

PBS Solutions  
For  
Supporting People With Alzheimer's

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## Session Objectives:

- Characteristics of Alzheimers/Dementia and Developmental Disabilities
- Current Research
- Presentation of a model for staff training in PBS and Alzheimer's and Developmental Disabilities



## Motivation for Development of Program:

### A. Specific needs of people with Alzheimer's

1. Skills diminish over time
2. Currently no cure
3. Medical focus

### B. Giving staff tools to support people with these specialized needs.

1. Knowledge of how disease progresses
2. Knowledge of how the disease affects individuals
3. Tips for support

- There was a need to combine service delivery elements from both seniors and disability communities.

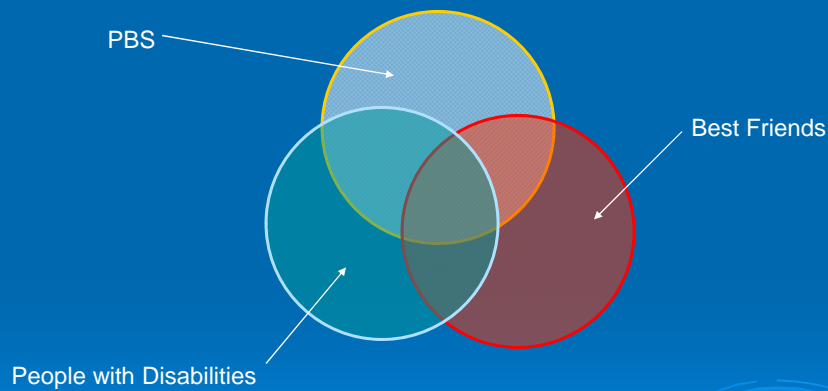


**Blend of three areas:**

- A. Best friends**
- B. Positive Behavior Support**
- C. People with disabilities**

**Motivation for using three areas, how they blend.**

**Blend of all three areas**



## Best Friends Approach

- **Knowing the basics**
- **Assessing strengths**
- **Having appropriate expectations**
- **Valuing basic rights**
- **Ingredients of good friendship**
- **Knowing the person's life story\***
- **Recasting relationships**
- **Result: The Knack**

## Positive Behavior Support

- **Includes:**
- **A. Environment**
- **B. Reduction of stressors**
- **C. Individualized supports**

**And always:**

- **Least intrusive**
- **Non-Aversive**

## Working with People with Disabilities

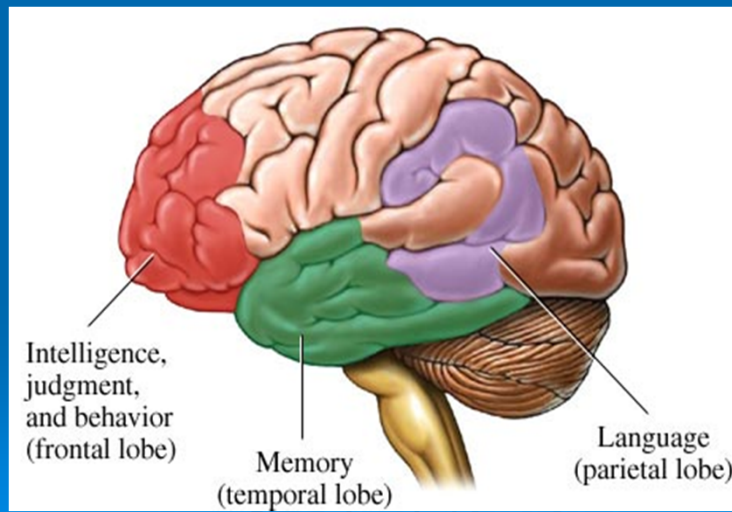
- 1. Know the disability
- 2. Processing time
- 3. Community access
- 4. Emphasize strengths
- 5. Be concrete
- 6. Break tasks into smaller steps

## What is Alzheimer's

- Dementia:
- A clinical syndrome characterized by a decline in mental function of long duration in an alert individual.
  
