Communication Strategies for Children and Adults with Angelman Syndrome

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Background

○ Mary-Louise Bertram: Early Childhood Teacher (B.Ed.)
  ● Further Qualifications and training in
    ○ Augmentative and Alternative Communication
    ○ PODD Communication Books
    ○ Cortical Vision Impairment
    ○ Sensory Processing Disorder
    ○ Movement and Positioning

○ Journey with Angelman syndrome began in 2009
  ● 4 students with deletion positive Angelman Syndrome
    ○ Special school (segregated, self-contained setting, Conductive Education Model) in Perth, Western Australia
  ● 2013 Statewide Communication Project for each person with AS in Western Australia (Funded by Angelman Syndrome Association of Western Australia and the state government)
    ○ group interventions
    ○ family and support workers played key role
    ○ 2 years to 45 years of age
    ○ All participants made communication gains but the adults made most significant gains
  ● 2011 began working with children with Angelman across Australia, USA and Canada
Aim of presentation

Based on my work and experiences, I aim to:

○ Develop a shared understanding regarding communication issues for people with Angelman

● What are the key issues which impact on the communication development of children with Angelman Syndrome?

● What are the key issues which impact on a child with Angelman Syndrome’s ability to use AAC effectively?

● What is research telling us is best practice for language acquisition and AAC intervention? How do we apply this to individuals with Angelman?

● What AAC systems and interventions are actually working for children and adults with Angelman? How are we measuring success?

● How can we support more children and adults with Angelman to become literate? What does literacy education look like for someone with Angelman?
“Communication is the essence of human life… Communication is about touching other people and about having our lives touched by others.”

Why I do what I do…

- Wants and needs
- More
- Finish/All done
- Toilet
- Food

Where are we focusing our intervention and our energy? What are we telling our children is more important? What are we inadvertently telling them doesn’t matter?

Light, Janice. (1997) “Communication is the essence of human life”;: reflections on communicative competence’, Augmentative and Alternative Communication,13:2,61 — 70
Developing a Shared Understanding: What are a child’s communication requirements?

- Varied reasons to communicate - varied communicative functions (Pragmatic Intents / Functions)
  - Asking questions
  - Greeting friends and family
  - Commenting
  - Expressing likes / dislikes
  - Indicating a problem
  - Complaining
  - Indicating preferences
  - Making requests
  - Recounting ‘news’, what’s happened
  - Telling jokes
  - Sharing secrets
  - Giving instructions, directions
  - Pretending
  - ......etc.

“Say what I want to say, to whoever I want to talk to, whenever I want to say it”.

Burkhart, L. & Porter, G. The Roads to Autonomous Communication Using Aided Language. ISAAC Pre-Conference Handout 2012
Developing a Shared Understanding: ‘Catch 22’ for children with AS

1. Professionals intervene - provide aided language based on their expectations of what’s possible
2. Child can only demonstrate ability to use what has been set up for use
3. Others can only be influenced by child’s use of what has been set up to use.

Burkhart, L. & Porter, G. The Roads to Autonomous Communication Using Aided Language. ISAAC Pre-Conference Handout 2012
Perception drives expectation
Expectation drives opportunity
Opportunity drives achievement
Achievement drives perception

wwwPrAACticalAAC.org
“The attitudes and expectations of people in the environment may to some extent influence all children’s language development, but they may be critical for children who use alternative forms because these children depend on the means and opportunities provided by professionals.”

(and all the people around them – including you and me)

Presume Competence

- What a student with Angelman syndrome can communicate now should be presumed to be the floor, not the ceiling, of her comprehension.

- Erin Sheldon (mother to 9 year old with AS and Autism), Masters Thesis ‘EDUCATING CHILDREN WITH ANGELMAN SYNDROME: MOVING BEYOND SOCIAL INCLUSION’
What the research into Communication in people with Angelman has told us

- Profound expressive communication disability (Williams et al., 2006) that is disproportionately severe in relation to the student’s overall development, cognitive abilities, and receptive language skills (Gentile et al., 2010; Jolleff, Emmerson, Ryan, & McConachie, 2006).

- The communication disability in Angelman syndrome is exacerbated by intellectual disability and is complicated by co-existing ataxia, apraxia, and dyspraxia (Gentile et al., 2010; Penner, Johnston, Faircloth, Irish, & Williams, 1993; Williams et al., 2006; Williams, Peters, & Calculator, 2009).

- While as many as one third of individuals with Angelman syndrome develop some manual sign language, their use of sign language tends to be idiosyncratic (recognizable only to people who know them well within the contexts in which the signs are used) with very few reported to use conventional sign language (Calculator, 2013; Clayton--Smith, 1993). Parents can be taught to help shape their child’s natural gestures into universally recognized gestures that even strangers can accurately interpret (Calculator, 2002).

- Students with Angelman syndrome use a wide variety of communication strategies and appear to develop strong preferences for whatever system is the most efficient to convey the messages they are most motivated to express (Calculator, 2013).
Research...

- Norm-referenced standardized communication assessments of individuals with Angelman syndrome rarely describe expressive language abilities above the 12-month age-equivalent or receptive understanding above the 24-month age-equivalent level (Gentile et al., 2010; Williams et al., 2006).

- Parents of children with Angelman syndrome complain that traditional norm-referenced or clinical assessment strategies underestimate their child’s receptive language and cognitive abilities (Gentile et al., 2010).

