

Ontario Rett Syndrome Association

Literacy Presentation

Nov. 6th and 8th, 2014

- Compiled with information and assistance from Judy Lariviere and Erin Sheldon
- Presented by Karen Congram



The Power of Literacy

Literacy and communication is when our children share thoughts we didn't know they were having.





Emergent literacy is
not spinach.





It should be irresistible...
like chocolate.



Emergent Literacy

- Emergent literacy behaviours and understandings are directly linked to opportunity and experience
- Students with significant disabilities have the fewest opportunities and experiences that lead to literacy



Emergent Literacy Behaviours

- Scribbling on paper, the wall or your baby sister
- Chewing, ripping or looking at a book
- Pretend reading a book to yourself or your stuffy animals
- Scribbling on the grocery list and telling Mom that you wrote “cookies”
- Holding a book upside down while pretending to read
- Insisting on “signing” the credit card receipt at the restaurant



What do these children know about books?



What do these children know about books?

- Books are important
- I can read all by myself.
- I love my books.
- I am important when I read
- I am a reader, just like everyone else
- Books bring me joy.



**What does this student know
about writing?**

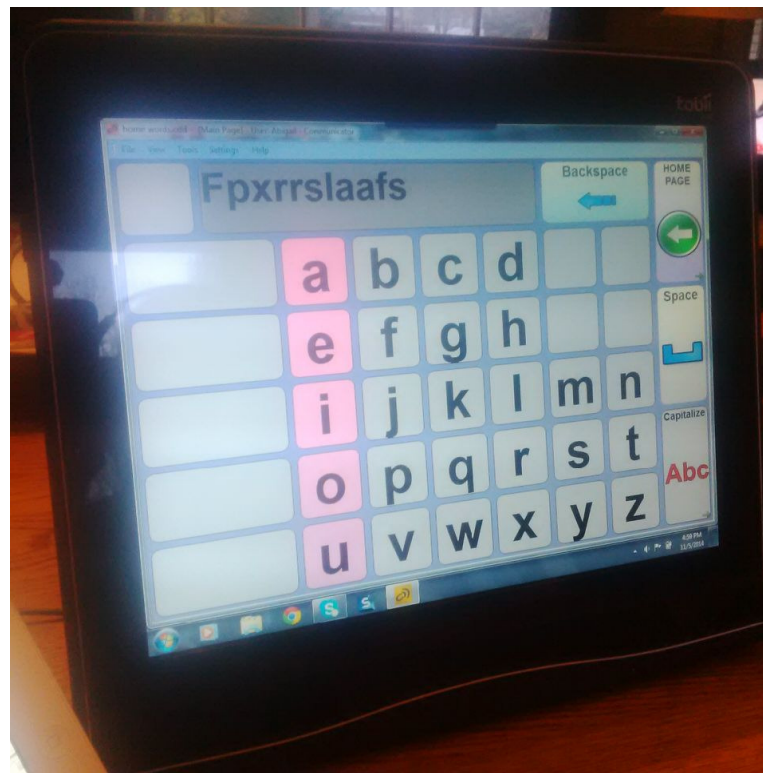


What does this student know about writing?

- Writing is important
- I can write
- I am a writer
- I can share a message across time and space when I write



What does this student know about writing?



What does this student know about writing?

- Writing is produced by letters
- People string letters together to send messages to each other
- Writing is important
- I can write
- I am a writer

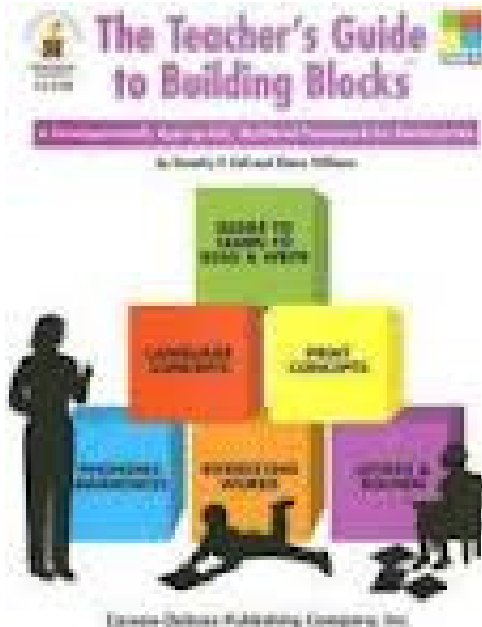


Early Literacy Activities

- Reading books and more books!
 - Language-rich books with a means for interacting about the books – build language concepts
 - Repetition with variety with simple books so can become very familiar with/memorize the books - story retelling
 - Develop concepts about print
 - Track print in left to right directions – books in which the text is highlighted
 - Develop phonological awareness
 - Access to the alphabet
 - Rhyming patterns
 - Not “drill and kill” or testing - play and fun
-

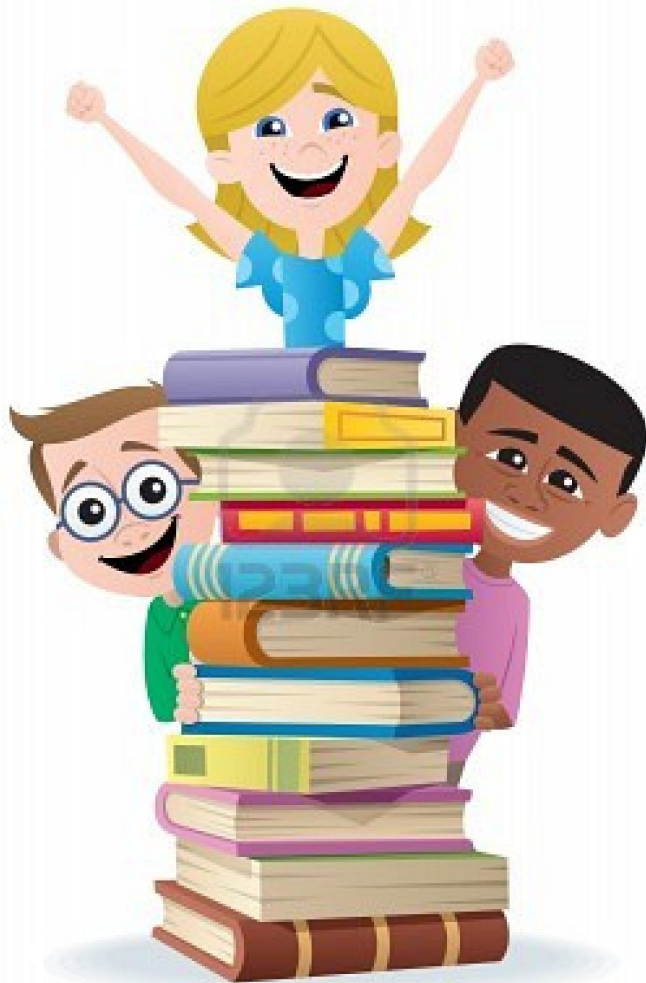
Building Blocks – Cunningham, 1997

Block #1



- Desired to learn to read and write
- Create an environment where all students see themselves becoming independent readers and writers through a variety of developmentally appropriate activities.
- Begin with books related to child's interests and then branch out from there.
- Repeated readings; typical children request their favorite book to be read 200 times

