SPRING IDD SUMMIT: POSITIVE APPROACH TO CARE FOR ALZHEIMER’S AND DEMENTIA RELATED ILLNESSES

Sharing best practices to support individuals with IDD and age-related illnesses.

Meaningful Engagement | Communication Styles | Nutrition | Caregiver Support | End of Life | Behavior Support

SCHEDULE OF EVENTS

9:30-10 a.m.  Registration
10 a.m.-12 p.m. Positive Approach to Care by Shelly Edwards  
– Part 1
12-1 p.m.  Lunch (provided)
1-3:30 p.m. Positive Approach to Care by Shelly Edwards  
– Part 2
-or-
1-4 p.m.  Medicaid 101 by Russell Nittler, KDHE

April 10, 2019
9:30 a.m.-4 p.m.

Johnson County Arts & Heritage Center
8788 Metcalf Ave.
Overland Park, KS 66212

ABOUT THE PRESENTER: SHELLY EDWARDS

Shelly Edwards is an accomplished professional trainer and educator. She joined Teepa Snow’s PAC Team in 2018, after four years as a PAC Certified Independent Trainer. She has been a trainer of adults for more than 30 years, specializing in Alzheimer’s and dementia training since 2007. During this time, Shelly has been training professional care partners, first responders, and families alike. She has also been a trainer for Oregon Care Partners since its inception in 2014, providing classes about dementia, challenging behaviors, and communication skills for care partners in the developmental disabilities community as well.
It’s All in Your Approach: Supporting Persons Living With Dementia

Shelly Edwards
Business Development Coordinator
shellye@teepasnow.com
Speaker Disclosures

Shelly Edwards is the Business Development Coordinator for Positive Approach® LLC
Objectives:

1. Understanding the progression of dementia: retained vs lost including visual perception, language, rhythm & executive function:

2. Demonstrate and practice the care partnering skills and their common modifications by state of dementia care partnering skills including: Visual-Verbal-Touch, and the Positive Physical Approach™ technique to approach and connect

3. Be introduced to, and thus describe the use of Hand-under-Hand™ to guide and assist
It Takes TWO to Tango ... or Tangle...

- The relationship is MOST critical NOT the outcome of one encounter

- Being ‘right’ doesn’t necessarily translate into a good outcome
Five Ways to Say, “I Am Sorry!”

**INTENT**
I’m sorry I was trying to help

**THIS IS HARD**
I’m sorry, this is hard, I hate it for you

**EMOTION**
I’m sorry I made you angry

**THAT HAPPENED**
I’m sorry, it should NOT have happened

**INTELLECTUAL CAPACITY**
I’m sorry, I had no right to make you feel that way
Caring for People with Dementia when *DD/ID* is involved?

Changing Attitudes through Building Awareness, Knowledge and Skill
Developmental Disabilities & Dementia

- Other than Down – Dementia affects about 5-10% of the DD population – but somewhat younger than the general population
- Increase after age 45 – 60
- Increases if # of head injury
- Increases if family members have AD
- Increases with other risk factors
Down and Alheimers

- Probably affects the vast majority of people with Downs
- Due to premature aging, onset is earlier
- 35 – 65 – numbers increase dramatically
- Some people will experience very rapid onset (1 – 3 years)
- Most progression lasts 3-10 years
- Frequently have other medical pxs
Unique Changes

- Attention losses are first – not memory
- Self-care skills are damaged early
- Seizures may be noted – ‘staring’
- Memory pxs are not the 1st noticed
- Reduced speech attempts – more slurring and repetitive words
- Increased stereotypical behaviors
- Sensory needs & tolerances change
- **Behaviors change** – ‘plans’ don’t help
Brain with Alzheimers

Normal Brain

used with permission from The Broken Brain: Alzheimers, 1999 University of Alabama
Brain Failure

The person’s brain is dying
Four Truths About Dementia

1. At least 2 parts of the brain are dying
   • *often the hippocampus (memory) is damaged early*

2. It is chronic
   • *can’t be fixed*

3. It is progressive
   • *it gets worse*

4. It is terminal
   • *eventually*
## Positron Emission Tomography (PET) 
### Alzheimer’s Disease Progression vs. Normal Brains

