FRONTOTEMPORAL DEMENTIA

Information and Intervention Suggestions With an Emphasis on Cognition

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This is an adaptation of the handout Caring Sheet #13 from the Michigan Dementia Care Series. More information is at the end of this Handout.

The Michigan Dementia Care Series can be found on the Michigan website called Improving MI Practices at **https://www.improvingmipractices.org**

This handout is a **brief summary** of information about **Frontotemporal Dementia (FTD)**, with an emphasis on cognitive abilities. It suggests some **intervention** strategies.

More intervention strategies are in the **CAIS Handout** "**#38 Frontotemporal Dementia: Interventions**". See the resources in the next section below for even more intervention suggestions with details and examples.

The information in this handout is intended to **highlight differences** between **Frontotemporal Dementia** (**FTD**) and two other types of dementia: **Alzheimer's Disease** (**AD**) and **Dementia with Lewy Bodies** (**DLB**).

FOR MORE DETAIL AND INTERVENTION STRATEGIES

More information and detail (especially about the brain and cognitive abilities in dementia) and suggestions of interventions (including support strategies) are in:

1. Other **CAIS Handouts** (for example, in **CAIS Handouts #38** about **interventions** for **Frontotemporal Dementia**, **#35** about interventions for the **frontal lobe**, **#7** and **#8** about **dementia**, and **#32** about **making decisions**). CAIS Handouts **#6**, **#7**, and **#8** also identify specific cognitive abilities associated with specific parts of the brain.
2. The *Cognitive Abilities and Intervention Strategies (CAIS) Questions to Ask* and the ***CAIS Intervention Strategies*** by S Weaverdyck. These provide **detailed intervention** strategies that address specific cognitive abilities, the environment, tasks and daily routines, and your communication with this person. These interventions can be **individualized** to a particular person and situation.
3. The **CAIS Educational Series** (for example, **Session #1**)
4. **Background resources** regarding the CAIS Educational Series and the CAIS online course

All of these are available on the above Michigan website at **https://www.improvingmipractices.org**

For a summary of information and possible intervention strategies for other specific disorders, see **CAIS Handout #19** (summary) and **#7** and **#8** about **Alzheimer's Disease**, **#20** (summary) and **#37** (interventions) about **Dementia with Lewy Bodies**, **#35** (interventions) about the **frontal lobe**, and **#36** (interventions) about the **right hemisphere** of the brain. All of these are also available on the above website at https://www.improvingmipractices.org

Additional information about Frontotemporal Dementia can be found on the following three websites: The Association for Frontotemporal Degeneration at **https://www.theaftd.org** and the National Institute on Aging at **https://www.nia.nih.gov/health/topics/frontotemporal-disorders** and the Alzheimer's

Association at **https://www.alz.org**

INTRODUCTION

CAIS Handouts #19 and #20 summarize information and intervention suggestions regarding **Alzheimer's Disease** (**#19**) and **Dementia with Lewy Bodies** (**#20**). With this handout **#21** about **Frontotemporal Dementia**, these three CAIS Handouts briefly outline the brain changes in each type of dementia, the impact these changes have on cognitive abilities and behavior, and implications for effective intervention. They **highlight** the **differences** among these three types of dementia.

The three CAIS Handouts (#19, #20, and #21) are **companion pieces** in outline form with essentially each line or section of one handout corresponding with each line or section of the other two. The three can be laid out side by side and compared section by section.

DEMENTIA

Dementia is a **gradual decline** in a person's cognitive abilities. This decline occurs because of changes in the **brain**.

Cognitive abilities include a person's ability to **think**, **understand** what they see or hear, figure out how to do things, **remember**, imagine, and many **other cognitive functions**. Cognitive abilities allow a person to **communicate**, understand and **respond** to their surroundings, create, and **perform tasks**.

If the decline in cognitive abilities is caused by a treatable disorder, for example, a urinary tract infection, vitamin deficiency, reactions to medications, dehydration, pain, or depression, it is likely **temporary** and **treatable**. (This is sometimes called delirium.)

In other cases the brain changes and resulting cognitive decline are **irreversible** and **progressive** (that is, increasingly severe). They are caused by disorders such as Alzheimer's Disease, vascular disorders, Creutzfeldt-Jakob Disease, Dementia with Lewy Bodies, or Frontotemporal Dementia. There are over 100 different disorders that can cause this progressive dementia.