Good, old fashion books



National Reading Panel

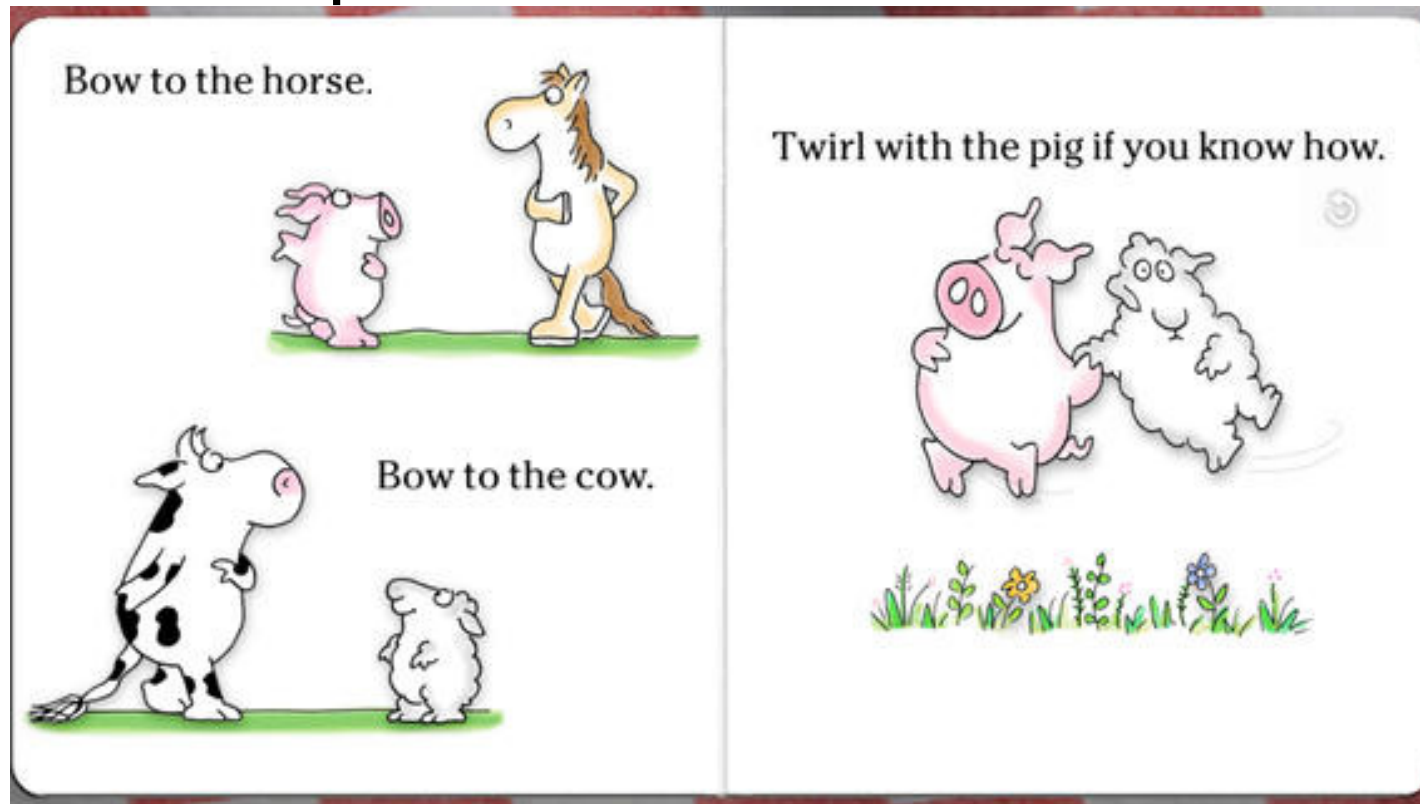
*Print Motivation

*Vocabulary

*Print Awareness

Adapted Play Books, iPad apps

Example: Sandra Boynton, Barnyard Dance





Adapted Play Book- EIEIO iTunes store - True UDL

Literacy Predictors

National Reading Panel
*Print Motivation
*Vocabulary
*Print Awareness

- Incorporates scanning for one or two switches or can use partner-assisted scanning



Single switch - Auditory Scanning - Auto Start - Auto Scan – First time

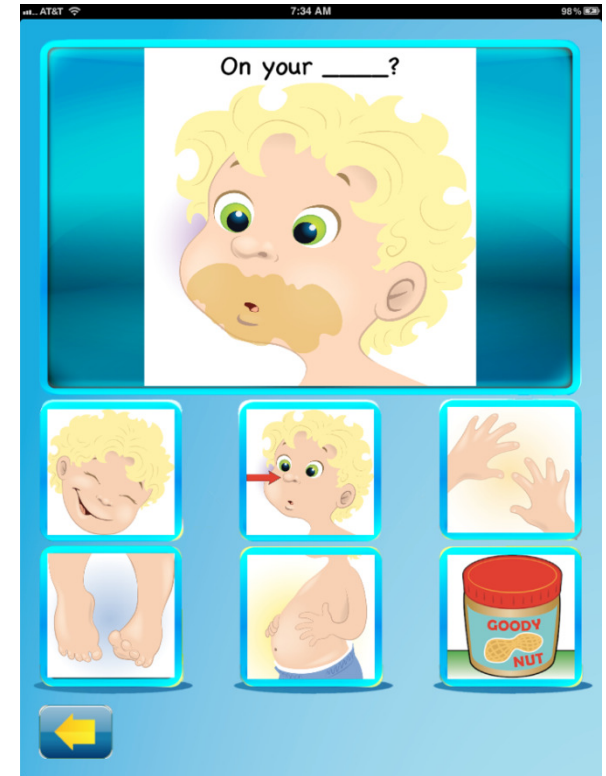
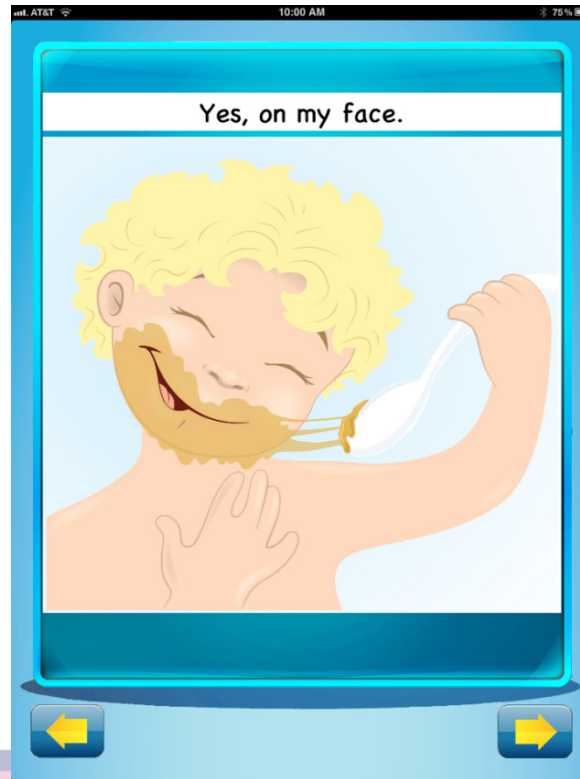
We showed a video of a child selecting stories with a single switch. Stories were presented by auditory scanning.





Auditory Prompt, multiple scan settings
touch sensitivity

Adapted Play Book Peanut Butter



Switch access from cheek

We showed a video of a child using her cheek to activate a switch to play the Peanut Butter play book.



More Adapted Play Books



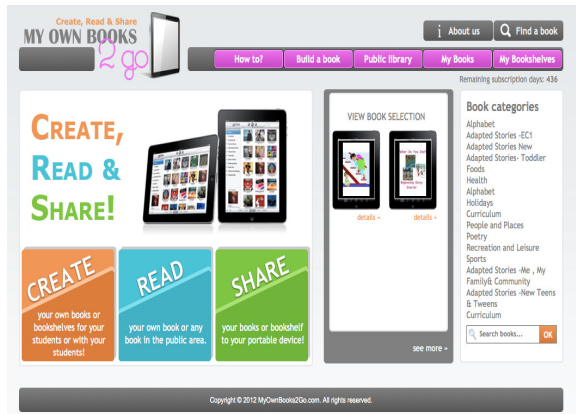
Adapted Play Books
Hurry! Hurry!



Adapted Play Books
Dirty Duds

National Reading Panel
*Print Motivation
*Vocabulary
*Print Awareness

MyOwnBooks2Go



- MyOwnBooks2go- A free app that allows you to access and play books from www.myownbooks2go.com with a subscription.
- Accessible books for early and emerging literacy skills all ages.
Switch Access built in
- iPad Access with Switches. 100's of books already created or you can create your own
- Cost: \$75.00 for a one-year subscription
- Free three-month subscription off website

Block #2

Language Concepts

- Foster the ability to read and write words through the use of morning messages, journal entries, sentence building activities, and environmental print.
 - Use books to teach concepts and add to their expressive vocabulary
 - Enable students to participate in reading and making comments
-
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Block #2

We showed a video of a girl participating in reading by making comments using her Tobii EyeMobile. Her mom was reading a regular old, low-tech book.



Block #3

Learn Print Concepts – also do with real books

- Reading from left to right and top to bottom
 - Right side up from upside down
 - Looking at left page first, followed by the right
 - Differentiating the text from the picture
 - Text tells the story
 - Tracking print – iPad apps with text highlighting
 - **!!Caution!!** Research is showing that when students are using interactive books on the iPad, they are more focused on the interactions than the book.
-
-

