Caregiver's CORNER

HDSA welcomes you to Caregiver's Corner

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Huntington's Disease Society of America

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Facilitating Access and Communication Through the Use of Assistive Technology

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Agenda

- Overview of Assistive Technology (AT)

- Discussion of the SETT/IETT process for selecting AT

- Focus on HD symptoms

- Relate HD symptoms to tasks

- Connect AT tools to tasks

- Q & A

Who am I?

- Mother

- Wife

- Educator

- Friend

- Daughter

- Caregiver

What is Assistive Technology (AT)?

- **Assistive technology**:   includes assistive, adaptive, and rehabilitative devices for people with disabilities—ranging from low to high tech.

- **Process**: Also refers to the process used in selecting, locating, and using them.

- **Promotes Independence**: AT promotes greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing

- **Breaks down Barriers**: Provides enhancements to or changed methods of interacting with the technology needed to accomplish such tasks.

IETT/SETT Model

I= Individual

E= Environment

T= Task

T= Tool

Based on Joy Zabala's SETT framework
http://www.joyzabala.com/Documents.html

Individual

- What are the individual's current abilities?

- What are the individual's special needs?

- What are the functional areas of concern?

- What does the individual need to be able to do that is difficult or impossible to accomplish independently at this time?

Environment

- What activities take place in the environment?

- What is the physical arrangement?

- What assistive technology does the individual have access to or currently use?

Task

- What specific tasks occur in the environment?

Tool

- Tools are devices and services—anything that is needed to help the student participate and access learning programs.

- Are the tools being considered on a continuum from no/low to high-tech?

- Are the tools human-centered and task oriented and reflect the person's current needs?

- Are tools being considered because of their features that are needed rather than brand names?

What makes good AT?

- Able to level out the playing field
- Work in cross-settings
- Portable
- Easy to maintain
- Affordable to replace and/or maintain
- Good and reliable technological support
- Accessible training format

So what do we know about the individual?

We know that the individual has Huntington's Disease

- What is Huntington's disease?
  - Huntington's Disease: a devastating, hereditary, degenerative brain disorder for which there is, at present, no cure and only one FDA-approved treatment (Xenazine) for a symptom of HD.. HD slowly diminishes the affected individual's ability to walk, talk and reason.

  - How many times have we read and heard that definition?

    - Taken from HDSA website: http://www.hdsa.org/

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I=Individual

- Depression/Mood swings
- Forgetfulness/Short-term memory
- Clumsiness/Lack of coordination
- Impulse Control

- Involuntary twitching and or movements of the head, trunk and limbs
- Walking/Mobility
- Speaking
- Swallowing
- Cognitive Ability

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E=Environment

- Family homes
  - One floor
  - Two floor
- Apartments
  - Floors
  - Access to sidewalks, etc
  - Elevators

- Group homes
- Assisted living
- Hospitals
- Nursing homes
- Work
- Automobile
- Other

T=Task

- Connected to the environment
- At work
- Run the home
- Stay independent at home
- Care for family
- Caring for self
- Getting around the community

Tool

So, what are some tools that can be effectively used to better enable our loved-ones with HD?

So Individuals with HD may struggle with:

- Speaking/Communication
- Forgetfulness/short-term memory
- Depression/Mood swings
- Clumsiness/lack of coordination

- Involuntary twitching and or movements of the head, trunk and limbs
- Walking/mobility
- Swallowing
- Cognitive ability
- Impulse Control

Promote Independence and Break Down Barriers

- Speaking/Communication

- Forgetfulness/short-term memory

- Depression/Mood swings

- Cognitive ability

- Impulse Control

Speaking and Communication

- AAC Device with Dynamic Display
- High Tech
  - Portable electronic devices with text to speech capability
- Low Tech
  - Posters, folders, portable cards