- Alzheimer's Disease:
- A chronic, progressive disease of unknown cause that attacks brain cells or tissues.



## Areas of the brain affected by Alzheimer's and other dementias



Rate of Alzheimer's disease  
among persons with mental retardation

- Same as regular population:
- 6% of persons age 60 and older
- However, for people with Downs much higher:
- 25% over 40
- 65% over 60

- What is rate of occurrence of dementia with in other learning disabilities?

At 50 years + : 13% of population

At 65 years + : 22% of population



## What are they going through??

- Diminished:
- Visual/spatial perception
- Judgment
- Language skills
- Short and long term memory

## What are they going through??

- Worry and Anxiety
- Frustration
- Confusion
- Loss
- Isolation and Loneliness
- Sadness
- Embarrassment
- Paranoia
- Anger

## What are they going through??

Now add in their disability, and age related problems:

- Down's Syndrome
- MR/DD
- Eye sight, hearing, joints

## Typical symptoms, early phase

3,5,7

- Becoming confused, gets lost easily.
- Slowed learning ability.
- Loses ability to start tasks
- Speaks more slowly
- Avoids unfamiliar situations.
- Difficulty handling money
- Delayed reactions
- Poor judgment
- Mood swings

## Typical symptoms, middle phase

- Has problems recognizing close friends and family.
- Becomes restless and wanders, especially in late afternoon and at night. (sundowning)
- Has problems reading, writing, and dealing with numbers.
- Has problems organizing thoughts and thinking logically.

## Typical symptoms, middle phase

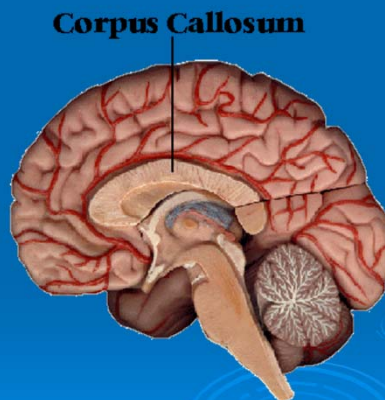
- **Can't find the right words to say what he or she means or makes up stories to fill in the blanks.**
- **Has trouble dressing.**
- **Gets upset easily and can be hostile or unwilling to cooperate.**
- **Has firmly held false beliefs (delusions), suspicion of others (paranoia), and agitation.**
- **Needs full-time supervision.**

## Typical symptoms, late phase

- Can no longer bathe, eat, dress,
- May become bedridden or confined to a wheelchair
- Loses the ability to chew and swallow.
- Has trouble with balance or walking and may fall frequently.
- Becomes more confused in the evening (sundowning)
- Cannot communicate using words.
- Loses bowel or bladder control (incontinence).

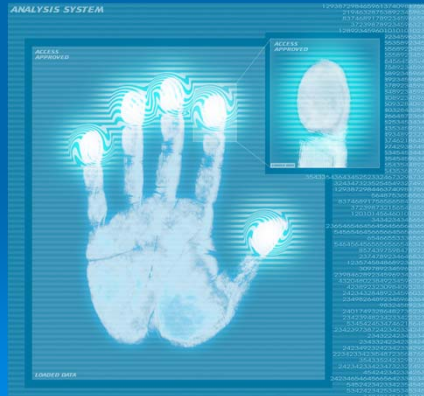
## Test your corpus callosum

- Turn to partner
- Have them close their eyes
- Touch finger on their left hand with pencil
- Have them copy on opposite hand with their thumb.



# Body Language vs. Language

- Follow along if you can!!!