Frontotemporal Dementia is one of these irreversible and progressive disorders, though there is less known about it. Alzheimer's Disease is by far the most common cause of dementia in persons over the age of 65 years. The term **Frontotemporal Dementia** is used in various ways. It is sometimes used to refer to **frontotemporal degeneration** and sometimes to a form of frontotemporal degeneration called behavior variant frontotemporal dementia (bvFTD).

In **this handout** frontotemporal dementia (**FTD**) will refer to **behavior variant frontotemporal dementia (bvFTD).**

Frontotemporal degeneration (sometimes called frontotemporal lobar degeneration or FTLD) is a group of progressive disorders that affect the frontal lobe and/or temporal lobes of the brain. It is the most common type of dementia to affect persons younger than 60 years old. The various types of dementia within that group have similar symptoms, but vary according to which symptoms appear first and are most obvious. Some of these disorders are identified below.

1. **Behavior Variant FTD** (bvFTD) where behavior changes are usually first and most obvious. About half of all frontotemporal degeneration disorders are bvFTD. (FTD in this handout refers to bvFTD and is described in detail.)
2. **Primary Progressive Aphasia** (PPA) where language (speaking, comprehending, reading, and writing) changes are usually the first and most obvious. There are three types of PPA, including **Nonfluent/Agrammatic variant** (with difficulty coordinating the mouth to speak and using grammar, such as tenses and order of words in a sentence), **Semantic variant**

(with difficulty naming an object and understanding what a word means), **Logopenic variant** (with difficulty finding the word they want to say).

3. **Corticobasal Syndrome** (**CBS**) and **Progressive Supranuclear Palsy** (**PSP**) and **ALS-Frontotemporal Spectrum Disorder** (**FTD-ALS**) where changes in movement are the usually first and most obvious. **ALS-Frontotemporal Spectrum Disorder** is diagnosed when there is both FTD and amyotrophic lateral sclerosis (ALS) at the same time.

While there is no cure for Frontotemporal Dementia, there is much we can do to help a person feel comfortable, competent, and engaged by addressing the changes in their cognitive abilities. This is addressed in more detail in the other CAIS Handouts and resources noted above.

The information below applies generally to Frontotemporal Dementia (FTD). Each person experiences FTD differently, so **careful observation** and **response** to each person as an **individual** is important.

CHARACTERISTICS

1. Brain disorder
2. Most obvious **symptoms**: behavior and personality changes and changes in cognitive abilities
3. **Progression**: increasing severity of symptoms over time (a progressive dementia)
4. **Onset**: insidious; 21-60; usually age 40-65; average age 50-60
5. **Duration**: approximately 7-13 years after onset of symptoms and ending in death (could be 20 years)
6. **Cause**: unknown; genes may play a role
7. **Cure**: no cure at this time, but there is treatment to address symptoms
8. **Diagnosis**: no single definitive test available; clinical diagnosis based on pattern of symptoms, imaging, and lab and other test results; verified at autopsy; supported by structural imaging (for example, CT, MRI) or functional imaging (for example, PET, SPECT) of this person's brain before death; often misdiagnosed in early stages as depression, Alzheimer's Disease, or a mental illness
9. More rare cause of dementia than DLB or AD
10. About 50,000-60,000 people in United States have FTD
11. Only known risk factor is family history (relative had similar disorder)
12. May be hereditary in approximately 40% of cases (mutations in genes: MAPT increases accumulation of tau protein; GRN reduces progranulin increases accumulation of TDP-43 protein; C9orf72 increases accumulation of TDP-43 protein)
13. **Course**: behavior and personality changes are first and most obvious symptoms throughout course; course varies with individual; slower course than AD usually; no stages have been identified
14. Name is based on location of neuropathology; a variety of diseases cause FTD
15. FTD is one of the Frontotemporal Disorders
16. Other terms used to identify or classify: Behavior Variant Frontotemporal Dementia (bvFTD), Frontotemporal Degeneration, Frontotemporal Lobar Degeneration (FTLD), Pick's Disease