Block #3



Free Books with Text Highlighting



Lazy Larry Lizard
bedtime story book
for preschoolers -
Wasabi
Productions

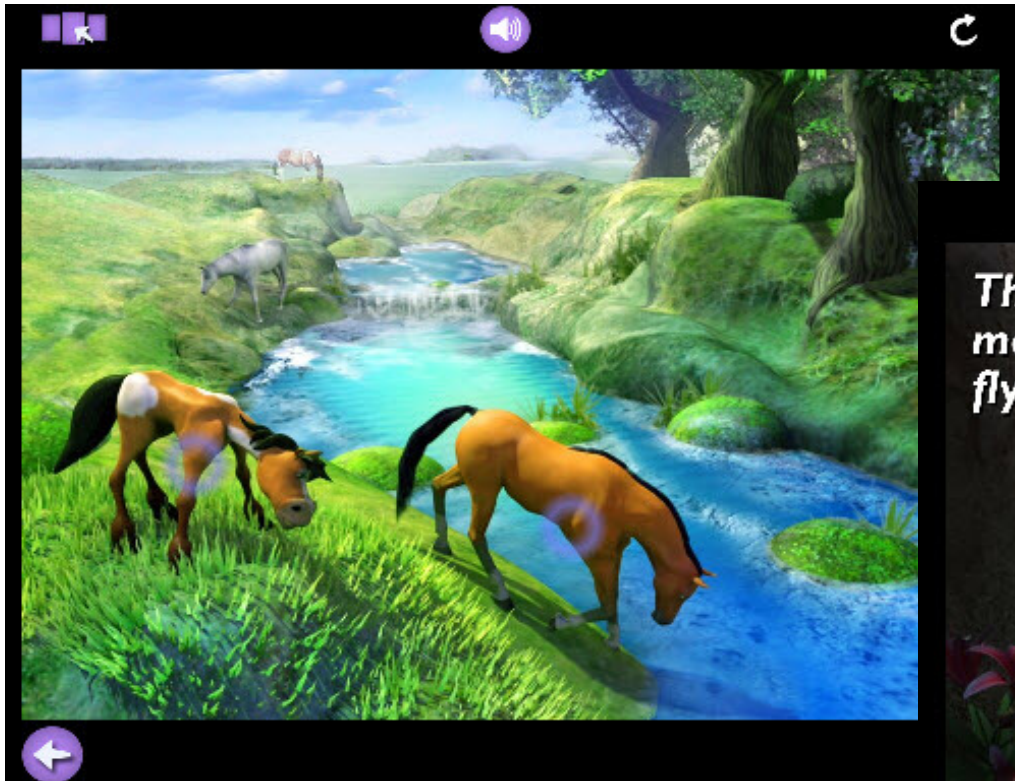


Read Me Stories
Free books – 1 new
book per day

Ask your schools if the board has
a license to other software,
ex. Premiere Literacy Suite

Tumblebooks

Read Me Stories – Continue from Bookmark



There was a big **Dark** Forest behind the meadow where the magical flying unicorns lived.



Free Books with text highlighting

By Collins Big Cat
Includes Story Creator feature



Farmer's Lunch



It was a Cold,
Dark Night



My Bike Ride

Block #4

Phonemic Awareness:

Develop phonemic awareness, including the concept of rhyme, through activities with poetry, rhyming books, tongue twisters, and alliteration.

Help students develop their auditory discrimination skills so they can tune into different sounds with words

Word “Play”

Word Chants (Caroline Musselwhite):

- Clap your word
- Tap your word
- Stretch it ‘til it’s long
- Spell your word
- Tell your word
- Say it like a cheer

Example was shown (in Ottawa): Word Chant with iPad app, "Explain Everything" and sister's voice

Rhyming

By Collins Big Cat
Includes Story Creator feature



Hideout:
Early Reading
Free



It was a Cold,
Dark Night



My Bike Ride

Block #5

Interesting Words: Extend the list of real-life words that students find personally relevant, such as favourite restaurant names, favourite cartoon characters, and family members.

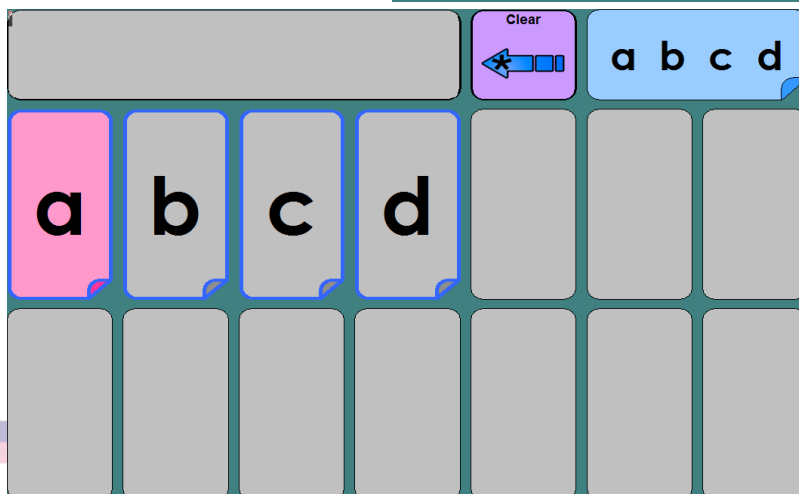
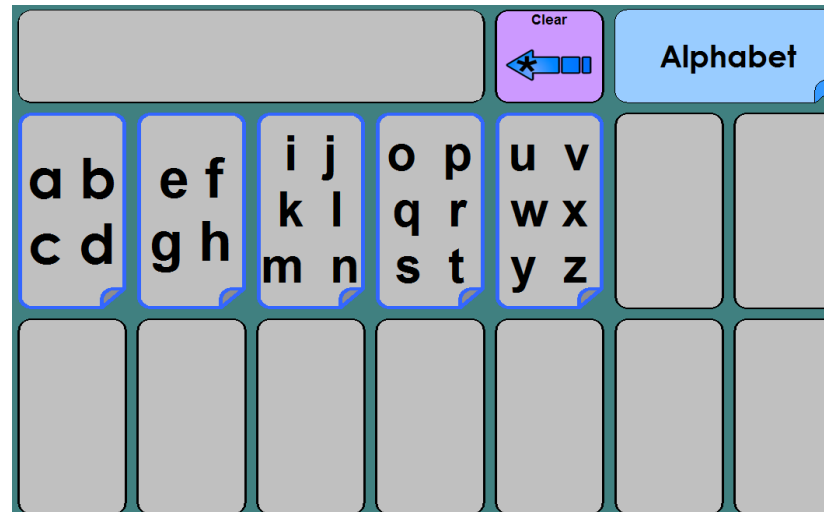
- Integrated this into customized alphabet on AAC device
 - Could make customized alphabet in book format for student
 - Put page fluffers between the pages so can easily turn them (sponge/foam)
-

Block #5

*Example was shown (Ottawa):
Daniel Radcliffe (Harry Potter) on Jimmy Fallon*

*~ to get thinking of ideas for alphabet
songs for older learners*

Customized Alphabet Book



Customized Alphabet Book

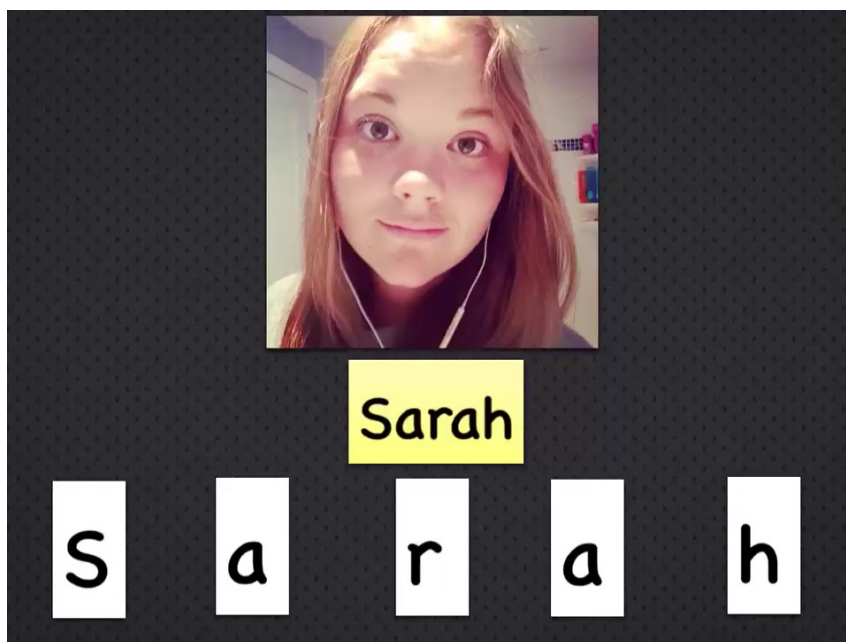
*We talked about making
books that have
individualized meaning
Example: “D is for Dora
and Daddy and donuts!”*



Even Older Girls

This slide had an example of using photos of friends and family to make A – Z pages on an eye-gaze device.

Even Older Girls



Here, we talked about Communication Circles and involving peers in creating word chants and/or word videos.

For more on Communication Circles, see a summary by Caroline Musselwhite at <http://aacgirls.blogspot.ca/2013/03/communication-circles-linguistic-social.html>

iPad Alphabet-based apps



ABC Wildlife

Cost: \$2.99

**Age
respectful for
teens/adults



Phonics Songs

Cost: \$2.99



ABC Mouse Music Videos—

Cost: ABC free
\$4.99 for all

iPad Alphabet-based apps



**Interactive
Alphabet**

Cost: \$2.99



**ABC
Alphabet
Phonics**
Free



**Animal Alphabet
with Geoffrey –**

Cost: ABC free
\$2.99 for all

Age respectful for
teens and adults

Exploring Customized Alphabet

We showed a video clip of a person accessing a customized alphabet using an eye-gaze device. There are many different examples of alphabet arrangements. The key is to make sure each child has access and knows how to choose each letter.

