Communication and Learning Strategies for Individuals with Angelman Syndrome

Linda J. Burkhart and Cori Stell

Closing the Gap Conference, October 2017

Ruby

- Entered public school in a mod-severe SDC placement
- High sensory needs, intense drive to chew and mouth inappropriate items
- Low impulse control, regularly grabs at people and items within reach
- Significant fine motor challenges - unable to properly grasp a pencil, still developing a consistent point
- In PreK, SLP assessment showed she could make choices between 2 to 3 pictures, not ready for a communication device.
- Easily distracted, often unable to attend to teacher-directed tasks
- Epilepsy, reflux

Sarah

- 8 years old
- Attends her neighborhood school in a general education classroom
- Requires assistive technology and other tools/strategies to engage in classroom content and activities
- Multi-modal communicator
- Began using a robust communication system in PreK, uses this to comment, request, direct, ask questions
- Also uses signs, gestures, vocalizations
- Emerging reader and writer
- Has regular play dates with her friends
- Benefits from a sensory diet to support self-regulation
- Engages in personally meaningful activities for 10 minutes or more

Meet Ruby & Sarah
Meet Ruby & Sarah

“Both of those were actually descriptions of my daughter Lily Grace”

“Everything on those 2 slides reflect how others have articulated and interpreted her strengths and challenges”

Medical vs. Social Model

Reframing Angelman Syndrome

Reframing Angelman syndrome: See the Whole Person

• Understand that disability is a natural part of life
• A diagnosis doesn’t tell you who that person is, what they know or can do, or what is possible
• Every person brings a range and depth of experiences, strengths, and challenges
• Have open expectations

Mary-Louise Bertram

www.youtube.com/user/cureangelman/playlists

Linda J. Burkhart & Cori Stell, Communication and Learning Strategies for Individuals with Angelman Syndrome
Presume competence!

*Presume competence means - assume your child is aware and able to understand even though they may not show this to you in a way that you are able to recognize or understand.

*Presume competence means talk to your child or the other person as you would a same age non-Autistic [non-disabled] child or person.

-- Excerpt from Emma's Hope Book, March 7, 2013

Presume competence!

*Read and have available age appropriate stories and give access and instruction to age appropriate learning material.

*Presumptions of competence mean treating the other person with respect and as an equal without pity or infantilizing.

-- Excerpt from Emma's Hope Book, March 7, 2013

Presume competence!

To presume competence is to acknowledge that all individuals have the ability to learn, to communicate, to participate in their own way. It means that we provide opportunities by creating accessible & inclusive spaces.

To presume competence is to respect the value of human diversity.

Not to presume competence is to actively harm.

--Women's Autism Network

Language and AAC are vital
Literacy is possible

Start Now!
Life full of Supports vs. Supports for a Full Life

person centered thinking and planning

Key Challenges for individuals with Angelman Syndrome:

• Complex Communication Needs
• Attention Issues
• Self-regulation, and impulse control
• Sensory processing differences
• Motor processing differences, dyspraxia
• Various other challenges: anxiety, affect regulation, visual differences, medical complications, and sleep disorders

Current Understandings about Children who have Angelman Syndrome

Complex Communication Needs

• Very minimal abilities to use speech for communication
• Communication may be impacted by dyspraxia causing initiations and responses to take quite a bit longer than expected from other individuals
Complex Communication Needs

• Very social and have internal drives to connect with others and to communicate pragmatic intents

• Often have developed their own strategic competencies to communicate

• Attention issues can interfere with message transmission

Communication strategies

• Use of a robust communication system

• Aided-Language stimulation across environments and throughout the day

What is a Robust Communication System?

• Must contain vocabulary to support communicating a full range of communicative functions:
  - complain
  - give an opinion
  - comment
  - protest
  - direct others
  - ask questions
  - Tease
  - request assistance, actions, objects, activities and to go places

What is a Robust Communication System?

• Robust language systems must contain consistent meaningful patterns for organizing vocabulary to represent a full range of pragmatic functions

• Helpful if the system is designed for discourse and ease of modeling
What is a Robust Communication System?

• Core words must be integrated with content, in any robust language system

• Core words by themselves are not enough to represent a full language

• Core words do not allow the child to set topic or talk out of context

AAC system in both 'light tech' and 'high tech' formats

Communication at any time!