- Access by
  - Direct Select
  - Mouse use
  - Scanning and Switch access
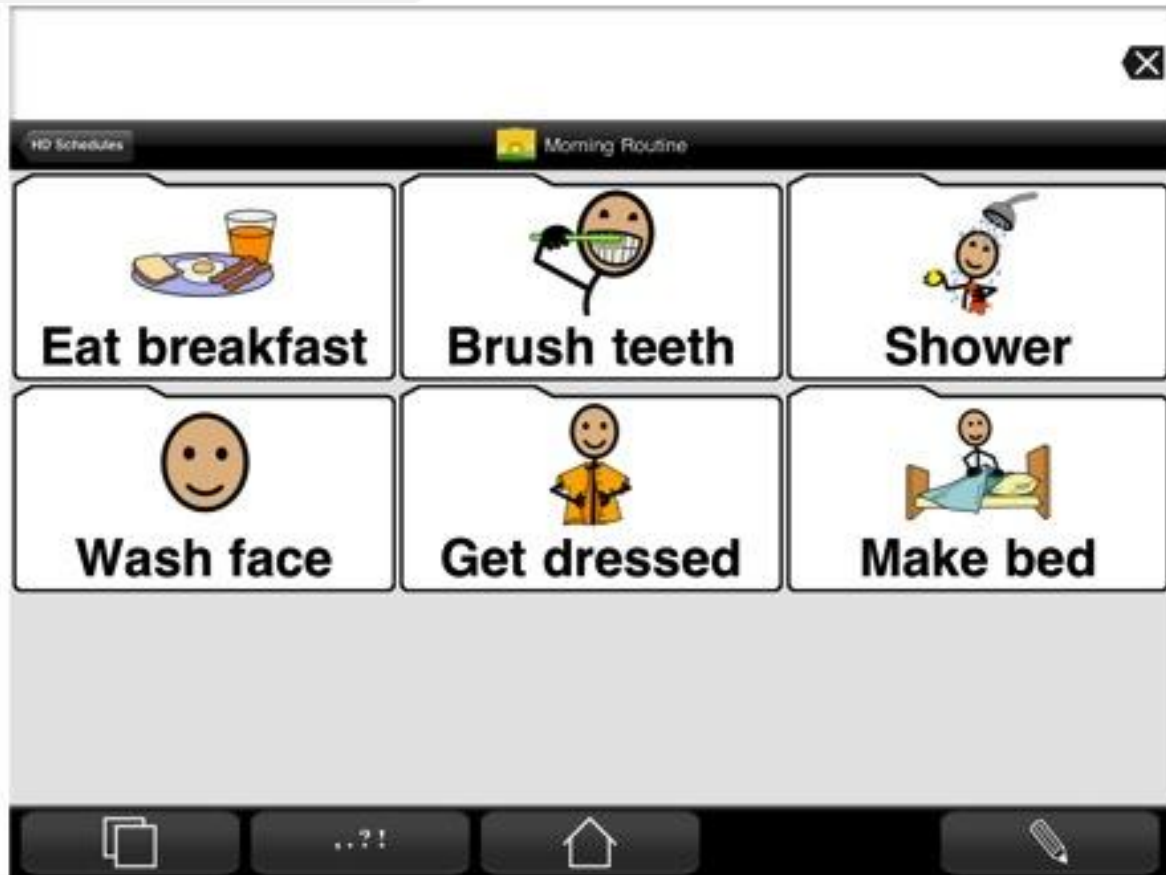 - Eye gaze
  - Mounting Arms

Programming for Communication

- Start early—even before AT might be beneficial
- Can support the continuum of the day
- Break down the task

- AM Routines
- Break down tasks
  – Brush teeth
  – Wash face
  – Get dressed
  – Eat breakfast