- **Issues with standardized assessments for children with AS**
  - apraxia
  - ataxia
  - dyspraxia
  - pressure and unfamiliarity
Key Issues impacting on effective AAC implementation in children with AS

- Happy demeanour – “as long as he’s happy”
- Belief in diagnosis of ‘severe to profound intellectual disability’
- Environments not supportive of AAC
- Lack of continuity across environments
- Lack of competent communication partners
  - Skilled
  - Positive, supportive, open expectations
- Challenging behaviour leads to more adult control language which often leads to more challenging behaviour
- Lack of use of evidence based practice
Calculator (2013) assessed 182 parent reports of their child’s exposure to various AAC interventions; his most significant finding was that students with Angelman syndrome, in general, have received neither the technological tools nor the instructional approaches that are considered evidence based within the field of speech language pathology to be effective at teaching students to use and adopt AAC.

When Calculator compared the interventions provided to students with Angelman syndrome to the practices most proven to result in long-term use and acceptance of AAC (Johnson, Inglebret, Jones, & Ray, 2006), only 5% of the practices reportedly used with students with Angelman syndrome were consistent with what could be termed evidence-based approaches. Lack of use of evidence based practice
Calculator concluded that students with Angelman syndrome are experiencing success with AAC tools, “despite marginal exposure to practices thought to foster their use” (p. 155). We cannot draw conclusions about what is possible for students with Angelman syndrome to learn regarding the use of AAC until we have at least exposed these students to effective instructional practices (Calculator, 2013).
Many children with Angelman are labelled “Pre-Intentional” or “Pre-Symbolic”

- These are stages in TYPICAL communication development.
- Issues when using this term with children who have motor challenges, sensory processing challenges. Difficulties occur when learning to produce expressive communication using conventional gesture, speech, or eye gaze.
- Difficulties may lie in interpreting what the child is trying to communicate and in our understanding of his or her intent but we cannot assume we know what another person is thinking.
Instead of labeling as ‘Pre-Intentional’

- We can communicate with the child using a form of language that they can communicate back to us with
- We can feed back to the child what we see them do
- We can use our understanding regarding motor planning issues, sensory processing issues and Complex Communication Needs to describe the communicative behaviours you see, and set goals accordingly.

Email conversation with Gayle Porter, Linda Burkhart, PODDChat Listserve. 2012
People with Angelman syndrome have Complex Communication Needs

- COMPLEX COMMUNICATION NEEDS
  - when an individual is “\textit{unable to use speech to meet their communication requirements, given their age and culture}” \cite{Porter1995}
    \begin{quote}
    \end{quote}
  - when gestural, speech or written communication is inadequate to meet all communication needs \cite{American1991}
    \begin{quote}
    \end{quote}
Where has this term come from?

International Society of Augmentative and Alternative Communication (ISAAC)

Previous terms: severe communication disorders or severe communication impairments

Currently preferred term:

- complex communication needs
- focus on identifying what is important for each person to meet his/her own goals of communication
COMPLEX COMMUNICATION NEEDS

○ Why say ‘Complex’?
  - Receptive communication
  - Expressive communication
  - Access issues
  - Sensory issues
  - Processing issues
  - Day to day changes
  - Individual
  - Multiple modes of communication
Aim of Alternative and Augmentative Communication Intervention

Why use AAC? Why intervene?

To enable the person with complex communication needs to achieve communicative competence:

“For the person to meet his/her varied communication requirements as intelligibly, specifically, efficiently, independently and in as socially valued a manner as possible in order to understand others and to be understood.”

Myths about AAC

- **Myth 1**: AAC is a “last resort” in speech-language intervention
  - “let’s work on speech first”

- **Myth 2**: AAC hinders or stops further speech development

- **Myth 3**: Children must have a certain set of skills to be able to benefit from AAC
  - Pre-requisites
  - ‘not ready yet’

Myths about AAC

Myth 4: Speech-generating AAC devices are only for children with intact cognition

- **MYTH**
  - How do we know what a child is thinking?
  - What tests are we using?

Myth 5: Children have to be a certain age to be able to benefit from AAC

- If you have CCN from infancy you need communication support from infancy
- How can a child develop language without AAC intervention?
- “Spontaneous Combustion of Skill”

Myths about AAC

Myth 6: There is a representational hierarchy of symbols from objects to written words
- Real objects ‘Objects of Reference’
- Colour Photographs
- Black and White Photographs
- Miniature Objects
- Symbol
- Words

Alternative and Augmentative Communication Intervention

Clarifying the long-term destination - Being able to

“Say what I want to say, to whoever I want to talk to, whenever I want to say it”.

Burkhart, L. & Porter, G. The Roads to Autonomous Communication Using Aided Language. ISAAC Pre-Conference Handout 2012
Key Issues impacting on effective AAC use in children with AS

Motor planning Issues

- Apraxia
- Dyspraxia
- Communication, Voice, Speech
- Hand-eye coordination
- Fine manipulation
- Body awareness
- Depth perception
- Ability to isolate body parts, associated movement
- Balance disorder and asymmetry
- Tremors
Key Issues impacting on effective AAC use in children with AS

‘Happy’ demeanour

- laugh ‘reflex’
- Passivity, ‘go with the flow’

- Laughing reflex
- Can interfere with communication
- Self modulation
- Not a way of saying yes
- Can be taught to use the laugh reflex to ‘push a laugh out’ to vocalise
Key Issues impacting on effective AAC use in children with AS