Block #6

Letters and Sounds:

- Encourage letter and sound recognition through activities with alphabet books
 - Beginning*** and ending sounds
 - Shared writing of predictable charts (I see_____, I like _____, The _____ is red
 - Learn letters in name first and initial letters of personally relevant names – “m” for Mom, “d” for Dad
-
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Block #6

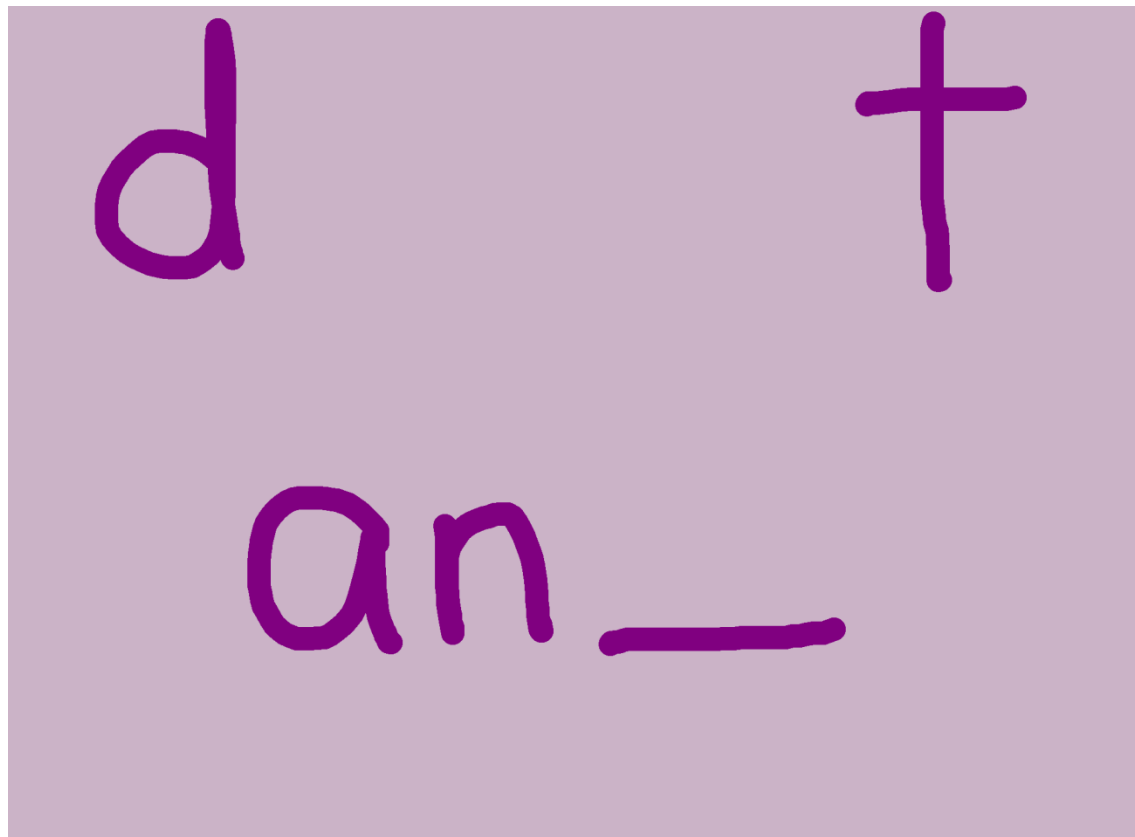


Word Wizard



Absolute Board (iPad app – Free)

- Perfect size for eye pointing to choice



iPad Working with Words apps



Hideout:
Early
Reading
Cost: Free



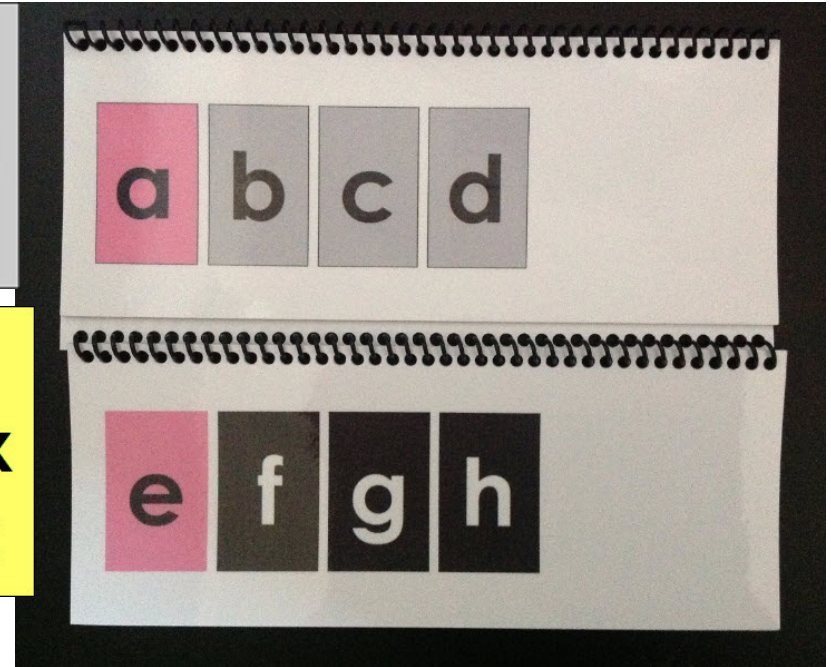
ISpy
Montessori
Cost: \$0.99



Word Magic—
Cost: \$0.99

Light Tech Alphabet Flipbook

a b c d	e f g h	i j k l m n	o p q r s t	u v w x y z
a b c d	e f g h	i j k l m n	o p q r s t	u v w x y z

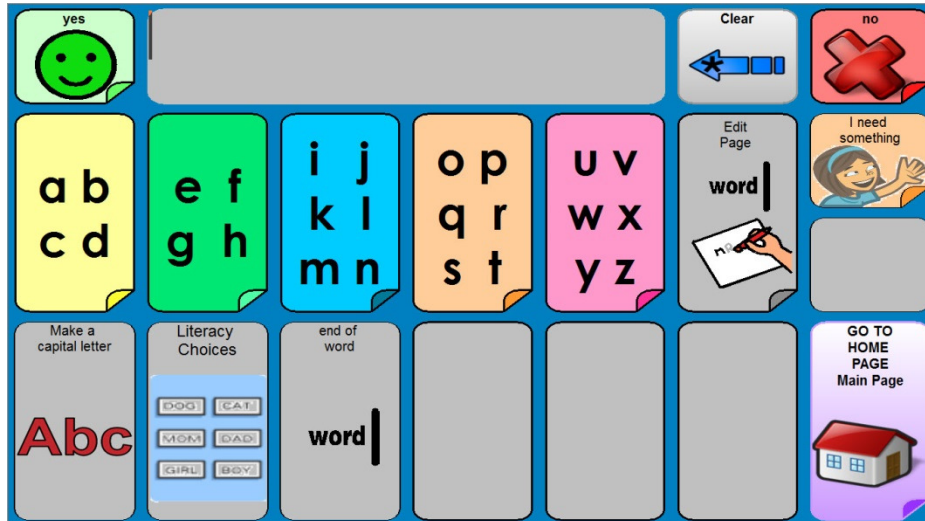


iPad (ABC Wildlife app) with Alphabet Flipbook

*Video of a child using the
alphabet flipbook to choose
letters to interact with the app.*

*(There were several examples of combining more than
one type of strategy/technology to reach a goal.)*

Alphabet – same as flipbook



Interaction

- Part of guided reading is interaction about the text.



Transition into Conventional Literacy

- Four Blocks Literacy Model
- Books by Patricia Cunningham & Dorothy Hall
- Also by Karen Erickson and David Koppenhaver – Children with Disabilities: Reading and Writing the Four Blocks Way



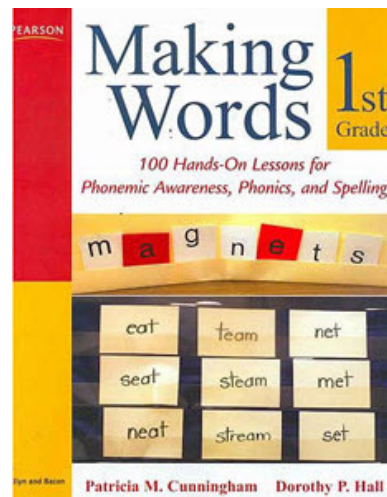
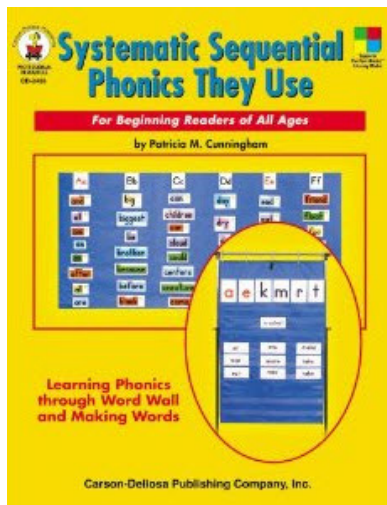
Select a Block for Information