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>Early Alzheimer’s</th>
<th>Late Alzheimer’s</th>
<th>18 month old child</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Normal Aging Image" /></td>
<td><img src="image2" alt="Early Alzheimer’s Image" /></td>
<td><img src="image3" alt="Late Alzheimer’s Image" /></td>
<td><img src="image4" alt="18 month old child Image" /></td>
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</table>

G. Small, UCLA School of Medicine
Impulse Control
Be Logical
Make Choices
Start-Sequence-Complete-Move On
Self Awareness
See Others’ Point of View
BIG Language CHANGE

Hearing Sound – Unchanged

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Amygdala

Left

DANGEROUS

Aroused/ Risky

Alert/ Aware

Right

NEED

Want

Like
Primitive Brain is in Charge of:

**Survival** –
- Autonomic protective – fright, flight, fight + hide or seek
- Pleasure seeking – meeting survival needs & finding joy

**Thriving – Running the Engine**
- Maintain vital systems (BP, BS, O₂ sat, Temp, pain)
- Breathe, suck, swallow, digest, void, defecate
- Circadian rhythm
- Infection control

**Learning New and Remembering:**
- Information
- Places (spatial orientation)
- Passage of Time (temporal orientation)
Vision Changes

With each new level of vision change, there is a decrease in safety awareness.

1. Loss of Peripheral Awareness
2. Tunnel Vision
3. Binocular Vision
4. Binocular + Object Confusion (discriminating senses)
5. Monocular Vision
6. Loss of Visual Regard
Hippocampus

BIG CHANGE

Learning & Memory Center

- Navigation (Way finding)
- Learning & memory
- Spatial orientation
3 Zones
Of Human Awareness
and How We take in Data

Changing Attitudes through Building Awareness, Knowledge and Skill
### 3 Zones of Human Awareness

<table>
<thead>
<tr>
<th>Zone</th>
<th>Distance</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Public Space</td>
<td>6 ft or more away</td>
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### 3 Ways to We take in Data

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<td>3. Touch</td>
<td>What we touch &amp; feel</td>
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Positive Physical Approach™

1. **Stop** moving 6 ft out
2. **Greet**: *Hi* sign (open by face), say name
3. Move hand **into a handshake** position
4. **SLOWLY** come in from the front - within visual range (or starts there)
5. Move into **Supportive Stance**
6. Hand shake—move into ‘**Hand-under-Hand®**’
7. Move to side; **Get low** – sits or kneels
8. Make **connection** (wait for their response!)
9. Deliver a message – using V-V-T cues
Positive Physical Approach™

1. **Stop** moving 6 ft out
3. Move **into a handshake**
4. **SLOWLY** come in from front
5. **Supportive Stance**
6. Move into **HuH®**
8. Make **connection** (wait!)

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If you can’t get low, find a chair
Hand-under-Hand™
To guide and assist

HUH™
Hand-under-Hand™ Assistance

✔ Helps assist doing WITH, not for

✔ Helps protect their:
  fingers, wrist, arm

✔ Helps protect us:
  Gives you cues before a PLWD wants to strike out

✔ Gives them something to squeeze/grab onto

✔ Helps direct gaze – eye-hand coordination

✔ Pressure in the palm is calming
Hand-under-Hand™ Assistance

Protects aging, thin, fragile, forearm skin
High Risk
Sensory Strip
Motor Strip
White Matter
Connections
BIG CHANGES

Formal Speech &
Language
Center
HUGE CHANGES

Automatic Speech
Rhythm – Music
Expletives
PRESERVED

Right
Left
Right
Left

Right
Left
Right
Left
Connection & Communication
Positive Personal Connections
Positive Action Starters
Positive Personal Connections (PPC)

1. Greet or Meet
   • introduce yourself and use their preferred name
     • “Hi ___, I am ___.” or, “I am ___ and you are?”

2. Say something NICE
   • Indicate something about them of value

3. Be friendly
   • Share about you then leave a blank
     • “I’m from Michigan, and you’re from?”

4. Notice something
   • Point out something in the environment

5. Be curious
   • Explore a possible unmet like, want or need
Positive Action Starters (PAS)

1. **Help** – Be sure to compliment their skill in this area, then ask for help. “I could use your help…”

2. **Try** – Hold up or point to the item you would like to use, possibly sharing in the dislike of the item or task, “Well, let’s try this.”

3. **Choice** – Try using visual cues to offer two possibilities or one choice with something else as the other option. “Coffee or Tea?” “This? Or something else?”