‘Challenging Behaviours’

Challenging Behaviour

- Robust tools
- crying
- Passivity, ‘go with the flow’
- ‘not motivated’
- ‘obsessed with saying the same words on the AAC’
- Sensory processing issues vs challenging behaviour
- Control language
  - Adult control language
  - Child control language
Key Issues impacting on effective AAC use in children with AS

**Sensory processing issues**

- May lead to varied, often repetitive sensory seeking / avoiding behaviours including
  - Proprioceptive based behaviours – banging, mouthing, stamping, tapping, knocking, vocalising
  - Vestibular based behaviours – rocking, head rolling, bouncing, jumping, flapping
  - Perseveration of touch, vocalisation

- Attention span / distractability – visual, auditory, tactile distractions
Key Issues impacting on effective AAC use in children with AS

- **Vision challenges**
  - Depth perception
  - CVI
  - Visual Discrimination
  - coordinating looking and listening
  - coordinating looking and reaching / touching

- **Difference in goals and focus**
  - Teacher “will match name to photograph”
  - Speech Pathologist “will identify symbol from a field of 2”
  - Vision Teacher “will attend to …”

- COMMUNICATION TRUMPS ALL!
12 cell General Interactive Aided Language Display adapted using Mayer-Johnson PCS™ High Contrast Symbols.

I do, me

I'm asking a question

more

I like this

uh oh

I want something

finish, all done
don't like

I don't know
go (I want to go)

stop, wait

something's wrong

I do, me
I'm asking a question
more
I like this

uh oh
I want something
finish
don't like

I don't know
go (I want to go)
stop, wait
something's wrong

Using a pull off symbol on a display

I don't know

I'm asking a question

I want something

I like this

I like this

go (I want to go)

stop, wait

something's wrong

Juggling means that the person may only have some of the ‘balls in the air’ at any given time, and having all the ‘balls in the air’ will be rare.

This explains why ‘performance’ is so inconsistent and can not always be predictably repeated.

‘CONSISTENTLY INCONSISTENT’

‘See it once, Believe it.’
The Juggling Act of Communicating

To be able to communicate effectively, many individual components must be coordinated. For example:

- **Sensory-motor demands**: motivation, strength, motor planning, muscle tone, endurance, motor automaticity, auditory filtering, auditory processing, tactile processing, proprioceptive processing, reaction time, visual discrimination, visual scanning/memory, visual tracking, integrating multiple sensory inputs.

- **Cognitive demands**: motivation, cause/effect, initiating, discriminating purpose and function, developing cognitive schemas, making active choices, trial and error, problem solving, memory

- **Language components**: motivation, processing of language in activity, relationship to and monitoring of the communication partner, pragmatics, processing of questions, auditory filtering, processing of symbol set, syntax/grammar, attention to task, memory

So what is evidence based practice for AAC intervention for children with Complex Communication Needs?
Aided Language Stimulation

(also called
Aided Language Input
Aided Language Modelling)
Input

Spoken Language Development

Spoken Language

Aided Language Development?

Spoken Language

Output

Spoken Language

Aided Language

(Burkhart & Porter, 2006)
Aided Language Development using Aided Language Stimulation

Input

Aided Language
Spoken Language
(Sign Language)

Output

Aided Language
(Spoken Language)
(Sign Language)

(Burkhart & Porter, 2006)
Why use aided language stimulation?

- ALS involves modelling how aided symbols can be used to communicate
- Children do not need ANY pre-requisite skills to begin using ALS techniques because...
- Others use aided symbols to provide *receptive input*
- Information *must* go **IN** before it can come out (Burkhart and Porter, 2006)
  - *Language acquisition studies*
  - *Learning a foreign language*
- Provides opportunities:
  - for child to learn *how* aided symbols are used to communicate for the full range of functions
  - to observe children’s responses and determine which strategies will support them to communicate more effectively
Aided Language Stimulation aids receptive communication

- Helps improve children’s understanding of what we are saying

**HOW?**

- Using symbols encourages us to use simpler vocabulary
- Using symbols slows down our own speech – this increase time allowed for children to process what we say
- Using aided symbols highlights the most important words in our message
- Provides additional visual, symbolic clues which are often more transparent than the spoken word
- ALS does not rely purely on auditory processing
- Children who use sign language / with hearing impairments need to learn to interact with people who cannot sign
- Children learning English as a second language can be helped to learn and understand spoken English
What about children who have some speech?

- Helps expand vocabulary
  - Encourages different words to be used to express different messages
  - Lots of our students tend to use very limited range of words / signs / symbols to communicate a very small range of messages

- Helps improve structure of spoken language
  - e.g. using 2 -3 word phrases, using full sentences
Aided Language Stimulation

- Aided Language Stimulation is about YOU not about the individual with AS
- Longitudinal studies suggest that aided language modeling approaches may have a significant long-term effect on language development for students with complex communication needs
Modelling use of aided symbols

WHY model?