NEUROPATHOLOGY

1. Varies with cause or type: (for example, Pick bodies are found in 20% of cases at autopsy)
2. Atrophy (that is, loss) of brain tissue; nerve cell death
3. Tao tangles inside nerve cells in brain (different from tao tangles in Alzheimer's Disease)
4. TDP-43 protein accumulation inside nerve cells in brain
5. Neurotransmitter reduction (for example, less Dopamine, Serotonin, and Glutamate)

LOCATION OF CORTICAL BRAIN CHANGES

1. Cortical refers to the cortex (that is, the outer layer) of the brain
2. Changes (neuropathology) occur in the cortex and in internal (subcortical) structures of the brain
3. Changes (neuropathology) occur on both sides of the brain
4. Only some of the brain structures affected in FTD are included here
5. Cortical brain structures affected:
    a. Frontal lobe
    b. Temporal lobe (anterior)

COGNITIVE CHANGES (decline due to FTD)

Among **many** changes in cognitive abilities, this person may experience **difficulty with**:

1. Processing information in general, including for example:
    a. **Comprehension**, for example, understanding words
    b. **Executive** functions, that is, using the information they receive to, for example, make decisions
    c. **Expressive** functions, that is their brain's ability to tell their body what words to say and how to speak
2. **Executive** and other **functions** with difficulty beginning earlier in the course than in AD, and increasing in difficulty over time including, for example:
    a. **Insight** into, for example, a situation, their own feelings or behavior, others' feelings or behavior
    b. **Switching** from one task, thought, or topic of conversation to another
    c. **Attention** and knowing what to pay attention to, for example, they may have difficulty filtering all the stimuli they encounter and so respond to the most powerful stimulus (a dog walking by) rather than the most important stimulus (what you are saying to them)
    d. Knowing which parts of a task or situation are important relative to other parts
    e. Maintaining focus or **concentration**, for example, their focus may dissipate, or they may be easily distracted
    f. Censoring, delaying, or modifying a thought, action, or emotional expression, for example, they may be **impulsive** and not think twice about saying or doing something
    g. Reasoning, judgment, problem solving, and planning
    h. Knowing the order (**sequence**) of, for example, steps of a task, points to make in a discussion, or clothes to put on when dressing
    i. **Abstract** thinking
    j. **Correcting mistakes**, being accurate, or completing a task, thought, or communication
    k. **Apathy** and inertia
    l. **Getting started** (initiation) on a task, an action, communication or a verbal response, for example, they may appear lethargic, lazy, or uninterested (for example, they may stay lying on the couch even though they said they want to do something else)
    m. Their sense of how much time is passing, or where they are regarding the past, present, and future
    n. Viewing from someone else's perspective
    o. **Empathizing** with someone else's emotions
    p. Monitoring their own behavior, needs, desires, thoughts
    q. **Adapting** to, for example, changes in plans or to a new situation
    r. The ability to leave a thought, action or word when it is done (**perseveration**), for example, they repeat the thought, action, or a word over a period of time
    s. Letting go of a thought or desire, for example, they may become obsessed with a particular food, behavioral ritual, or thought about wanting to see a particular person or to go to a particular place
    t. Controlling or stopping simple **repetitive body movements**, for example fingering the buttons on their shirt
3. **Changes in speech**: very obvious symptom (especially in the PPA type); beginning earlier in the

course than in AD, and increasing in difficulty over time including. This person may experience, for example:

a. Reduced spontaneity
b. Using **fewer words**
c. Repetition of a limited variety of words, phrases, and themes
d. Using **clichés** more often; they may have difficulty individualizing speech to a particular situation
e. Echolalia (they may immediately say the exact words or phrases they just heard)
f. Perseveration (they may mention over a period of time words or phrases they said or heard)
g. **Mutism** (lack of speech)
h. Producing speech as more difficult than understanding speech

4. Abilities later in the course that are **preserved early** in the course compared to AD, such as:
    a. Memory
    b. Visual & auditory perception, for example, they may understand what they see and hear, and be able to locate the source in space around them
    c. Spatial perception, for example, they may know how far an object is from their own body or from other objects
    d. Orientation to place and time
    e. The ability to coordinate movements in a meaningful purposeful way (unless a movement type of FTD disorder is present)
    f. Perception of time, for example, a sense of knowing how much time is passing
5. Abilities that are **still preserved later** in the course compared to AD, such as:
    a. Spatial orientation, for example, they don't get lost as often as might a person with AD