## Some signs and symptoms

- Development of seizures
- Changes in personality
- Long periods of inactivity or apathy
- Hyperactive reflexes
- Loss of activity of daily living skills
- Visual retention deficits

## What Behavior could we see???

- Shopping (taking EVERYTHING!!)
- Exit seeking
- Aggression
- Refusal to do anything
- Crying

## What can we do???

- 1. Proper diagnosis
- 2. Medications
- 3. Environment adaptations
- 4. Structure and Predictability
- 5. Behavior Support Program

## Proper Diagnosis

### Things that may mimic Alzheimer's

- **Adult Hydrocephalus**
- **Side affects to medications**
- **Stroke**
- ***Thyroid gland problems***
- ***Depression***
- **Fatigue**

## Proper Diagnosis

- A diagnosis is made with :
- careful medical history
- physical exam
- evaluation of the person's mental and functional status
- lab tests to rule out other possible causes
- CT, MRI, PET, SPECT scans

➤ computed tomography , magnetic resonance imaging, Positron emission tomography, single photon emission tomography

## Medications

- Currently, there are more than 50 medications being developed to treat Alzheimer's disease.
- Medications now available include: Aricept, Reminyl, Exelon, and Cognex, Exelon

These medications, called cholinesterase inhibitors, have been approved specifically for treatment of Alzheimer's disease.

- Leuprolide Acetate (Current trial, by Voyager)

## Environment

- High visual contrasts between floors and walls and doorways and walls
- Floors, walls and ceiling should be non-reflective to minimize glare;
- Adequate and even lighting which minimizes glare and shadows
- Plates and eating utensils which provide visual contrast between them and the table

## Environment

- Individually identify residents' rooms to assist residents in recognizing their room;
- Memory boxes, names on doors
- Toilet seat different color from toilet.
- Doors, closets same color as walls to curb access. (if needed)

## Creation of a person's Life Story

- Be their memory, or a human prosthesis.
  - Have life story or cue cards handy to aid support providers of life information.
- Creation of a person's life story:
- Helps person remember history and past events
  - Helps guide staff for activities
  - Helps support people recognize potential triggers for sadness, agitation, or concern.

## Structure & Predictability

- Having enough information to answer the following questions decreases their anxiety and stress:
  - Where am I going?
  - What am I doing?
  - How much am I doing?
  - How do I know when I'm finished?
  - What's next?

## Structure & Predictability

- Remember you will have to add to their support, and environment as skills diminish.
- Placing supports into the environment that take the place of internal functions lost.

## Structure & Predictability

- Schedules,( pictures, calendars)
- Consistency, (routines for bathing, eating, activities)
- Choice boards
- Social Stories
- Working systems

## Behavior Support Plan

Three main concepts:

Promoting remaining abilities for self-care;

Encouraging independence while recognizing limitations;

Providing safety and comfort;

# Behavior Support Plan

## **Positive Behavior Support:**

Designing an environment that reduces distractions and stressors.

Designing supports that offer a person clear information and that make the challenging behavior less necessary

# Behavior Support Plan

Four main sections of a Behavior Support Plan:

1. Pro-Active
2. Re-Active
3. Crisis
4. Recovery

## Pro-Active

- Adjusting the environment so that the person does not have to rely on challenging behavior in order to “communicate, or meet a need”.

## Behavior Support Plans

- Maintain abilities, particularly those affecting dignity (e.g., toileting, eating), rather than trying to teach new skills.
- Keep changes in environment and daily routine to an absolute minimum.
- Simplify routines and reduce choices to minimize feelings of anxiety and frustration.
- Use patience and redirection, keep verbal requests simple, and provide general supportive care.
- Maintain self-awareness by using reminiscing and talking about past experiences, when appropriate.
- Help the person maintain his or her orientation by naming events for the day, reminding him or her of the day, time and place, and repeating the names of others around him or her.

## Reactive

- Adjusting to changing conditions of the person to direct them to their “good day” level.

## Behavior Support Plans

- Learn verbal signs of escalating anger such as cursing, using a loud voice, and muttering.
- Change the environment or move to a quiet, smaller space.
- Reduce expectations by allowing more time to accomplish fewer activities/tasks.
- Slow down your actions as the person speeds up. Your nonverbal and verbal slowing can have a calming effect.
- Never surround or gang up on someone who is about to lose control. If the person feels cornered or overwhelmed, it can prompt a "fight, flight, or freeze."
- Do not make any assumptions about what is safe.