Create an Aided-Language Learning Environment

• Model general receptive language

• Variety of genuine messages and functions

• Range of environments and partners

• Talk to the child and others around the child

• At any time

• Genuine interaction

• Immersion
Aided Language Stimulation (Partner Augmented Input)

• Partners need to use the robust system to talk to the individual in everyday natural contexts
• Using the robust language system to talk to the individual teaches the patterns within the system as well as how aided-language works in real contexts
• Receptive use of the AAC system should focus upon context and mapping language on to observed behavior and attention of the individual

Talking to the child and others using his/her language form:

• Validates the child’s means of communication
• Gives the partner a good perspective on communicating using AAC

Children will learn to use their system in the way partners model it

Watch Angelman video # 1 at:
http://lindaburkhart.com/index.php/handout_angelman_17
Then return to this handout
Modeling general receptive input with no expectation that the child will say anything particular at that time.

Model ideas of what to say - kid talk.

This is very different from a Mand Model.

### Modeling by Peers

"The use of AAC by peers to provide augmented input was associated with stronger language growth; the use of prompting and question asking by teachers was associated with weaker language growth."

Barker, Akaba, Brady & Thiemann-Bourque (2013 p334)  
(71 children with developmental disabilities over 2 years)

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Watch Angelman video #2 at:  
http://lindaburkhart.com/index.php/handout_angelman_17  
Then return to this handout.

Watch Angelman video #3 at:  
http://lindaburkhart.com/index.php/handout_angelman_17  
Then return to this handout.
**Use Strategic Feedback Instead of Prompting -**
Say what the child did or is doing

**Focus on Commenting and Making Statements (Reduce Questions)**

**Describe What is Going on Around the Child**

**Recognize Opportunities to Model Language**

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**Respond to Babbling**

“I think **HURRY UP** was one of the first words Lily Grace learned clearly via babbling and then having us respond and map meaning to it. I still remember being in the kitchen with her. She was watching a video while I prepared a meal. She was tapping around on her 12 PODD book and tapped **HURRY UP**. I responded, “Oh, you want me to **HURRY UP**? Well I better go faster!” And then I dramatically rushed around the kitchen. Lily Grace’s face lit up and she tapped **HURRY UP** again, thrilled with the result.”

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**Expand and Recast what the Child Says**

**Focus on Relationship**

**Enjoy!**

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**The Goal is Develop Autonomous Communication**

Being able to say **what** I want to say, to **whoever** I want to say it to, **whenever** I want to say **however** I want to say it

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Linda J. Burkhart and Cori Stell, Communication and Learning Strategies for Individuals with Angelman Syndrome
Autonomous Communication Enables Meaningful Participation

“Abby recently started going to preschool 2 mornings a week in September. It was the first time she'd been left with anyone other than a grandparent and she was not happy about it. She cried for the first couple of weeks and her teacher told me that she used her talker several times to say, "I don't like this - scary". We had modeled the "I don't like this" branch frequently but it was the first time Abby used it.”

It's never too late!

• When it comes to AAC and literacy, start now!

• It's never too early.

• It’s never too late.
JASMINE

* Jasmine is 14 years old. Her mom introduced her to a robust AAC system (PODD) when she was 10.

* Before AAC: she seemed depressed, would stay in her room at home, was spitting non-stop at school.

* Today: she’s super social, follows her mom around all day, chatting, and demanding her mom listen! Following the intro of PODD, the school team had wonderful things to say about her engagement and the drop in challenging behaviors.

* According to Mom: Jas loves when she meets people who speak PODD. Her face truly lights up.

This year she transitioned to High School, and we are all amazed at how well she is doing. Having AAC in place has made the biggest most positive and powerful impact for us all.

In the classroom (includes peer support and engagement)

* Intro to and availability of AAC:
  - Class talked about ways everyone communicates
  - Read stories/books about AAC
  - Played games using AAC, e.g., “I spy”
  - Have extra PODD books and talker in classroom

JESS

* Evaluated for high tech AAC at age 20, dismissed because they felt she didn’t have the fine motor skills or sufficient comprehension

* Jess’ mom shared: “Typical children are raised with “presumed competence.” Our kids are no different. Culture automatically dismisses the non-verbal as less and stops teaching.”

* Parents introduced SFY, her robust AAC system, when she was 21

* Of the 4,000 words available on SFY, her first word was "exceptional"

Check out You Don’t Say blog: www.youdontsayaac.com

In the classroom (includes peer support and engagement)

* Communication Circles
  - Small group with AAC user and their peers
  - Engaging activities to talk about using AAC, e.g., cooking, science, topics of interest
  - Predictable chart writing
In the classroom (includes peer support and engagement)

- Descriptive teaching

What is co-planning and why should we try it?

- Co-planning is a way to help our students or loved ones share their stories.
- It doesn’t take a big investment or learning curve to do it.
- You can co-plan with your child whether or not they have a robust AAC system in place.
- For kids that use robust AAC systems, they’re still likely to have much more they’d like to share than their current vocabulary or operational skills will allow them.