EMOTIONAL CHANGES

This person may experience:

1. Depression
2. **Anxiety**
3. Excessive tearfulness
4. Suicidal thoughts
5. Delusions
6. Hypochondriasis
7. Bizarre somatic preoccupation, for example, excessive focus on their own body
8. **Apparent emotional unconcern**, for example, indifference, remoteness, lack of empathy, apathy, blank facial expressions
9. Inappropriate emotional expressions:
    a. Laughing instead of crying
    b. **Exaggerated expression** of emotions
    c. Switching emotions quickly (emotional lability)

BEHAVIORAL CHANGES

This person may experience, for example:

1. Mood and behavior changes beginning early in the course:
    a. Less personal awareness, for example, **poor personal hygiene** and grooming
    b. Less social awareness, for example, a lack of social tact, petty crimes
    c. **Vulnerability to scams**, for example, giving away their house in exchange for a leaky rowboat, responding to mail or social media enticements and scams
    d. **Disinhibition**, for example, inappropriate sexual behavior, physical aggression, inappropriate laughter and joking, or restless pacing
    e. Lethargy

    f. A lack of apparent interest in family or work, for example, ignoring it or giving it less attention
    g. Incontinence
2. Unpredicted changes unique to each person, such as acting:
    a. Quiet and withdrawn or instead. disinhibited and disruptive
    b. Lethargic or instead, hyperactive
3. **Repetitive** behaviors, for example, roaming, clapping, singing, dancing
4. **Ritualistic** behaviors, for example, repeatedly cleaning even if the surface or item is clean
5. Hoarding, for example, collecting items they have difficulty organizing or disposing of
6. Fixations and **obsessions**
7. Impulsivity
8. Resistance to change
9. Hyperorality, for example, overeating, excessive food cravings, excessive smoking, excessive alcohol consumption, putting nonfood objects in their mouth
10. Exploring and handling objects in their environment excessively or inappropriately
11. Increase in time sleeping and increased drowsiness
12. Hallucinations
13. Movement that becomes rigid in the later part of the course (unless a movement type of FTD disorder is present)

EXAMPLES

Examples from persons living with Frontotemporal Dementia (FTD):

1. **A good deed without awareness of social consequences**: A woman with FTD plucked parking tickets off parked cars because "No one likes getting a parking ticket".
2. **Trouble with the law**: The first sign that there was a problem with their mother was when the family heard from the police that she was caught shoplifting. The family thought there was a mistake until they found stacks of shop-lifted dresses in their mother's basement.
3. **Impulsivity**: A man suddenly took his clothes off in public because he felt too hot.
4. **Doing only one thing at a time**: A son walked up to his father, patted him on the shoulder as he asked his father "How are you doing, Dad?". His father gruffly pushed his son away. The next time, the son entered his father's visual field, watched his eyes to make sure his father saw him, said "Hello, Dad. It's me John.", then continuing to watch his father's eyes and body for evidence of confusion or anxiety, walked slowly to his father's chair from the front, sat down, and put his hand on his father's hand. His father smiled. John did only one thing at a time (entered his visual field, then spoke, then moved) to avoid confusing his father or requiring his father to process more than one stimulus at a time. Instead of immediately asking a question (even a rhetorical question) John gave his father time to get used to being with him first.

INTERVENTIONS: COGNITIVE AND NONMEDICAL

1. See **detailed intervention** and support strategies in the **resources** identified at the beginning of this handout, including interventions that address **specific cognitive abilities** associated with **specific brain structures**. The resources also include a method of identifying an individual's particular cognitive strengths and needs, so that interventions can be **individualized** to this person and situation.
2. **Address cognitive changes** associated with each part of the brain that is affected in FTD (for example, **executive functions** for the frontal lobe and **language** for the left temporal lobe).
    a. Due to the frontal lobe changes, for example, it is usually helpful to **structure** this person's **time** with events and routines, and keep the order, time, and duration of these **consistent**. That is, avoid changing the events and routines unless necessary as this person's specific needs and preferences change, and then change them as little as possible. (For example, see **CAIS Handout #35** about frontal lobe interventions.)