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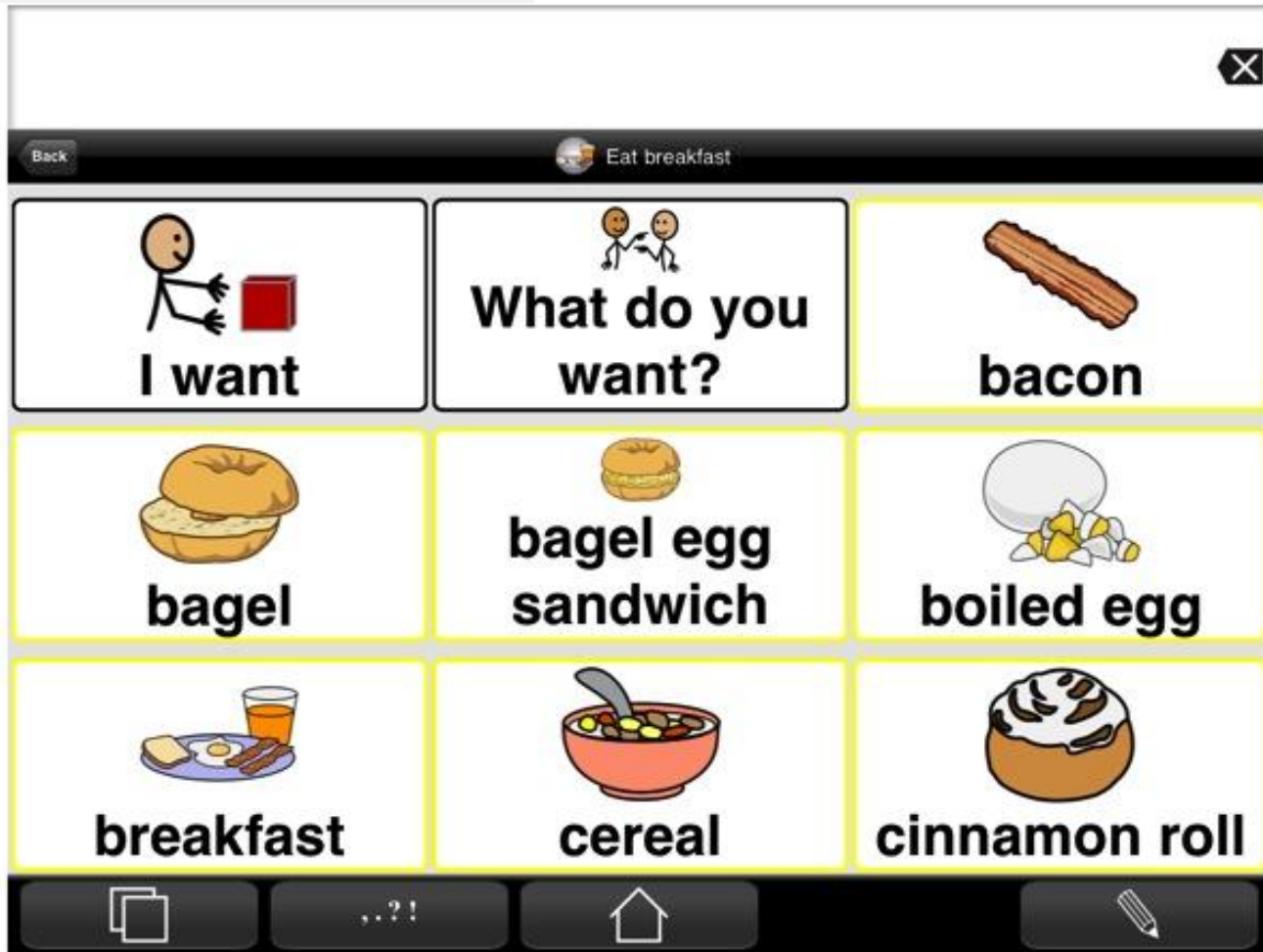
Example of Dynamic Display Device

Sub-Menu

Steps and Reminders

Short-term memory and forgetfulness

- Timer

- Visual Schedules

- Picture Phone

- Medication Reminders

- Pill Organizer

- To Do lists

- Personal Digital assistant

- Photo reminders

- Video reminders

Visual Timers

More Timers

Visual Schedules

Medication Reminders

Depression and Mood Swings

Calming

- Music
- Shows/movies
- Games
- Social Networking
- Digital books
  - Speech to text

Therapeutic

- Systematic procedure in place
- Habitual
- Use of many AT systems for memory loss
- Predictability and routine keep mood more stable

Lack of coordinati

- Word Prediction
- Adapted mice
- Alternative access
  - Touch Screen
  - Switch Access

iPod iPad Technology

- ## What are Apps?
  - Look like a shortcut
  - Function as software
  - Have unique purposes
  - Many are free!
  - Commonly .99-3.99

Dragon Dictate App

Facebook App

Google App

iPad

- 9.5" x 7.3"
- .34" thick
- Weights 1.3 pounds
- Includes
  - Camera
  - Digital recorder
  - Built in microphone
  - Built in speakers
  - 10 hour battery life

Questions down the road?
Contact:

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Questions & Discussion