*Children learn to communicate in the way they experience their system of communication being used.*

Porter and Kirkland (1995); Beukelman and Mirenda (1998); Porter (2007)

- Children need to see their own and other AAC strategies (or aided language?) used frequently
- Real messages, real situations, real daily activities
- Use AAC (aided symbols?) to say different messages
- Problems of using AAC in a limited way
Aided Language Stimulation

- More to be learnt than just what each symbol means
- AAC can be used for different communicative functions
  - When things can be said
  - How to initiate communication in different situations
  - How wonderful it is to be able to get those words out of my head!
Modelling use of aided symbols

Use aided symbols during ongoing interactions – any chat or talk with child – to provide **receptive input**

**HOW?**

- Point to the symbols
- Highlight symbols using a torch
- Pull off individually Velcroed symbols to show child
- Model access techniques the children need to learn to use
  - Direct access
  - Eye pointing
  - Partner assisted auditory scanning
- May need to use different indication methods at different times
Modelling tips

- Children do not always need to be directly watching you model

  - It’s Individual – difficult to look and listen
  - Use of Peripheral vision
  - Listening
  - Being there, being a part of the interaction, being relaxed, being comfortable. It is about Communication: not testing, not teaching.

So what do I model?

- Aided Language Displays
- Signing
- High tech systems
- paper based systems
- PODD Communication Books

- YOU model the language you want your child to one day use to communicate with you.
I do, me  
I'm asking a question  
more  
I like this  

uh oh  
I want something  
finish  
don't like  

I don't know  
go (I want to go)  
stop, wait  
something's wrong  

12 cell General Interactive Aided Language Display adapted using Mayer-Johnson PCS™ High Contrast Symbols.
<table>
<thead>
<tr>
<th>Questions</th>
<th>People subjects</th>
<th>Verbs</th>
<th>Descriptors (adjectives + prepositions)</th>
<th>Object nouns</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. what, where etc</td>
<td>e.g. I, me; you</td>
<td>e.g. want, hold, make, play etc</td>
<td>e.g. on, in, big great, fun, etc</td>
<td>e.g. water, ball, food etc</td>
</tr>
<tr>
<td>Exclamations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Uh Oh, wow</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Visual & verbal referencing

- Tell the child what you see him doing
- Tell the child if you don’t understand
- Tell the child what he can do to help you understand
Partner assisted scanning

- Partners provide scanning by showing/pointing and/or speaking the names of items.

- It is used as a means of access for children who have difficulty pointing accurately due to:
  - Physical disability
  - Sensory processing difficulties
  - Visual and/or hearing impairment

- AND ALSO to familiarise children with all the vocabulary available to them.
Movements for Communication

- Accept everything to start with
- Teach the movements needed
- Yes, No, I don’t know
- Access methods
Yes and No

- Different functional purposes
  - Accept – reject
  - Confirm – deny
  - Agree – disagree
  - Protest

- Smiling for Yes? No!

- Teach the movements needed

- A today plan and a tomorrow plan – Katie's yes and no development

- May be easier to nod in agreement in the beginning – automatic

- NOT to say show me yes etc eg do you want a drink, child looks away, you looked away you are telling me no, child looks at you and reaches for drink, oh you are saying yes (adult nods) you do want a drink. Give child a drink- Do not say show me yes – he has already made it clear he wants a drink!

- Frame your questions ‘ you need to tell me yes or no’, model the movement you want

- Verbally reference what you see
Choice making and Aided Language Stimulation

Choice making IS NOT Aided Language Stimulation. Choice Making is another strategy available to you and the person with CCN.

- Can be really hard, especially if the choice you want isn't there, has moved, is lost, or might appear later but you just don't know. This makes choosing very difficult.
- Need a 'the one I want isn’t there’ choice. (Sometimes there are only two choices- that’s ok. Well, unless there are only two choices of cake – that’s devastating.)

- People keep moving the objects/symbols of choice around – makes choosing much more difficult – automaticity of motor planning...
  Confuses motor planning, uses up working memory.
Working memory and Automaticity. What on earth has that got to do with Communication?

- Remember The Juggling Act?
- Working Memory can only deal with a limited amount of information at a time
  - Cognitive attention is needed to focus on anything that is not automatic

- Problem of available working memory - what to focus on? – Touch the iPad? What did she just ask me? Look at her? Who just walked in the door? What was that noise? What do I know about this? How could I answer that? Why does my stomach hurt? What do I want?
Memory is stored as patterns not individual details and must contain some variety in order to be generalized to a broad number of situations.

- **Once a pattern is learned it becomes automatic and operates subconsciously, until there is a need to use it or change it.**
- If something is not automatic yet, it will occupy the person’s working memory instead of operating in the background.
- For many people who have severe multiple challenges (including people with Autism), motor control requires cognitive attention and effort.
- We need to be helping people to get to a point where cognitive efforts can be redirected from the motor skill to the content of the task.
Choice making, communication opportunities, and Motor Planning…
Choice making and Motor Planning…

- oatmeal
- Corn Flakes
- toast
Choice making and Motor Planning…

[Diagram of oatmeal and Corn Flakes]
Choice making and Motor Planning...

- oatmeal
- toast
- Corn Flakes
Choice making

- oatmeal
- socks

or
12 cell Breakfast Aided Language Display (ALD)…

Communication benefits? Of user? Of Smart Partner?

Motor Planning benefits?