3. Identify this particular person's cognitive abilities (including their **cognitive strengths** and their cognitive **needs**) and their ability to perform tasks. Avoid generalizing the symptoms of FTD, that is, don't assume this person has all of the symptoms of FTD; each person is different
4. Assess this person regularly **over time** as their dementia progresses
5. Examine and modify their **environment**, your **interactions** with this person, and their **tasks** and daily routines to build on this person's cognitive strengths and support or **compensate** for this person's cognitive needs **throughout the course** of FTD (For example, see the ***CAIS Intervention Strategies*** noted at the beginning of this handout.). Modify expectations and interventions as change occurs
6. Acknowledge that comprehension is usually better than expression of language:
    a. Talk to this person directly
    b. Avoid talking about this person in front of this person
7. Avoid giving **unintended cues** or information, for example, avoid talking about one task when they are focused on another task; ensure clocks and notes are accurate
8. Orient this person to time, when that is helpful
9. **Structure** this person's **time** with activities and events, so they can sense where they are with regard to time throughout the day
10. Tell this person clearly but gently the schedule, social expectations, and the steps of a task
11. Emphasize **consistency**; and **predictability** in:
    a. The **schedule** of events and daily routines (in time, duration, and order)
    b. Who is assisting or providing care (**same person** each time)
    c. The way a task is done (for example, the same order of task steps, same task objects)
    d. Where events and activities take place
    e. The environment (for example, avoid changing rooms or furniture)
    f. The methods of communication
12. When communicating:
    a. **Watch** and **listen** to this person to make sure they understand what you are saying
    b. **Give this person time** to absorb and process what you said, prepare to respond, and then to respond
    c. When this person speaks, make sure they **mean what they said**, for example, if they reply "Yes" make sure they meant "yes" (since sometimes they might say the opposite of what they intended to say), or if they say "pip" instead of "pen" try to discern what they had intended to say
    d. If this person has difficulty understanding what you said try, for example, to **explain** it, **demonstrate** it, or **point** to the object that you are referring to
    e. Increase **nonverbal** forms of communication, for example, use gestures, body language, and how you position your body so this person can more easily see and interpret what you are saying and doing
    f. Get and keep this person's **attention**; be the most powerful stimulus they encounter when you speak, use eye contact or touch if they are comfortable with eye contact or touch; reduce other noise and distractions
    g. Give time for this person to start an action
    h. Keep information and requests **concret**e
    i. Use **familiar** words
    j. Use **few** words, short words and phrases
    k. Use the **most important words first**
    l. Use music, singing, or rhythm to help this person talk or to move; this may use other parts of the brain to help this person convey their thought or to do an action; it also can shift their attention slightly away from the task, if they can speak or move more easily when they don't think about it
    m. Be calm, clear and respectful with requests; minimize emotional energy and the content of the request if the request is upsetting to this person

13. Use speech therapy
14. Rely on intact parietal lobe abilities rather than difficult frontal lobe abilities (for example, use nonverbal stimuli and methods of communications, music, rhythm, fewer lengthy explanations or questions) (See **CAIS Handout #35** about **interventions** for the **frontal lobe**)
15. Do nonverbal activities with this person rather than simply conversing, for example, sort through photos or cards, put together a picture puzzle, knit, rake leaves, take a radio apart (safely)
16. Shift from one thought or activity to another **slowly**; give time
17. **Reduce** the **number** of people they must see and interact with
18. **Exercise** and walk to help maintain movement
19. Address social behavior of this person, including, for example, the:
    a. **Distress** of others regarding this person's behavior (resulting in embarrassment or concern from others)
    b. Impact on this person's **children** (possibly teenagers) and coworkers
    c. **Community** awareness; arrange support; communicate with law enforcement to explain this person's FTD
    d. Vulnerability to scams, for example, add a family member to this person's checking account, monitor and limit if necessary this person's access to cash and deeds
20. Support family and others:
    a. Address their surprise, anger, pain, and other emotions
    b. Educate and remind them that FTD is a brain disorder
    c. Prepare them for possible employment and financial implications, since this person was probably young enough to be employed when the symptoms began
    d. Prepare for **future** care
21. Discuss with or explain to this person, family, or others:
    a. A description of the course of FTD
    b. That their expectations must match this person's particular abilities
    c. That **comprehension** is usually **easier** for this person **than speech** (so avoid talking about this person in front of this person; avoid excluding this person from the conversation if they might benefit from it)
    d. The need to be **predictable**: minimize change; do things the same way each time

