessful?

In hindsight, can you identify

What the client was feeling: _____

Their unexpressed need: _____

The triggers: _____

The soothers: _____

Environmental adaptations for future use:

Soothers that may be useful in the future:

Staff Log on Behavioral Intervention

Client Name _____ **Date** _____

Location of incident _____ **Time of day** _____

What was going on in room at time of incident?
(motor session, cognitive verbal sessions, social session, structured or unstructured, quiet, noisy, note any distractions, motor participation requested, verbal participation requested, peers entering/exiting room, etc.)

How had client been participating?

What behaviors did client display?
(anxiety, irritability, motor restlessness, arguing, yelling, trying to leave building, crying, refusal to eat, etc.)

How did staff react?

What was successful?

What was unsuccessful?

In hindsight, can you identify

What the client was feeling: _____

Their unexpressed need: _____

The triggers: _____

The soothers: _____

Environmental adaptations for future use:

Soothers that may be useful in the future:

Staff Log on Behavioral Intervention

Client Name _____ **Date** _____

Location of incident _____ **Time of day** _____

What was going on in room at time of incident?
(motor session, cognitive verbal sessions, social session, structured or unstructured, quiet, noisy, note any distractions, motor participation requested, verbal participation requested, peers entering/exiting room, etc.)

How had client been participating?

What behaviors did client display?
(anxiety, irritability, motor restlessness, arguing, yelling, trying to leave building, crying, refusal to eat, etc.)

How did staff react?

What was successful?

What was unsuccessful?

In hindsight, can you identify

What the client was feeling: _____

Their unexpressed need: _____

The triggers: _____

The soothers: _____

Environmental adaptations for future use:

Soothers that may be useful in the future:

Staff Collaboration

Our work as Adult Day Program Professionals is a collaborative team effort.

- Data collection needs to be ongoing by all staff
- Success stories need to be shared
- Group brainstorming sessions are essential

Recall the scene in the video depicting the importance of staff team work. Dannielle becomes anxious and confused when faced with boarding the van to go home. Due to her memory loss, she does not remember that she lives with her daughter in Middlesex. She thinks that she still lives in her own home in South Orange. When she approaches the bus, she asks the driver to confirm that he is taking her to East Orange. The bus driver looks at his list and says, "No, I am taking you to Middlesex." Dannielle experiences a behavioral disturbance. Now, recall the corrective scene, when Rita approaches the bus driver prior to Dannielle's arrival and fills the driver in on Dannielle's memory impairment and asks him to go along with her and give her the reassurance she needs. In the corrective scene, the bus driver goes along and says, "Yes, I am taking you to South Orange", even though he is taking her to Middlesex. The staff is able to work collaboratively, providing environmental modifications, sharing information, avoiding triggers, offering effective soothers all based on their understanding of Dannielle's strengths and weaknesses.

EXERCISE A

➤ Can you recall a time when your center was able to collaborate effectively in dealing with a behavioral disturbance? Describe it below:

EXERCISE B

➤ Think about a client with a challenging behavioral disturbance. Using the principles of the Circle of Harmony, brainstorm on your own, with a colleague, or during a staff meeting, about how your center can work together to help alleviate the behavioral disturbance. Record some of your ideas below:

In Conclusion

We hope that ***The Circle of Harmony*** *training video and workbook have given you a deeper appreciation for the importance and value of your work. Our hope is that, as you serve this fragile population in our society, you will remember to link behaviors to feelings that come from difficulties with functioning . . . difficulties which stem from changes in the brain.*

Further, we hope that you find joy and satisfaction in your work, that you see the beauty in each encounter with your clients, and that you are transformed by your relationships and humbled by the profound responsibility you have been given. For together, each and every day, we have an opportunity to make a dramatic difference in the lives of so many through our ongoing dedication to being true instruments of harmony.