PODD Communication Books

Gayle Porter

Pragmatic Organisation Dynamic Dynamic Display

- Developed by Gayle Porter (Speech Pathologist)
- 20+ years in development and use
- whole language system
- evidence based best practice in AAC
PODD Training in Scandinavia, Europe

- podd.eu
- 2 day training
- 5 day training

Certified EU PODD Trainers:
Norway: Tone Mjøen
Denmark: Edda Medici, Emmy Kjelmann
UK: Rosie Clark
PODD Communication Books

Child presented with limited items per page
• routine presentation

Additional vocabulary always available on other pages
• hidden from current view
• routine pathways
PODD Communication Books

Use of PODD Communication books with individuals who have AS

- Tough and waterproof
- ‘Smart Partner’
- Light Tech vs High Tech
- PODD for The Grid 2 (Sensory Software UK)
- PODD for DynaVox Compass iOS App (mid 2014)
FAQ/Comments

- He won’t be able to attend as you turn all those pages
- He doesn’t understand when I just talk to him so how can he possibly understand when I talk and use the book?
- I understand everything he communicates
- He has signs
- He has vocalisations / word approximations / some words
- I just want him to be happy
- School is a controlled environment
- He just likes to use his voice
- He’d eat that
- He’d play with the book / flick/
Use child’s PODD book during ongoing interactions – any chat or talk with child – to provide **receptive input**

**HOW?**

- Model the child’s initiating method
- ALWAYS begin on Page 1 and use branch pathways
- Say the label as you point
- Recap the message so far regularly
- Repeat the message in normal speech at the end
- Use the child’s access method some of the time
- Verbally reference what you are doing to operate the PODD book

*Porter 2007*
Core Vocabulary

“There are two types of vocabulary, core and fringe. Core vocabulary is composed of high frequency words that are very versatile. In contrast, fringe vocabulary is composed of words that occur infrequently and lack versatility.”

- Personal Core (seizure, sensory needs etc)
- Core Vocab based systems
- PODD and Core
  - Janelle Sampson (Twowaystreet.net.au)
    - "PODD vocabulary supports the combination of core words for fast and predictably associated vocabulary, while also including a wide range of extended vocabulary to ensure that specificity and diversity of expression is possible."
Pragmatic Intent in PODD

- I like this (4a)
- I want ... (do an activity) (11)
- I'm asking a question (8)
- I don't like this (4c)
- Let's go .. (12)
- I'm telling you something (3)
- something's wrong (5)
- do something (actions/verbs) (10)
- do a group activity (25)
Pragmatic Intent in PODD

What we are seeing in children with AS?

Before PODD implementation:
- sign, gesture, voice
- eg “Mamma”

Why are these Pragmatic Intents so important?

What we are seeing in children with AS?

After PODD implementation:
- sign, gesture, voice, AAC, PODD
- eg “Mamma”

How are we measuring a child’s communication growth?
- Pragmatic Profile
- Anecdotal records
- video, video, video
What are a child’s communication requirements?

- Varied reasons to communicate - varied communicative functions
  - Asking questions
  - Greeting friends and family
  - Commenting
  - Expressing likes / dislikes
  - Indicating a problem
  - Complaining
  - Indicating preferences
  - Making requests
  - Recounting ‘news’, what’s happened
  - Telling jokes
  - Sharing secrets
  - Giving instructions, directions
  - Pretending
  - ......etc.

“Say what I want to say, to whoever I want to talk to, whenever I want to say it”.
‘Organising the Environment’

- From the amazing (1992) work *Engineering the Preschool Environment for Interactive, Symbolic Communication*
  - Pamela Elder, MA CCC-SLP
  - Sharon Sapp Crain, MS, CCC-SLP
  - Carol Goossens’, Ph.D., CCC-SLP

- Language available for modeling
- Language available all the time
  - Activity displays
  - Aided Language Displays
  - Communication Books

- Core Boards
- Visual Supports – Schedules, Timetables, First / Then
High Tech, Light Tech

- **High Tech systems**
  - Dynamic Display
  - Sequential
  - Static

- **Light Tech systems**
  - PODD
  - Core Vocab / Pixon
  - Choice Board
  - Yes/No/I don’t know

- **No Tech systems**
  - Sign / Gesture / Body Language
  - Yes/No Question and Answer
  - Partner Assisted (Scanning)
Memory is stored as patterns not individual details and must contain some variety in order to be generalized to a broad number of situations.

- **Once a pattern is learned it becomes automatic and operates subconsciously, until there is a need to use it or change it.**
- If something is not automatic yet, it will occupy the person’s working memory instead of operating in the background.
- For many people who have severe multiple challenges (including people with Autism), motor control requires cognitive attention and effort.
- We need to be helping people to get to a point where cognitive efforts can be redirected from the motor skill to the content of the task.
How are we measuring and recording change?

- Video, video, video
- Anecdotal records
- Many children are involved in the Natural History Study in USA
- Pragmatic Profile of Everyday Communication Skills
  - http://wwwedit.wmin.ac.uk/psychology/pp/children.htm
Fostering a culture that supports and expects communication

- Autonomy of Message is Critical
- Must be the Child’s Message - Even if She Needs Help to Communicate it
- Not Just a Response to the Options Provided by Others
- Communication is NOT just an activity. It occurs all day long in a variety of natural contexts
- Getting from Intent to Action is What is Difficult for many children who have multiple disabilities
- The result of the effort, must be worth the effort
- Keep your expectations open
Multi-Modal Communication

Total Communication

- Everything is accepted
- Multiples modes/ ways to communicate:
  - ‘Hello’: wave, vocalise, use words or word approximations, use communication book, use speech generating device / AAC.
  - “drink”: bring mum a cup, go to the tap, stand at the fridge, take dad to the cupboard, sign ‘drink’, use words or word approximations, use communication book, use speech generating device / AAC.
Emergent Literacy

Emergent literacy is “... the reading and writing behaviours that precede and develop into conventional literacy.”
(Sulzby, 1991)
Literacy

- There are no pre-requisites for literacy instruction.
- Every activity and skill feeds every other activity and skill (reading, writing, communication, etc.).
- The least dangerous assumption is that every student benefits from literacy instruction everyday.