Invented Spelling

- Using partner-assisted scanning/eye gaze to alphabet flipbook; minimizes motor demands
 - Can see the benefits a student is getting from Word Study
 - Making Words lessons
 - Initially spelling words – bg for bag; hg for hug in Making Words lessons
 - Developmental Spelling Assessment
 - monser for Monster
 - ders - then dres for dress
 - cdlos – then closd for closed
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Working with Words

- Expo Neon Dry Erase Board from Amazon
- Eyes are like magnets to it
- I “am” a girl.
- “and” – think



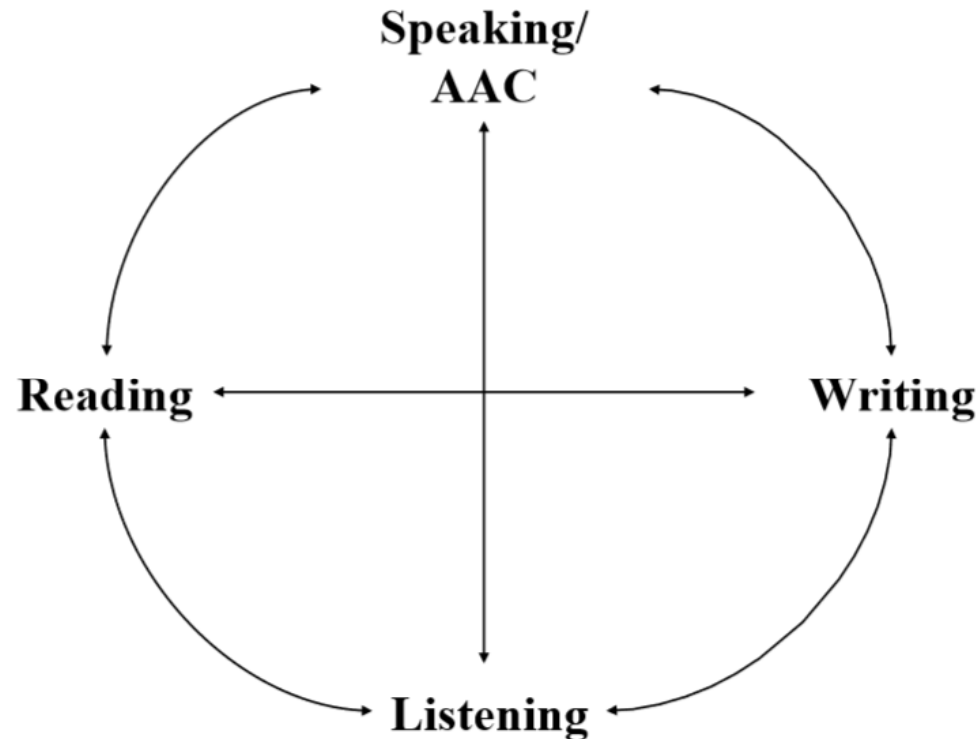
Raising the bar for Literacy – What should we expect?

- Based on multiple case studies - individuals with Rett Syndrome are **learning to read and write** with implementation of best practices for literacy instruction and supported access to tools and materials they can use
 - **Success = lowering the motor demands** so can focus on learning to read and write and demonstrating what they know
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Part 2

*(We had a break
before delving into
some research.)*

Literacy Model – no prerequisites



Koppenhaver,
Coleman, Kalman, &

Dr. David Koppenhaver, 2013

- Research - has been completing reading profiles with students with Down Syndrome over Skype.
- Posted about his beliefs in his blog on his website, www.litdis.com

“Too late to learn to read and write? Really?!”

- “I choose to believe that people learn what they are taught, if teachers figure out how to teach them in ways that make sense to the students. I choose not to predetermine students’ learning success or failure. I take the blame when my students fail to learn, and try to do better tomorrow and tomorrow and tomorrow.”
-

Additional Road Blocks to Literacy

- Same material presented over and over again
- Minimal teaching and modeling
- Time constraints due to medical, physical, and sensory regulation needs
- Read to all the time but passively involved in process and not always have visual access to text
- Always listening to text read aloud on the computer
- When expected to read connected text in books silently, partners tend to describe too much
- Limited opportunities for independent generative language and written communication

Apraxia

- Interferes with their response to a request to do something upon command, especially out of context
 - Affects motor movements, including the muscles controlling their eyes when using technology
 - Does not mean they don't understand what you are asking them to do or just being "stubborn"
 - The message from brain to a part of her body gets scrambled or takes longer' response times
 - "Do this" or "look at the..."
-

Apraxia

Strategies for working around apraxia:

- Present/participate in motivating activities based on a child/teen/adult's interests or talk with them about a life experience
 - Say requests in such a way so they don't seem like a command/directive and wait quietly and watch....the gentle approach
 - Engage in natural and spontaneous interactions
-

Teaching vs. Testing

- What is difficult for individuals with RTT is constant question-answer (input-then output in form of motor response) or command – motor response
- Testing for knowledge all the time constantly taps into a girl's apraxia
- Embed opportunities for responses within instruction
- Initially, there is a limit to the number of questions can be asking girls before she starts shutting down

Why is writing important?

- Some children/adults learn to speak/communicate by writing
- Some children/adults learn to read by writing
- Writing requires us to pay attention to the letters and sound relationships
- Writing/spelling reveal a writer's understanding of sounds/letters and words

Source: Dr. David Koppenhaver and Barbara Wollack, Closing the Gap, 2013 – A Writing Teacher's Toolbox- Technology Supported Instruction for Students with Disabilities

<http://www.litdis.com/>

Incredible Literacy Resources

- <http://www.litdis.com/research.html>
 - Scroll down the page to Resource Setup for Down Syndrome Reading Profile participants
 - Resource Website
 - Click on Words
 - Scroll down to **Beginning Reading Model** -Morris, et al., 2003) – relates to how individuals learn to read
 - Absolutely applies to individuals with Rett Syndrome
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Writing

Access to the alphabet

Context

- meaningful
- based on her life adventures
- high motivation

Other “pencil” choices

- Light tech alphabet for partner-assisted scanning

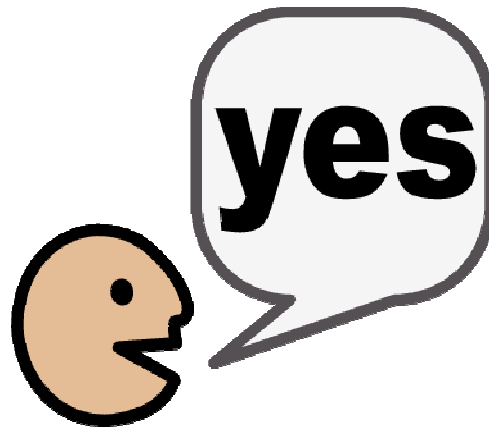
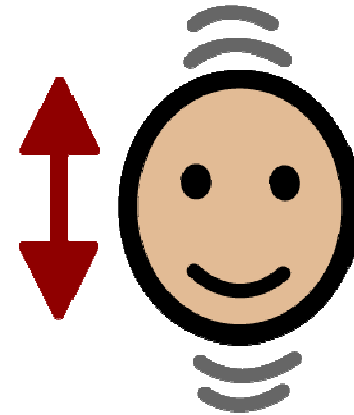
Sentence starters

Motivate, Model, Move Away!

Need something to talk about

- Adds motivation - Life experiences – we all tell stories about our experiences
 - Share in open-ended fashion
 - No right or wrong answer
 - Pages programmed so girl can choose what to say
 - Different than day-to-day communication shared on a step by step
 - Add “Remember” – that reminds me of something
 - Text-to-self connections for supporting lessons in reading comprehension
-

Capitalize on “yes” response(s) using Partner-assisted scanning



Partner-assisted Scanning (PAS)

- Present choices verbally and visually with a definite pause between and wait for the child to respond to indicate choice
 - Only need a “yes” response or a signal from child – lowers motor demands – focus on interaction and get more engagement
 - Allows for you to present more than two choices at one time; expand on what can access with hands or eyes directly
-
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Partner-assisted Scanning (PAS)

- Incredibly useful technique for students
 - Use for teaching and evaluating knowledge of academic concepts, including literacy
 - Also for introducing communication system or the vocabulary on a new page or if having a harder “motor” day, so there is less motor demands.
 - Example: 25 year old girl with Rett Syndrome taking classes at City College in San Francisco – completed 100 question multiple choice tests using partner-assisted scanning over multiple sessions
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Following a girl's lead

- School visit on with girl in middle school – 2nd year in middle school; entire writing lesson planned out
 - Started with training in literacy instruction in fall, more consistent in Feb/March 2014
 - Setting up video cameras and Tobii – teenager independently navigated to My Activities – Shopping
 - “I want to buy something for someone,” “It’s not on this page,” “I love shopping,” “I want to hold it”
 - Repeated these selections
 - Trying to tell me something!
-
-

Shopping Page

from Dynamic Communication Book

<p>yes</p> 	<p>I want to buy something for someone. I'll hold it! I love shopping! </p>				<p>Clear</p> 	<p>no</p> 
<p>Hey, look at that!</p> 	<p>I'll pick it.</p> 	<p>I want to get something new</p> 	<p>Let's go to a different store</p> 	<p>Please! Can we get that?</p> 	<p>That is thing I saw on TV</p> 	<p>I need something</p> 
<p>I love shopping!</p> 	<p>I want to leave!</p> 	<p>I'll hold it!</p> 	<p>I want to buy for someone</p> 	<p>Let me tell you what else I think</p> 	<p>not on this page</p> 	<p>BACK TO MY ACTIVITIES Shopping</p> 

Self-selected topic – essential for writing!