MEDICAL TREATMENTS

1. Cure unknown
2. Treat symptoms
3. Increase serotonin for repetitive and obsessive behaviors
4. Medications used for Alzheimer's Disease may be helpful with symptoms, but may also have adverse side effects

COMMENTS

1. In 1994 consensus criteria for clinical and pathologic diagnosis were created and have since been updated.
2. Pick bodies were first described in a patient by Arnold Pick in 1906.
3. FTD is often misdiagnosed as depression, Alzheimer's Disease, or a mental illness

MORE ABOUT CHANGES IN THE BRAIN AND COGNITIVE ABILTIES

More details about changes in the brain and resulting changes in cognitive abilities in dementia are in **CAIS Handouts #7** and **#8**.

Though these changes in behavior and cognitive abilities result from brain changes, changes in a person's behavior or cognition are often mistakenly viewed as intentional or manipulative. For example, this person may mistakenly be seen as stubborn, "mean", ornery, or lazy.

There is wide variation in the many changes in the brain among individuals with Frontotemporal Dementia (FTD), partially because the name (Frontotemporal) refers to the location rather than to the name of the neuropathology. As was stated earlier, there are various types of Frontotemporal disorders. Pick bodies (the neuropathology found in Pick's disease) are found in Pick's Disease.

Four **neuropathological** changes are: atrophy**,** tao tangles, TDP-43 protein accumulation, and neurochemical changes.

1. **Atrophy** is the **reduction** in **size** of a structure. Atrophy due to death of nerve cells in Frontotemporal Dementia causes much of the confusion and change in cognitive abilities. The atrophy is visible on a computed tomography (CT) scan, a magnetic resonance imaging (MRI) scan, or at autopsy.
2. **Tao tangles** are **inside nerve cells** in the brain in Frontotemporal Dementia. They are collections of a protein called tau that begins to act abnormally to disrupt the transport of cell nutrients within the nerve cell, contributing to the cell's death. These are different from the tao tangles found in Alzheimer's Disease.
3. **TDP-43 protein** is **inside nerve cells** in the brain**.** The accumulation of this protein is evident in FTD and in ALS, as well as in some other dementia disorders.
4. **Neurochemicals** (or neurotransmitters) facilitate the process of communication between nerve cells (that is, neurons), so essential to the brain's maintenance and functioning. A neurotransmitter is released from a nerve cell into the gap between it and another nerve cell. There are many types of neurotransmitters. In Frontotemporal Dementia, there is a **reduction** in the **amount** of some of these neurotransmitters, including three neurotransmitters called dopamine, serotonin, and glutamate.

For more information

1. The Michigan website called Improving MI Practices at **https://www.improvingmipractices.org** has updates and many additional handouts and resources, including **all of these CAIS** H**andouts** (43 total), the Cognitive Abilities and Intervention Strategies (**CAIS**) **Questions to Ask** and the **CAIS Intervention Strategies**, **CAIS** information and background **resources**, and the **Caring Sheets**:Thoughts and Suggestions for Caring that are a part of the Michigan Dementia Care Series.
2. Mace, N., Coons, D., Weaverdyck, SE. (2005) Teaching Dementia Care: Skill and Understanding. Baltimore, Md.: Johns Hopkins University Press.

Original Sources

3. Weaverdyck, S.E. (1991) "Assessment as a Basis for Intervention" and "Intervention to Address Dementia as a Cognitive Disorder". Chapters 12 & 13 in D. Coons (Ed.) Specialized Dementia Care Units. Baltimore, Md.: Johns Hopkins University Press.
4. Weaverdyck, S.E. (1990) "Neuropsychological Assessment as a Basis for Intervention in Dementia". Chapter 3 in N. Mace (Ed.) Dementia Care: Patient, Family, and Community. Baltimore, Md.: Johns Hopkins University Press.

Dementia Care Series

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All Caring Sheets are available online at the following websites: **http://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_38495_38498---,00.html** (Michigan Department of Health and Human Services MDHHS), at **http://www.lcc.edu/mhap** (Mental Health and Aging Project (MHAP) of Michigan at Lansing Community College in Lansing, Michigan), and at **https://www.improvingmipractices.org** (Michigan Improving MI Practices website)

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