Nancy Steele, NCBD
Louisiana Literacy Institute
Baton Rouge, LA
December 2009
leads to true autonomous communication – being able to say what I want, when I want, to whomever I want.
Balanced Literacy Program

- Reading to self
- Reading with others
- Working with letters
- Working with words
- Writing
- Language (Oral / AAC) to talk about literacy
Four Blocks Literacy

Children with Disabilities: Reading and Writing the Four-Blocks Way

- Extensive Examples of Assistive Technology
- Lessons for Each of the Four Blocks
- Variations for Students with Disabilities
- Teacher’s Checklist for Each of the Four Blocks
- Commonly Asked Questions

by David Koppenhaver and Karen Erickson

Carson-Dellosa Publishing Company, Inc.
Center for Literacy and Disability Studies UNC

Department of Allied Health Sciences
Center for Literacy and Disability Studies

News
- 4 Million Books Read!
  Oct 10, 2012
- Check Out Certain Proof
  Apr 13, 2011
- Family Network Radio Interview
  Apr 13, 2011
- Route 66 Literacy Launch
  Apr 13, 2011
- Two Million Books Read in a Week!

Products
- Reading Assessment and Assistive Technology DVDs
- Writing With Alternative Pencils CD

Addressing the literacy learning needs of persons with disabilities of all ages.

TAR HEEL READER
Tar Heel Reader is a growing free library of accessible, beginning level readers for students of all ages.
Assessment

- Kathy Staugler Literacy Rubric
  - Can be completed by you to give your child’s teacher an idea of your child as a literacy learner! Yay!
- Dr Janet Sturm Developmental Writing Scale
- First Author Software (Don Johnston inc)
<table>
<thead>
<tr>
<th></th>
<th>Early Emerging Literacy</th>
<th>Transitional Emerging Literacy</th>
<th>Early Conventional</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1 point) Interest/Awareness</td>
<td>(2 point) Participation</td>
<td></td>
</tr>
<tr>
<td><strong>Phonemic Awareness</strong></td>
<td>Shows some interest or enjoyment in rhyme play activities</td>
<td>Participates during rhyme play by repeating words of similar sound patterns</td>
<td>Identifies similarities and differences of sounds within words; associates consonant letters and sounds</td>
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<tr>
<td><strong>Concepts of Print</strong></td>
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<td>Attends to story reading and graphics with minimal prompts</td>
<td>Creates new words within word families; associates consonant letters and sounds</td>
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<tr>
<td><strong>Word Recognition</strong></td>
<td>Shows beginning interest or attends to graphics or pictures</td>
<td>Identifies named pictures or graphics</td>
<td>Identifies some text words without graphic support</td>
</tr>
<tr>
<td></td>
<td>Shows beginning awareness of repetitive lines in story reading</td>
<td>Participates with a repetitive line during story reading</td>
<td>Identifies an increasing # of high frequency sight words</td>
</tr>
<tr>
<td><strong>Fluency</strong></td>
<td>Shows indications of spoken word and object recognition within own experiences</td>
<td>Associates spoken word to graphics within a story page read</td>
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<td>Associates connected speech with supporting graphics during story reading</td>
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**Total Score**

| Early Emerging Literacy: 0 - 5 | Early Transitional Emerging Literacy 6 - 10 | Transitional Emerging Literacy 11 - 15 | Late Transitional Emerging Literacy 15 - 20 | Early Conventional Literacy 21 - 25 |

**Directions:** Engage the student in story reading and/or reading related activities. Observe student’s behaviors and level of participation. Mark the space in each row that most clearly defines the student’s level of concept understanding. Calculate the total points for the student. Within each of the five areas, note the level of text that you should select to help the student move further in their skill and understanding.

Student Name __________________________ Date __________ Assessed by _______________________

Kathy Staugler © 2007
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<td>(3 points)</td>
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<td>Recognition</td>
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<td><strong>Phonemic Awareness</strong></td>
<td>Shows some interest or</td>
<td>Participates during rhyme play</td>
<td>Attempts to create</td>
</tr>
<tr>
<td></td>
<td>enjoyment in rhyme</td>
<td>by repeating words of</td>
<td>word similarities,</td>
</tr>
<tr>
<td></td>
<td>play activities</td>
<td>similar sound patterns</td>
<td>such as rhyme or</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>initial sound</td>
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<td></td>
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<td>graphics with minimal</td>
<td>right sequence of</td>
</tr>
<tr>
<td></td>
<td>to book reading</td>
<td>prompts</td>
<td>text within page</td>
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<td>Recognizes familiar</td>
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<td>signs, names, or</td>
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<td>to graphics or pictures</td>
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<td>text words with</td>
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<td></td>
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<td>Predicts or repeats</td>
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<td>awareness of</td>
<td>repetitive line during</td>
<td>repeated lines within</td>
</tr>
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<td>story reading</td>
<td>story</td>
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<td></td>
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<td></td>
<td></td>
</tr>
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<td>Shows indications of</td>
<td>Associates spoken word to</td>
<td>Associates connected</td>
</tr>
<tr>
<td></td>
<td>spoken word and</td>
<td>graphics within a story page</td>
<td>speech with</td>
</tr>
<tr>
<td></td>
<td>object recognition</td>
<td>read</td>
<td>supporting graphics</td>
</tr>
<tr>
<td></td>
<td>within own experiences</td>
<td></td>
<td>during story reading</td>
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**Total Score**