*Video of a girl
choosing to talk
about shopping*

Partner-assisted Scanning with alphabet flipbook

*Video of same girl
choosing letters to
tell what she wants
to buy*

Final Written Product

- **a f d (original a d f h)**
 - New word after select “a”
 - After selected these letters, she independently navigated to “telephone conversation” page – “I want to call someone” “Hi, it’s name” “I love you,” “I miss you.”
 - Had email from girl’s Mom – food she liked and things she wanted to buy... **cell phone and dress.**
 - Writing is “window” into what learning from literacy lessons; expand on communication – Beginning Consonants (BC) in Beginning Reading Model, Morris, et al., 2003)
-
-

8 year old girl

- November 1, 2012
 - Mom worked with her during the summer on Making Words lessons
 - Modeled writing first – showing a picture from my Halloween; used her sentence starters on her ECOPoint and then her alphabet on her device
 - She watched a video from her Halloween – trick or treating at a house
 - She used her sentence starters on her ECOPoint - wrote “I like, I had, can have” then used light tech alphabet with partner-assisted scanning - name choices and she tells me with one of her best “yes” responses her selections
-
-

Used Sentence Starters from Dynamic Communication Book

*Video of a girl
choosing her own
sentence starters*

Using Alphabet Flipbook for invented spelling of word

- *Video of a girl choosing “c” and “a”*
 - *She was finishing her sentence starters with the word, “candy”*
-
-

More Writing

April 2013

- Writing activity in class – write about what you like at school.
- Sentence starter – I like
- Using light tech alphabet, she spelled “frein”
- And then another day, “cupcdkes” for “cupcakes”



Using Tobii I-12 to spontaneously select letters in Tobii rep' s name

This is the one where they were talking about something else and then Kevin walked in and she chose “k” and “e” and “i”.

Using Explain Everything app to review writing activities



An idea that works well is to create tutorial videos of literacy activities, reviewing the child's own progress. She can choose to watch them over and over (with headphones) to review concepts in a low-pressure setting. (And she does.)

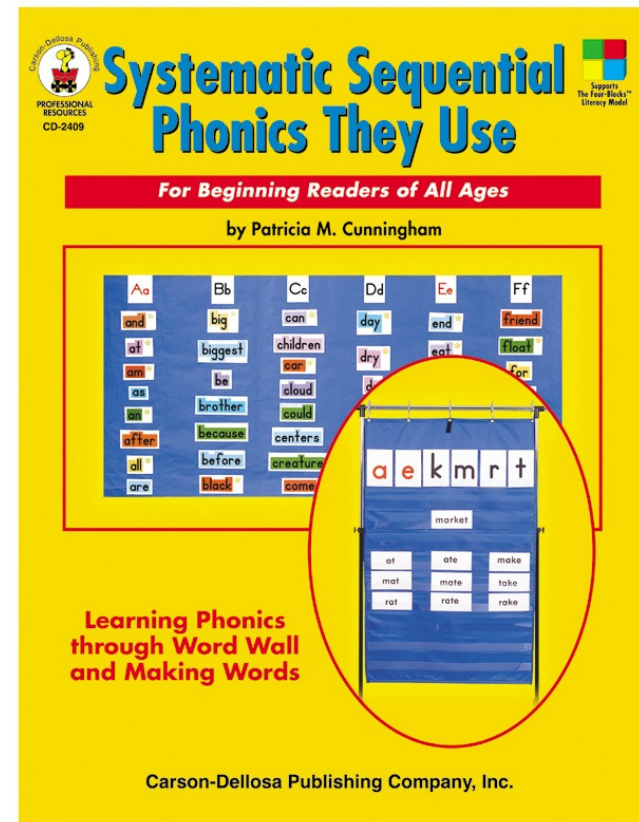
Working with Words – Making Words

- Expo Neon Dry Erase Board from Amazon
- Eyes are like magnets to it
- Patricia Cunningham's Making Words; supported by research by Dr. Karen Erickson and Dr. David Koppenhaver – Center for Literacy and Disability Studies



Working with Words

Systematic Sequential Phonics They Use Resource Book



Making Words – Fall 2012

*Video of a girl doing
a writing activity
from the Making
Words program*

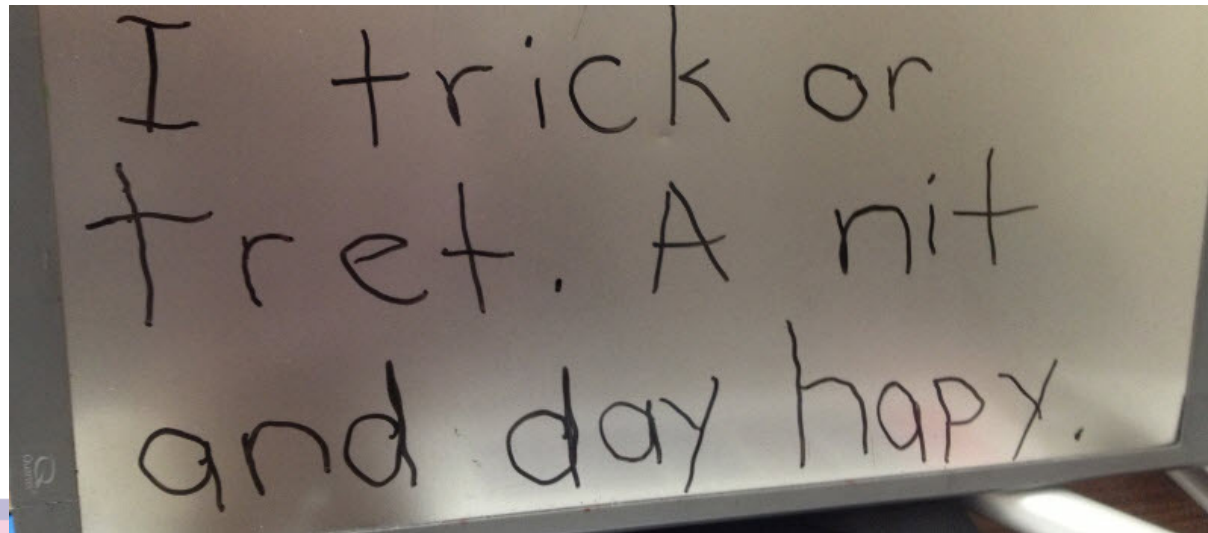
Making Words – Fall 2013

*Video of a girl doing a
writing activity from the
Making Words program
– same girl – showed
progress*

Writing – 9 years old

October 31, 2013

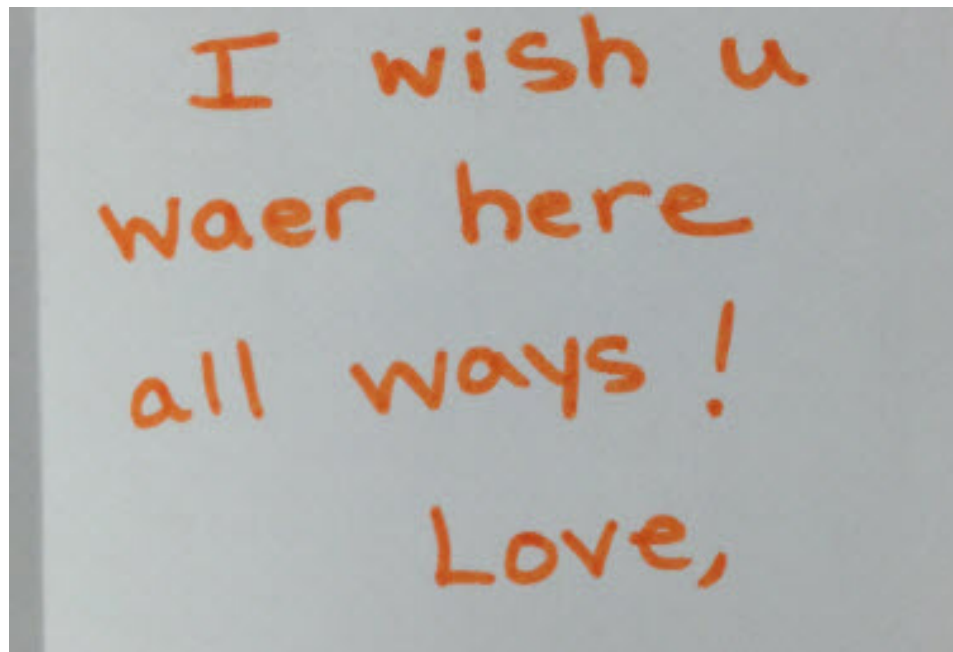
- Tobii C12 with CEye Module for 3 years
- Started with “hg” for “hug” – SPBE –Spelling Beginning and Ending sounds
- Spelled using alphabet flipbook with partner-assisted scanning