Co-Planning: Supporting our kids to share their stories

You can co-plan all sorts of things

Light-tech examples

"About Me" school worksheet
You can co-plan all sorts of things

High-tech examples

"My Stories" page in AAC system (Compass w/PODD)

Social Script in GoTalk Now

Going to Sesame Place

Co-Planning a page in Lily Grace’s remnant book

Where do we start? Set context and expectations

- Before we start co-planning anything, we talk about WHAT we’re going to do and WHY.
- We also talk about WHEN we’ll do it. Are we hoping to do something this morning, over the course of a weekend, over a longer period?
- We review a visual support for co-planning to help set an expectation about HOW we’re going to do it.

Watch Angelman video # 4 at: http://lindaburkhart.com/index.php/handout_angelman_17
Then return to this handout
Co-planning in Four Steps!

1. Talk
   - We talked a lot about our trip to Disney.
   - We used AAC as we talked, including special Disney displays that we used during our trip.
   - We looked at photos and watched videos from the trip.
   - We noted what Lily Grace seemed most excited about by writing it on a white board.
   - We reminded Lily Grace that we’d come back later to choose what she wanted to put in her remnant book.

Talk about it

2. Choose something to share

Choose something to share

We took a break so Lily Grace had time to process!
3. Put in Remnant Book

- Then I used the choices Lily Grace made to make a page for the remnant book.
- I added simple, objective explanatory language.
- After I set the page up for her, I made sure to show Lily Grace and talk about it some more.

4. Share!

- We give lots of opportunities to share!
- At school to share with her friends.
- Remnant book is a source of personally-meaningful writing topics.
- She can use it to initiate a conversation.

Please, please keep in mind...

- Don't worry whether your child is understanding the steps at first. We don't expect them to!
- Just roll with it. It comes together in time.
- You are co-constructing this with your child. You may want or need to fill in gaps to help complete the process. That's totally okay!
- Allow lots of processing time!
- Just try it! It will be messy and imperfect. Have fun!

Attention Issues in children with Angelman Syndrome

- Fleeting glances instead of sustained visual interest
- Difficulty filtering out irrelevant input
- No natural filter for what is important to attend to
Attention Issues in children with Angelman Syndrome

- Dyspraxia and Apraxia impact child’s ability to attend on demand
- Difficulty controlling impulses
- Increased need for repetition for memory and retrieval

Strategies to Encourage Attention

- Encourage attention, but don’t demand it
- Bring materials closer - in the child’s view
- Flashlight - highlight what you model
- Pull-off symbols (not as effective with Angelman Syndrome)

Keep modeling - even if child does not appear to be attending

“Our dear friend Milo (also using PODD) went through quite a phase of saying IT’S NOT FAIR. It’s not something we (the parents) really modeled for Lily Grace, but apparently there was some peer modeling happening unbeknownst to us! After being on a play date with Milo, later that weekend, in response to not being allowed to do something she wanted, Lily Grace said MORE TO SAY/SOMETHING’S WRONG/(TURN THE PAGE)/ IT’S NOT FAIR. I don’t think any of us were aware that Lily Grace was paying such close to attention to what Milo had been saying with PODD, but clearly she was!”
Sirlei’s communication circle we were writing a book called I Can. We talked about all the movement things we can do with our bodies then students would use their talkers to write the sentence and finish it with a movement word, for example “I can jump.” They would stand up say their sentence with the talker and then I would take a picture of them doing the movement…. This is the first time Sirlei has independently constructed her own sentence for one of our books we make in class! She was bouncing back and forth between me, her desk, her chair, and her aide the whole time so we were curious if she was engaged or not but she came up to the front by me pushed her talker and said “Me throw ball”.

Strategies to Encourage Attention

• Adapted materials that are durable and can be manipulated

Video modeling with pragmatic context
Steps in a writing task

Visual supports for task steps and sequences

1. choose
2. talk
3. write
4. show/share
5. finished

Making things personally meaningful

* Increase the likelihood for making neurological connections to current knowledge
  * Adapted books (Pictello, GTN, homemade)
  * Remnant books

Sound, Rhythm and Rhyme

* Use of video
* Music
* Voice amplification
* Rhyming and alliteration
* etc.