**Early Emerging Literacy:**
- **0 - 5**
- **Early Transitional Literacy:**
- **6 - 10**
- **Transitional Emerging Literacy:**
- **11 - 15**
- **Late Transitional Emerging Literacy:**
- **15 - 20**
- **Early Conventional Literacy:**
- **21 - 25**

**Directions:** Engage the student in story reading and/or reading related activities. Observe student’s behaviors and level of participation. Mark the space in each row that most clearly defines the student’s level of concept understanding. Calculate the total points for the student. Within each of the five areas, note the level of text that you should select to help the student move further in their skill and understanding.

Assessed by

Kathy Staugler © 2007
### Early Emerging Literacy

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</thead>
<tbody>
<tr>
<td>(2 points) Participation</td>
<td>(3 points) Recognition</td>
<td>(4 points) Demonstration</td>
<td>(5 points) Purposeful Engagement</td>
</tr>
<tr>
<td>Participates during rhyme play by repeating words of similar sound patterns</td>
<td>Attempts to create word similarities, such as rhyme or initial sound patterns</td>
<td>Identifies similarities and differences of sounds within words; Identifies some letters</td>
<td>Creates new words within word families; associates consonant letters and sounds</td>
</tr>
<tr>
<td>Attends to story reading and graphics with minimal prompts</td>
<td>Recognizes left to right sequence of text within page format</td>
<td>Follows the left-right; top-bottom flow of text and page to page progression of stories</td>
<td>Reads words in text while following a left-right; page to page flow</td>
</tr>
<tr>
<td>Identifies named pictures or graphics</td>
<td>Recognizes familiar signs, names, or text words with graphic support</td>
<td>Identifies some text words without graphic support</td>
<td>Identifies an increasing # of high frequency sight words</td>
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<tr>
<td>Participates with a repetitive line during story reading</td>
<td>Predicts or repeats repeated lines within a story</td>
<td>Attempts to read/reread text within a repeated story.</td>
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### Directions:

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Student Name:

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Reading with Individuals with AS

- any book that works
- feely books
- movement books
- magazines
- iPad books
- Alphabet Books
- Remnant Books
Shared Reading

What Do Students Learn During Shared Reading?

(Clay, 1993)

- Builds language
- Builds critical background knowledge
- How & why we use books
- Concepts about print
- Reading is worthwhile & enjoyable
- Student gradually takes on more responsibility in reading over time
Shared Reading

- Let child turn the pages if they wish
  - If they turn 3-4 pages at a time, just talk about the pages that you see
- Let child decide when they are finished and move on
- Have Aided Language Available
- Talk about what child says, points to, or does
- As children get older ask harder questions
  - What do you see?
  - What do you think will happen?
Concepts about Print

- Concepts About Print (Clay, 1993)
  - Book orientation
  - Print carries meaning—it is what we read
  - Turning pages
  - Read from left to right
  - Start at top and move to bottom
  - Words are separate units made up of letters
  - Idea of first and last letter
  - Different punctuation carries different meaning

Why Attribute Meaning?
Make your own books!

- Make Your Own:
  - Inexpensive, Dispensable Books
    - Fun Foam Books
    - Fabric Books
    - Board Book Makeover
    - Brag books/small photo albums
    - Box Books
    - Baggy Books
    - Calendar Books
    - Holiday Card Books
Tar Heel Reader

- Tar Heel Reader
- www.tarheelreader.org
- Developed by Gary Bishop & Karen Erickson
- Resource from University of North Carolina, Chapel Hill, NC
- **Free** resource for easy, easy, easy books
- Designed for students with significant disabilities who are struggling readers, including older students
- Accessible via switches and Intellikeys
- Can read books online OR books can be downloaded in PowerPoint or iPad
- Professionals can author their own books
Welcome

Welcome to the Tar Heel Reader, a collection of free, easy-to-read, and accessible books on a wide range of topics. Each book can be speech enabled and accessed using multiple interfaces, including touch screens, the IntelliKeys with custom overlays, and 1 to 3 switches. Click here to learn more about alternative access methods.

You may write your own books using pictures from the huge collection at Flickr or pictures you upload. All books should be complete, edited, and revised to the best of your ability before publishing them to the site. While you are working on them, please save them as drafts.

Note the little well icon in the upper left corner of the page; clicking it will allow you to access the main menu. You can also click the settings icon to change settings on some pages.

Ready to get started?

Find a book
Write a book

This site is also available in other languages. To help with translation, contact us.

Are you having a problem with the site? Consider Classic Mode or report a bug.
Writing

- Literacy is FOR EVERYONE
- Cannot truly be an autonomous communicator until you are able to spell (or spell enough to use word prediction)
- Literacy IS a life skill
- Writing is personal, meaningful, and do-able
- Writing is for social connection
- Writing is a cognitive act – not a fine motor act
Writing

- Form and Function in Writing
  - **Form**: how writing is made
  - **Function**: the purposes of writing
- For students with significant disabilities focus is often on form due to motor difficulties
- Pick a pencil that has the least brainpower going to form
- Focus on FUNCTION!