Same girl – 9 years old

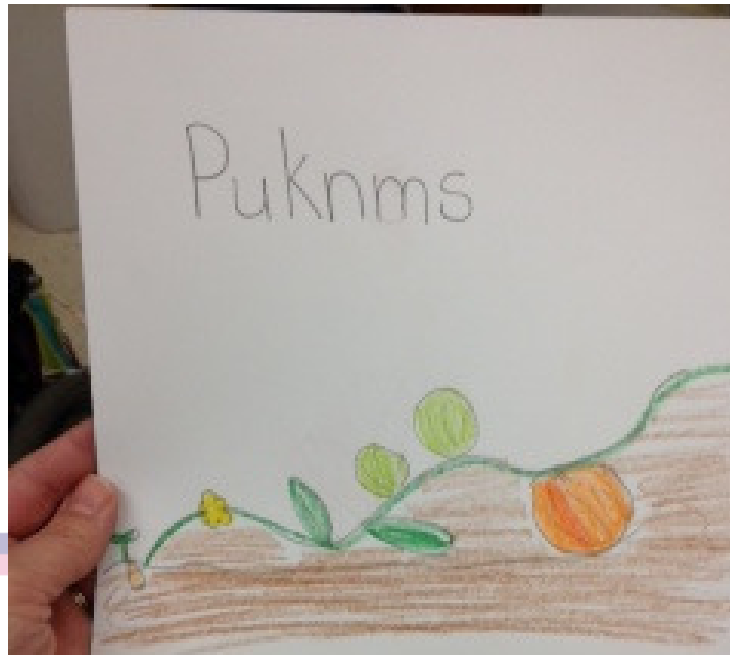
Writing Dec 2013

- Spelled using alphabet flipbook with partner-assisted scanning (just like the other girls in the videos)



Girl in Kindergarten

- Using alphabet flipbook starting in September 2013 to spell words such as frends (friends), bat, thumb
- Used her Tobii to tell 1:1 aide what to draw and then spelled “Puknms” on her Tobii using alphabet corresponding to alphabet flipbook
- Started with customized alphabet with Leapfrog fridge magnets

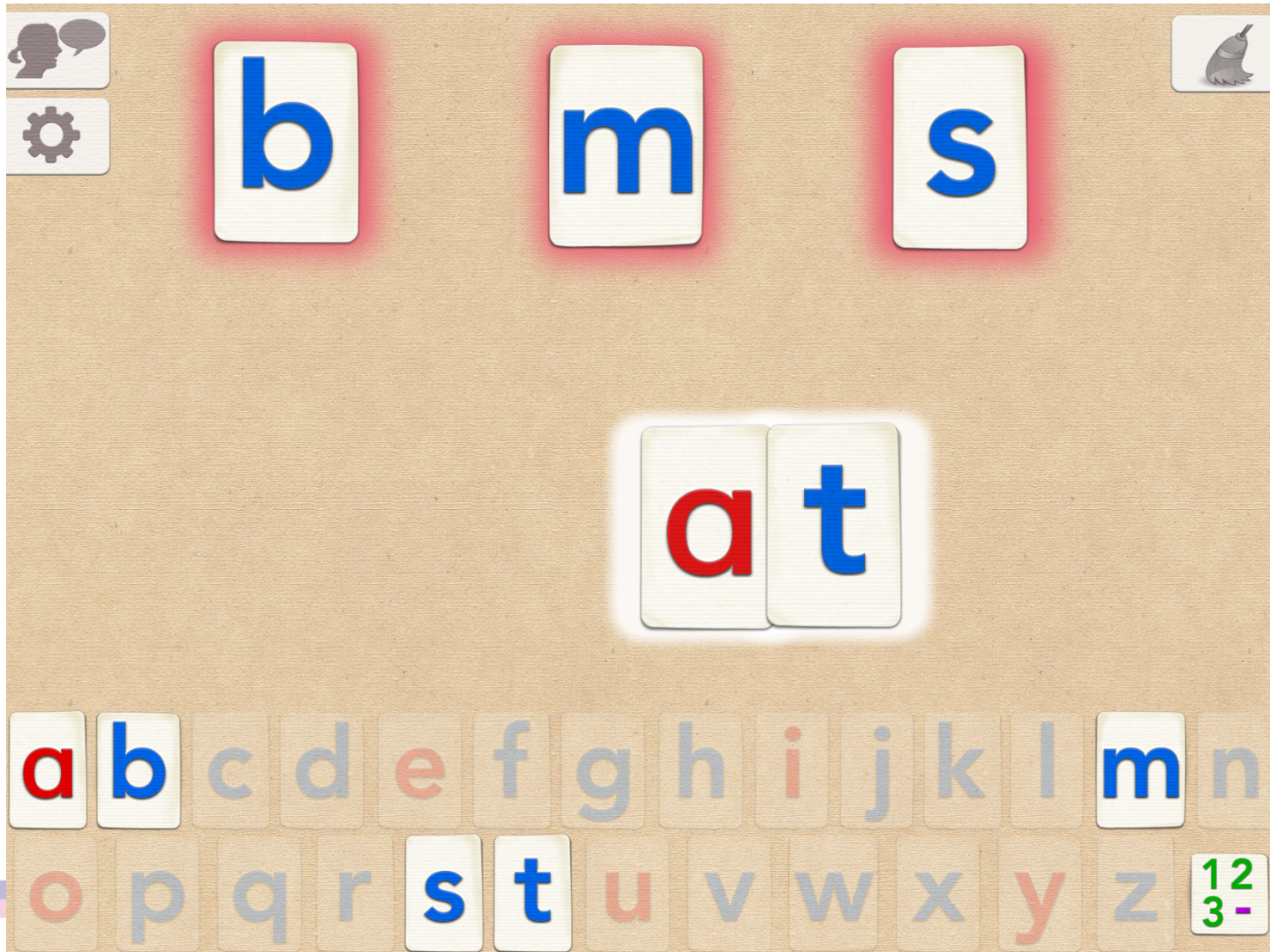


Word Wizard – Talking Movable Alphabet and Spelling Tests

- Cost: \$2.99; Amazing app
- For Making Words Lessons – says letter sounds
- Create users and generate reports
- Must buy!
- Sounds out letters and parts of words phonetically



Word Wizard



Word Wizard - Settings

Voice Transformer [Reset](#)

Speed

Tone

Uppercase ☒ Qwerty ☒

Phonics ☒ [Choose Voice](#)

Grid ☒ [Exceptions](#)

Background [Colors](#) [Paper](#)

[More Settings](#)

[Main Menu](#) [Help](#)