4. **Short and Simple** – Give only the first piece of information, “It’s about time to …”

5. **Step by Step** – Only give a small part of the task at first, “Lean forward….”
Who has the bigger brain?  
YOU have the POWER to choose

Thank you
The GEMS...

Sapphires: True Blue – Healthy Brain
Diamonds: Routines & Routines Rule - Clear/Sharp
Emeralds: Green/On the Go with Purpose– Naturally Flawed
Ambers: Caught In a moment of time – Caution Required
Rubies: Deep & Strong – Others stop seeing what is possible
Pearls: Hidden in a Shell – Beautiful Moments to Behold
Positive Physical Approach™

To the tune of Amazing Grace

Come to the front, Go slow
Get to the side, Get low
Offer your hand, Call out their name
Then wait.....
If you will try, then you will see
How different life can be
For those you’re car-ing for.
He Just Does That: Moving From Behaviors to Meeting Unmet Needs

Shelly Edwards
Business Development Coordinator
shellye@teepasnow.com
Objectives:

1. Understanding the ways people take in data

2. Identify the 10 Physical and Emotional Unmet Needs to demystify challenging situations in dementia

3. Plan for the use of 6 Pieces of the Puzzle tool to help de-code challenging situations
10 Early Warning Signs of Dementia

1. memory loss for recent or new info – repeats self frequently
2. difficulty doing familiar, but difficult tasks – managing money, medications, driving
3. Problems word finding – mis-naming, mis-understanding
4. confused about time or place – getting lost while driving, missing appointments (>2!)
5. worsening judgment – not thinking thing through like before
6. difficulty problem solving or reasoning
7. misplacing things – putting in ‘odd places’
8. changes in typical personality
9. loss of initiation – withdraws from normal activities/interests
Could It Be Something Else?

- Another form of dementia… 85+
- A worsening medical condition
- Medication side-effects
- Un detected hearing or vision loss
- Depression or other mental health issue
- Delirium – ACUTE medical emergency
- Severe pain or overdose of pain meds
- Other things…
Challenging Situations:

Or Unmet Needs?
Dementia Challenge Situations

A woman who will spend the day beating the chairs and tables loudly with a musical instrument

Any approach is met with “GIT!”

If you persist, “she will swat ya.”

She refuses all offers of water, sitting down, or going to the bathroom
What are you Examples of “Challenging” Behaviors?
Examples of What Are Usually Called “Challenging” Behaviors

‘Losing’ Important Things
Getting Lost – time, place
Unsafe task performance
Repeated calls & contacts
Refusing help & care
‘Bad mouthing’ about staff
Making up stories - confabulation
Undoing what is done
Swearing/cursing, sex talk, slur
Making frequent 911 calls
Mixing day & night
Sleep problems
Not following care/rx plans
No initiation – can’t get started
Not talking any more
Infections & pneumonias

Paranoid/delusional thinking
Shadowing - following
Eloping or Wandering
Hallucinations
Getting ‘into’ things
Threatening caregivers
Problems w/intimacy & sexuality
Being rude - intruding
Feeling ‘sick’ – not doing ‘anything’
Use of drugs or alcohol to ‘cope’
Striking out at others
Contractures & immobility
Falls & injuries
Problems w/ eating or drinking
Perseveration–can’t stop repeating
Undressing in public OR not changing when needed
Examples of What Are Usually Called “Challenging” Behaviors

- Losing’ Important Things
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- Shadowing - following
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- Hallucinations
- Getting ‘into’ things
- Threatening caregivers
- Problems w/intimacy & sex
- ‘Black out’ - intruding
- ‘Black out’ – not doing
- Using drugs, alcohol
- Smoking
- Copying others
- Contractures & immobility
- Falls & injuries
- Problems w/eating or drinking
- Perseveration - can’t stop repeating
- Undressing in public OR not changing when needed

Problems w/ eating or drinking
# Top Ten Unmet Needs of People Living with Dementia

## Five *Expressions of Emotional Distress*
- **Angry**
  - irritated – angry – furious
- **Sad**
  - dissatisfied – sad – hopeless
- **Lonely**
  - solitary – lonely – abandoned/trapped
- **Scared**
  - anxious – scared – terrified
- **Bored**
  - disengaged – bored – useless