Gretchen Hanser PhD
gotgretchen@hotmail.com
Alternative Pencils

- Center for Literacy and Disability
  UNC, North Carolina
- Can be ANYTHING!
  - keyboard
  - iPhone
  - iPad
  - app
  - super cheap laminated flip chart or Alphabet page
  - super expensive special keyboard / software
Alternative Pencils

Selecting an Alternative Pencil

- Pick a pencil that has the most potential for students to EASILY use.
- Students **DO NOT** need to know their letters in order to get an alternative pencil.
- Students learn about pencils and letters by writing. Early writing is a PERFECT way to work on motor skills and letter knowledge.
- Students must have access to the full alphabet.
- Their “scribble” will look different—it is not about how the actual letter is physically formed by hand.
Alternative Pencils

- Pencils Are Pointless Without... a Meaningful Purpose
  - Journaling
  - Emails, cards, notes, and letters
  - Picture/tactual captions
  - Signs & posters
  - Poetry
  - Artwork
  - Write books
  - Using during alphabet activities
  - Can be related to current book
  - *Offer a VARIETY of activities-avoid burnout
Alternative Pencils

- Give Informative Feedback
- Give the Scribbles Meaning
- • “You’ve written a lot of letters—let’s see if we can count them.”
- • “Point to one of your letters—let’s see if it is in someone’s name.”
- • “You have a lot of ‘c’ s in your writing. Let’s find all of them.”
- • “Pick a letter and let’s find something in the room that starts with that letter.”
- • “Pick a letter and let’s write a letter book with it.”
Scaffolding Scribblers
Providing Instructional Feedback

• Student uses their remnant book to pick topic.
  – Topic: Going to the beach
• Student writes freely: aabbcuoiueufdsaitt
• Adult gives instructional feedback
  – “You have written alot of letters! I can use some of
    them to write a word about beach.”
  – “I see a, d.” (point to each letter in writing)
  – “I can use these letters to write the word “sand.”
• There is sand at the beach. I like to walk on the sand.”
• Partner models writing the word with the student’s pencil.
Reasons to Write

- Authentic Reasons to Write Name
- (DPI Summer Institute Teachers, Greensboro, July, 2008)
  - Sign in when arriving at school
  - Artwork
  - Lunch choice sign up sheet
  - Book checkout at library
  - Morning attendance under “here” or “not here”
  - Sign up sheets for centers/games
  - Sign in for therapy sessions
  - Communication log home to parents
  - Cards & invitations
  - From Toy Dills-Booth: IEP, yearbook, awards
kl Dlo. qq
c deenl
BBBBFFFFMYWWQOB

QWERTYUIO

ASDFGHJKL

ZXCVBNM,
Conversation started April 15

Eli Dickenson
Jhhjjjjjj
Oloo

Mary-Louise Bertram
Hi Eli! How are you?

Eli Dickenson
K,

Sent from Midland Junction, Western Australia
Remnant Books

- Conversation Books
- Chat Books
- Social Connection
- Peer Referenced
- 1st Person Language
- Albums, Binders, Paper
- iPad, iPod, Visual Scene Display
- Personally meaningful
  - photos
  - collections
  - real objects (ziploc baggies may be your BFF)
I went to the dentist because I am getting 2 new teeth and they hurt. I love playing with their latex gloves and they always share them with me.
My family went on vacation in Phoenix, Arizona. We had so much fun exploring and swimming.

I chose to watch Monster’s University at the movie theater today. I thought it was funny.
Name Writing

- Name Writing for Authentic Reasons
- Always Model Correct Attempt Afterwards
  - Student makes attempt with alternative pencil. Meryl’s attempt: QBC
  - Adult follows up with:
    - “You wrote QBC. Here’s how I write your name.”
    - Adult uses alternative pencil to write correctly.
  - Providing a model afterwards gives a cognitive structure for later use.
- Focus on teaching students to “think like writers.” (Karen Erickson, 2009)
Developmental Spelling Stages
(Adapted by Erickson, Gentry, 1982)

- Print has meaning NMNEWRPAPDPDMCMCMLF
  - graphic elements can represent ideas
  - scribble, numbers, letter-like strings, letters...

- Random Letters NCXKJLAFDSUIOASJLKDJD
  - Only letters are used but no awareness of alphabetic principle

- Semi-phonemic U R MI FND ?
  - Attempt to represent sounds in words—uses 1 or 2 letters/sounds

- Phonetic I LIK CAK
  - Includes most sounds

- Transitional TURN ON THE LITE.
  - Words look like real words. Errors based on visuals—not sounds.
The Alphabetic Principle

- Emergent readers & writers need to learn the alphabetic principle.
- Letters are linked to specific sounds.
- Words can be segmented into individual sounds.
- Variety of activities lead to these understandings.
- Letter knowledge
- Sound awareness
- Letter names & sounds should be taught in parallel.
- Alphabet is best learned when letters are linked to personally meaningful things, i.e. foods, people.
Teaching the Alphabet:
Make it Meaningful
- Read alphabet books
- Point out letters and print in the environment
- Talk about letters and their sounds when you encounter them in every day activities
- Provide opportunities to play with letter shapes and sounds
- Explicitly reference letter names and sounds in shared reading and writing activities
- Use actions
- Use NAMES!
Children acquire a working knowledge of the alphabetic system not only through reading, but also through writing. (IRA & NAEYC, 1998)
Rys viumwcnqxzmdgafb-
mrrllyyryrowwwwwmmnwwz
why owe le

+ttt+nnn=dayadd
three day

I like the painting.