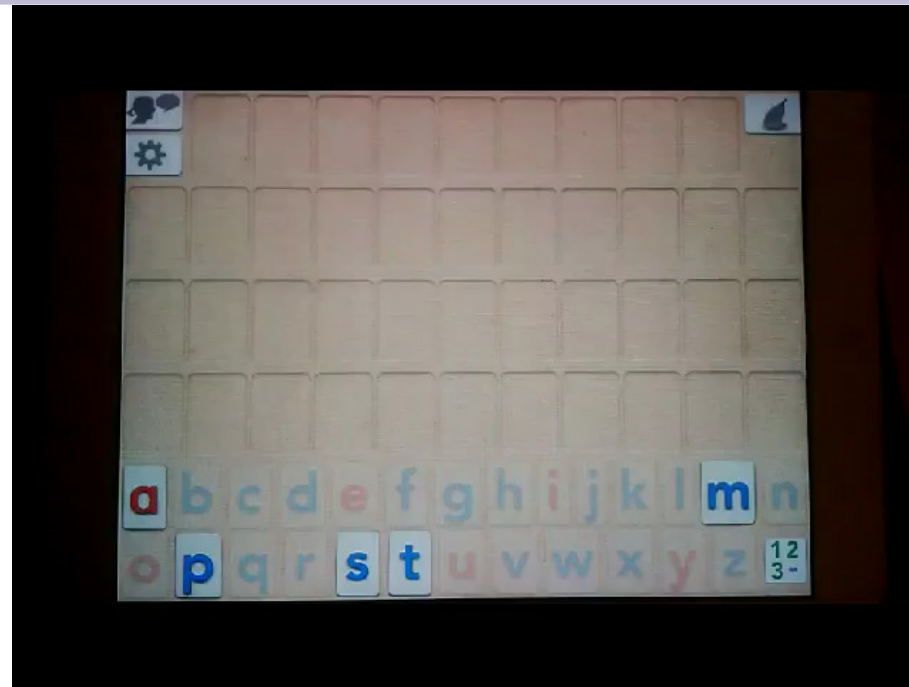
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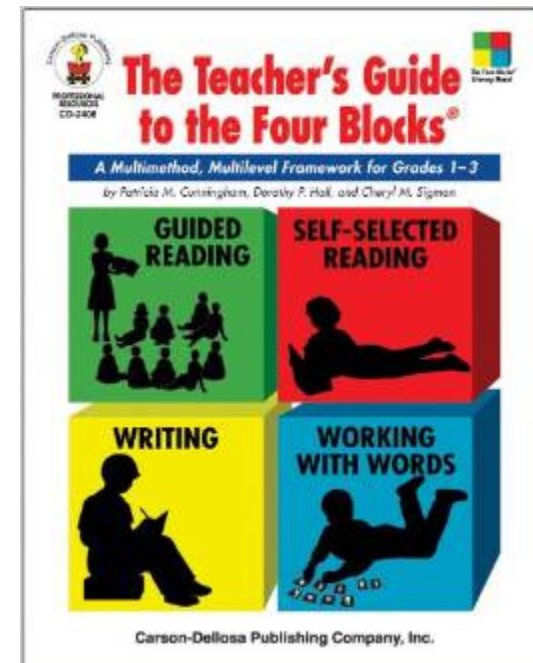
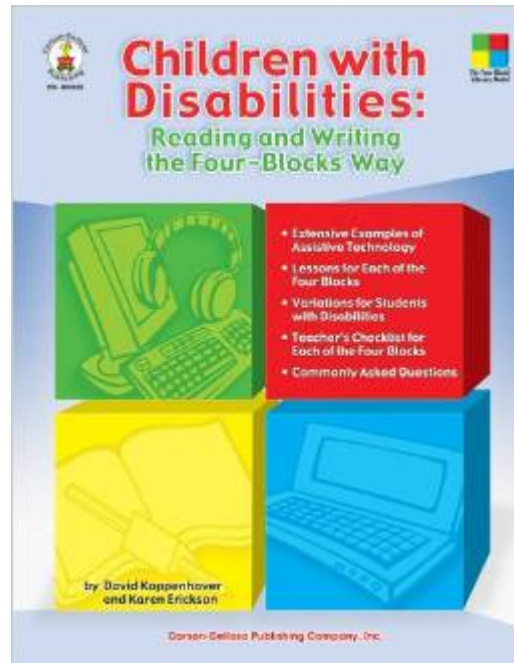
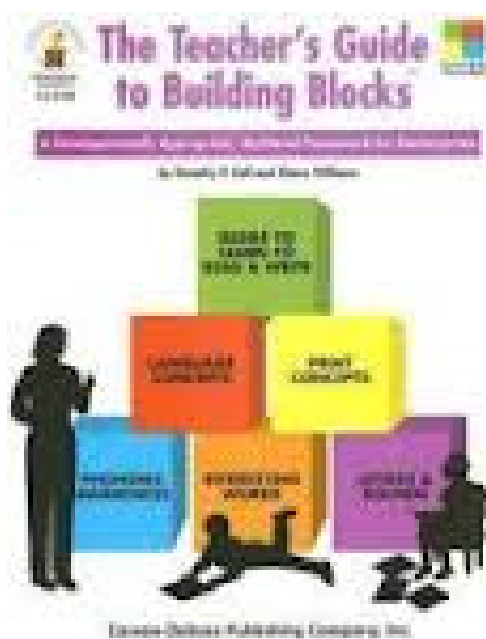
u v w x y z 12 3 -

Sequential Phonics



Karen used Cunningham's Systematic Sequential Phonics and the Word Wizard iPad app to create phonics lesson videos for Abby's Tobii. Abby can choose to watch them by eye-gaze. (And she does.)

Where do I start?

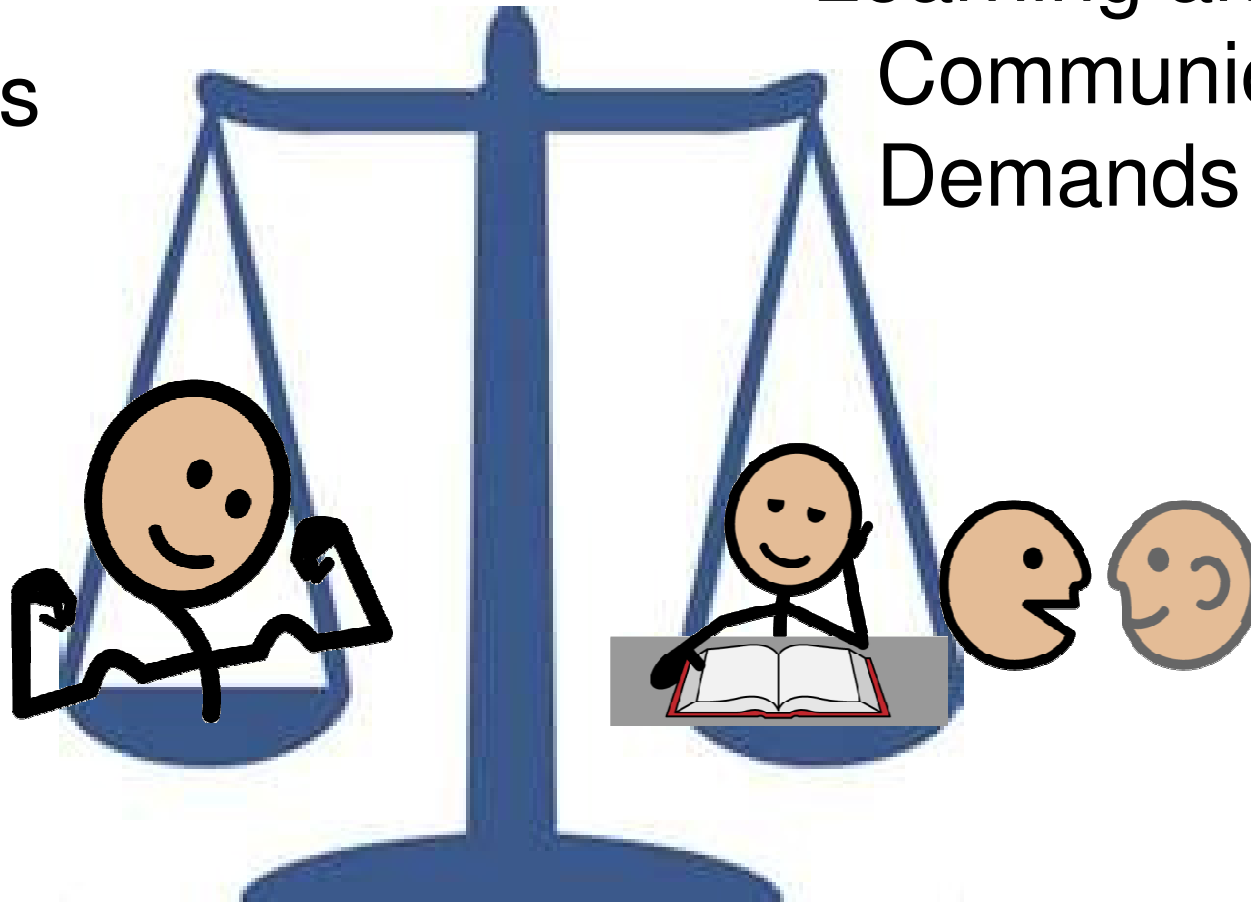


We talked about books by Karen Erickson and David Koppenhaver and teacher's guides by Patricia Cunningham.

Success - It is always a balance between...

- Motor Demands

Learning and/or
Communication
Demands



©2011, N2Y Inc.

Raising the bar – What should we expect?

- Much more than making choices of foods, toys/activities, or DVDs
 - Expressing needs and wants and that something hurts
 - Being able to have a conversation where you “talk with a student” – expressing his/her feelings, opinions, protesting, asking questions, teasing, sharing accounts of life experiences, etc.
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-

Raising the bar – What should we expect?

- Learning to read and write with access to tools and materials they can use with best practices for literacy instruction
 - Combining sentence starters/core words with phonetic spelling to write/express messages that are not on their communication device.
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In closing

- **Believe** that your son/daughter/student with Rett Syndrome can learn to read and write
 - Highly motivated to learn...just need to start by participating in literacy learning activities in a fun way!
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Teach Me AAC-CLL – Conversations, Language, and Literacy:

- Specifically designed for students with Rett Syndrome
- Watch Judy's and Pati's websites for details

<http://jlariviere.com>

www.creativecommunicating.com



Teach Me AAC-CLL Conversations, Language and Literacy a Curriculum for Rett Syndrome

Developed by Pati King-DeBaun and Judy Lariviere January 2014

This course is specially designed for students with Rett Syndrome. Adaptations and suggestions within this course will address the unique learning and access needs of this population. This course moves beyond the Beginning Communicator's Program and goes more in depth into conversation, literacy and language instruction. This course will have approximately 350 lessons for one year's worth with approximately 2 sessions per week .

Resources

Judy's Lowercase Alphabet Flipbooks

- Yellow background or light gray background
- Combined with the alphabet in the same layout in Tobii Communicator
- Available soon!
- Check website <http://jlariviere.com> for details