## Behavior Support Plans

- Try not to "force" him or her back to your reality, but also don't allow a move into a delusion that you may be inadvertently reinforcing.
- Reassure the person daily, even when there is no response.
- Try to understand the words and symbols the person is using in communicating.
- Be patient, and don't try to force the person to understand your means of communicating; adapt to his or hers.
- Provide appropriate foods and liquids to maintain nutrition and hydration.

## Crisis

- The only goal is to maintain Health and Safety for the person and you.

## Crisis

- Most interventions rely on evasions and deflections.
- Use of restraints may cause more challenging behaviors.

## Recovery

- After Crisis, help the person get back to “baseline” behavior.
- Support for person should be at a level as if the person had the worst day of their life.

## Other Behavior Support

- Respond to suspicions and delusions with reassurance.
- Minimize toileting accidents by establishing a toileting routine.
- Convey affection and protection by a quiet voice and use touch for reassurance and praise.
- Tie activities into a person's past skills and interests.

## Activities are important to the person

- Activities:
- Create interest
- Stimulate the senses
- Tap into remaining skills
- Help with range of motion
- Builds skills
- Gives a sense of control

## Areas of Activities

- Activities should be incorporated into the following areas:
- **Gross motor**; e.g., exercise, dancing, gardening, cooking,
- **Self care**; e.g., dressing, personal hygiene/grooming;
- **Social**; e.g., games, music;
- **Crafts**; e.g., decorations, pictures, etc.;
- **Sensory enhancement**; e.g., distinguishing pictures and picture books, reminiscing, and scent and tactile stimulation, etc.; and
- **Outdoor activities**; e.g., walking outdoors, field trips, etc.

## Ideas for Activities

- Dressing is a fashion show
- Brushing teeth is a tooth paste taste test
- Combing hair is a quiet sing along
- Polishing a table can make a person feel useful
- Folding clothing helps eye hand coordination

## Other things to help

- Signs on doors
- Doors or cupboards to avoid, color the same as walls
- Black patches on floors
- Velcro Stop signs
- Put things out for them to take (shoppers)

## Interaction parameters

- Use good communication
- Be careful of non-verbal communication
- Treat person as an adult
- Remind person of their past
- Be aware of emotional needs
- Your behavior communicates a message
- Do not take person literally
- Timing is everything
- Use repetition
- Do not argue or confront
- Screen out troubling information
- Use humor

## Current Research

- Social/psychological research
- Promoting brain repair
- Alzheimer's disease and diabetes
- Stem cell research
- Statins :Cholesterol-reducing agents
- Anti-inflammatory agents
- Cognitive rehabilitation

Hand out

## Alzheimer's Disease Vaccine Update

- 2001, Elan and Wyeth began actively immunizing over 300 patients
- trials were halted in 2002 , side effects
- a large amount of beta amyloid had been cleared from their brains

American Health Assistance Foundation, 2007

## Nun Study

- **Early Risk Study**
- **Sisters of Notre Dame religious order**
- **The nuns, who were age 75 years or older when enrolled in the study, have donated their brains for examination upon death.**
- **Over 300 are participating**
- **The hope is to find trends**
- **The nuns' lifestyle excludes other potential variables such as drinking, smoking and child bearing, which can confound data obtained from studies in the population at large.**

## In Summary

- **1. People with Disabilities diagnosed with Alzheimer's have special needs.**
- **2. Utilizing components of support from the field of Seniors blends well with Positive Behavior Support.**
- **3. As support plans are developed for these individuals it's important to remember.**
  - **A. Take into account how the disease develops, and how it affects the person.**
  - **B. Add support, not skills as disease progresses. Plan ahead.**
  - **C. Challenging behaviors have medical foundation.**

## Velcro stop sign



## Memory Box



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➤ Thank You!!!!!!

Questions?????