## Five *Physical Needs*
- **Intake**
  - hunger or thirst
- **Energy**
  - tired or revved up
- **Elimination**
  - need to go or did
- **Discomfort**
  - temperature or sensations
- **PAIN!!!**
  - joints, internal or external systems
So what works

Meeting Unmet Needs
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Hand-under-Hand™ Assistance

✔ Helps assist doing WITH, not *for*
✔ Helps protect their:
   fingers, wrist, arm
✔ Helps protect us:
   Gives you cues before a PLWD wants to strike out
✔ Gives them something to squeeze/grab onto
✔ Helps direct gaze – eye-hand coordination
✔ Pressure in the palm is calming
Connection & Communication

Positive Personal Connections
Positive Action Starters
Give SIMPLE INFO

• Visual matched WITH verbal
  • *It’s about time for...* tap your watch/wrist
  • *Let’s go this way.* Point
  • *Here’s your socks.* Hold up their sock
  • *Coffee or tea?* Raise coffee carafe then tea bag

• DON’T ask questions you DON’T want to hear the answer to...

• Acknowledge their response/reaction

• LIMIT words – Keep it SIMPLE

  And then WAIT!!!!
What makes situations happen?

SIX pieces...

- The person & who they have been
  - Personality, preferences & history
- Other conditions & sensory status & meds/ fluids/ fuels
- The type & level of cognitive impairment(s) ... NOW
- People - How the helper helps & others
  - Approach, behaviors, words, actions, & reactions
- The environment – setting, sound, sights – 4 F’s
- The whole day... how things fit together – finding balance
What Makes ‘Behaviors’ Happen?

**Person:**
- personality
- preferences
- history, then & now

**Dementia:**
- Type(s)
- Stage
- Retained abilities
- Lost abilities

**Medical Condition and Sensory Status**
(fuel, fluids, meds)

**Environment**
- Friendly
- Familiar
- Functional
- Forgiving
- Surface
- Social
- Sensations
- Space

**People/Helpers**
- Approach
- Behaviors
- Words
- Actions
- Reactions

**Time: Structure of the Day**
- Balance; wait
- Rest
- Self-care, wellness
- Leisure/fun
- Productive/work

**What you can’t control**

**What you can control**
The Person and Who They’ve Been

Personality traits
- Introvert or Extrovert
- Detail or Big Picture
- Logical/thinking or Emotional
- Planner (controlling) or In the Moment

Preferences…MATTER
- We like what we like, we want what we like
- Likes can change
- Appearance, routine, foods, music

Personal history
Medical Condition & Sensory Status*

- Fuel and fluids
- Other medical & psychiatric conditions
- Sensory status – vision, hearing, sense of touch, balance, smell, taste
- Medications and treatments

*may have ability to modify or attenuate some of these
Dementia (The 3 D’s)

Delirium: dangerous and deadly
- Possible PAIN, infections, med changes/side effects, physiological changes (dehydration, blood chemistry, $O_2$ saturation)

Depression: treatable
- Most elders with depression describe themselves as having memory problems or somatic complaints
- Look for changes in appetite, sleep, self-care (sudden), pleasures, irritability, ‘I can’t take this’

Dementia
- Type(s)
- Stage
- Retained abilities
- Lost abilities
Gem Dementia Abilities
Based on Allen Cognitive Levels

- A Cognitive Disability Theory – OT based
- Creates a common language and approach to providing:
  ✓ Environmental support
  ✓ Caregiver support and cueing strategies
  ✓ Expectations for retained ability and lost skill
  ✓ Promotes graded task modification
- Each Gem state requires a special ‘setting’ and ‘just right’ care
  ✓ Visual, verbal, touch communication cues
- Each can shine
- Encourages in the moment assessment of ability and need
  ✓ Accounts for chemistry as well as structure change
The GEMS...

Sapphires: True Blue – Healthy Brain

Diamonds: Routines & Routines Rule - Clear/Sharp

Emeralds: Green/On the Go with Purpose– Naturally Flawed

Ambers: Caught In a moment of time – Caution Required

Rubies: Deep & Strong – Others stop seeing what is possible

Pearls: Hidden in a Shell – Beautiful Moments to Behold
Environment
4 F’s: Friendly, Familiar, Functional, Forgiving
-What helps? What hurts?
-Physical (sensory experience)
-People or how to engage socially
-Programming: to support what they like and need

4 S’s: Surface, Social, Sensations, Space
-Surface: Sit-stand-lie down-work
-Social: People-activities-role-expectations
-Sensations: See-hear-feel-smell-taste
-Space: Intimate-personal-public
US! People & Caregivers

• People around
• Our history
• Awareness, knowledge, & skills
  • Competence??
• Relationship
  • PPA™, HuH™
  • Positive Action Starters
• Our agenda
US! People & Caregivers

Should **NOT:**

- Argue
- Make up stuff not true
- Ignore behavior problems
- Try a possible solution only once
- Give up
- Let them do whatever they want
- Force them to do what you want
- Remember who has healthy brain
- We have to control us; we can change
- They’re doing the best they can!
Structure of the Day

Time Awareness:
Where in life
Time of Day

- Balance of Meaningful Activities
- Productive: give value and purpose
- Leisure: have fun, interact
- Self-care, wellness: personal care, body & brain
- Restorative: re-energize and restore spirit
Progression of the Condition

To the tune of *This Old Man*

The LIVING GEMS®
SAPPHIRE true, you and me

The choice is ours, and we are free

To change our habits, to read, and think and do

We’re flexible, we think it through!
DIAMOND bright, share with me

Right before, where I can be

I need routine and different things to do

Don’t forget, I get to choose!
EMERALD – go, I like to do

I make mistakes, but I am through!

Show me only one step at a time

Break it down and I’ll be fine!
AMBER – HEY!, I touch and feel

I work my fingers - rarely still

I can do things, if I copy you

What I need is what I do!
RUBY – skill – it just won’t go

Changing something must go slow

Use your body to show me what you need

Guide, don’t force me. Don’t use speed!
Now a PEARL, I’m near the end

But I still feel things through my skin

Keep your handling always firm and slow

Use your voice to calm my soul.
Sapphires

True Blue

Optimal Cognition, Healthy Brain
Optimal Cognition: flexible in capacity
Normal aging will slow, yet not change ability
More time to process with stress
True to self: likes/dislikes are the same
Able to learn: takes more practice
Stress, fatigue or pain can induce Diamond moments
Time to recharge or heal can restore to Sapphire
Diamonds

Clear and Sharp

Routines and Rituals Rule
Diamond
Clear and Sharp

Routines and Rituals Rule: likes familiar
May resist change or won’t let things go
Rigid under pressure: limited perspective
Becoming protective: may be territorial or isolate
Repeats self: hard to integrate new information
Can cover mistakes in social interaction
Symptoms may or may not be dementia related
Emeralds

Green and

On the Go with a Purpose

Naturally Flawed
Emerald
Green and On the Go with a Purpose
Naturally Flawed

Desires independence: noticeable ability change
Vocabulary and comprehension diminishing
Communication becoming vague
May neglect personal care routines
On the go: needs guidance and structure
Difficulty finding way to and from places
May be lost in time
Ambers

Caught in a Moment of Time

Caution Required
Amber
Caught in a Moment of Time

Caution Required
Focused on sensation
Will react to how things: look, sound, feel, smell or taste
Lives in the moment: not socially aware
No safety awareness: typically very busy
Difficulty understanding and expressing needs
No ability to delay needs or wants
Needs help with tasks: may resist
Hard to connect with: may exhaust care partners

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Rubies
Deep and Strong
Others Stop Seeing What Is Possible
Rubies
Deep and Strong

Others stop seeing what is possible
Retains rhythm: can sing, hum, pray, sway and dance
Understands expressions and tone of voice
Losing ability to understand language
Limited skill in mouth, eyes, fingers, and feet
Can mimic big movements: gross motor abilities
Loss of depth perception; monocular vision
Falls prevalent: can only move forward
Care Partners will have to anticipate unmet needs
Pearls
Hidden Within a Shell
Beautiful Moments to Behold
Pearls

Hidden Within a Shell

Person is still there
Moments of connection take time and will be short
Knows familiar: unmet needs may cause distress
Unable to move by themselves: fetal position, still and quiet
Primitive reflexes have taken over: difficulty swallowing
Brain failure shuts down body: diminishes need to eat or drink
Care Partners need to give permission to let go
6 Pieces of the Puzzle

Person:  
Dementia  
Medical/Sensory  
Environment  
People/Helpers  
Time  

What you can’t control  
What you can control
Who has the bigger brain?
YOU have the POWER to choose

Thank you