Watch Angelman video # 4 at: http://lindaburkhart.com/index.php/handout_angelman_17
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Classroom Strategies

- Books added to classroom library
- Videos searched for with peers and shared with class
- iPad framing

Sensory processing, self-regulation, and impulse control

- Many have differences in how they process the world
- Frequently have challenges with knowing where their body is in space (reduced proprioceptive feedback)
- Sensory seeking
- Need to Move
- Need to touch and to explore the world

Sensory processing, self-regulation, and impulse control

- Some have auditory processing challenges and need visual supports to augment understanding of speech
- Some have difficulty looking and listening at the same time
- Some have difficulty looking and touching at the same time

Self-regulation, not compliance

- We need our children to learn how to regulate themselves
- They also need to learn that they have the right to say "no" AND have it respected
- People with disabilities - especially women with disabilities - are at very high risk for abuse
- We need to support people with disabilities to know they have a right to self-determination
Strategies for sensory processing differences

• Sensory diet available to be used on an as needed basis developed with occupational therapist

Based on “Spectrum of Maggie” by Erin Sheldon

Strategies for sensory processing differences

• Self-regulation strategies
• Self-talk
• Reminders

Based on “Spectrum of Maggie” by Erin Sheldon
Strategies for sensory processing differences

• Communication strategies for meeting sensory needs

Strategies for sensory processing differences

• Opportunities to move around as needed
• Self-directed selection and viewing of video modeling with pragmatic context
• In the classroom (quiet corner, sensory toolbox available to all students, reminders at every table)

Strategies for sensory processing differences

Quiet corner & sensory toolbox in every classroom

• Motor Processing Differences

Sensory area in resource room

• Dyspraxia and Apraxia
• Motor planning challenges
• Limited feedback (as discussed in sensory processing challenges)
• Fine motor control (range)
Strategies for Motor Processing Differences

* Extra processing time (could be over a class period, a day, a week, or longer)
* Reduce pressure of demands
* Distance to move to target to increase time from intent to action
* Reduce quantity

Strategies for Motor Processing Differences

* Utilize internal motivation
* Eliminate or limit hand over hand assistance
* Occupational therapy for developing and refining motor skills (pointing, gestures, etc.)

Strategies for Motor Processing Differences

* Have concrete product to share for individual’s work
* In the classroom (shared writing with AAC, with alt pencils; access to AT tools)

Strategies for Motor Processing Differences

Writing without standards

“Stealing letters” to build off what Lily Grace wrote

Alterative pencil: Abilipad
Dictating with AAC

Other possible challenges in children with Angelman Syndrome

• Anxiety (Need to trust communication partners and understand what is happening)

• Affect regulation (need to learn words to express mood)

Other possible challenges in children with Angelman Syndrome

• Some have a range of Cortical Visual Impairment (CVI)
  • More difficulty in handling the visual complexity of the display
  • Space between symbols reduces complexity
  • Allow for visual latency

Other possible challenges in children with Angelman Syndrome

• Higher contrast symbols with solid shapes may be easier to see with a quick glance

• Possibly getting some information peripherally—so may benefit from high contrast
Other possible challenges in children with Angelman Syndrome

- Medical complications and seizures
- Sleep issues
- Sometimes dual diagnosis / autism

Assessment

- Dynamic Assessment Process
  - Ongoing part of teaching
  - Observation, intervention, observation...

- Portfolio Assessment: collecting data over time

Collecting Data: Language Sampling

Collecting Data: One-Minute Writing Checklist

Linda J. Burkhart and Cori Stell, Communication and Learning Strategies for Individuals with Angelman Syndrome
Inclusion strategies to help others get started

• Sharing Beliefs
  • As outlined in this presentation
  • People typically interpret and act based upon their core beliefs
  • Flip the script:
    • Life full of supports vs. supports for a full life
    • person centered thinking

Provide instruction in a way that enables every student to participate

• Every instruction needs to give all students a clear way that they can follow it and meet expectations.

• For a student with CCN, this lets them and their classmates know that everyone is expected to participate.

• If an instruction is given with no way for Lily Grace to follow it, we aren't including her in that opportunity.

Peer Support and Problem Solving

“In library, the students sit on the carpet and listen to a story. Sophie sits in her chair. The teachers asked me if she could get out of her chair and sit down on the floor in a bean bag or cube chair. I said, “sure”. That afternoon she was “laughing” but her aide said it wasn't happy, it was anxious. She then used her talker to say, “out of chair” several times. The students later told her case worker that she wants to sit on the floor. The case worker said they were working on it. So the students have decided some of them will sit on chairs near Sophie until then so she doesn't feel alone.”
Model, Model, Model

* Vital that all students see these tools and strategies being made available to and used by others, both adults and peers

* Provides models to learn from AND validates tools and strategies primarily introduced for the student with complex support needs.

Provide informative feedback

* Whether we're talking about literacy, communication, or self-regulation, students needs to hear what meaning others are attributing to their actions and their work.

* Every time we reflect what we’re seeing and what meaning we might attribute to that, it builds their understanding of their own power to impact the world around them.

Team Planning Tools

Plan for Modeling Targets for Lily Bruce

Use this calendar as a guide to plan your modeling targets. Every 2-3 weeks, the team will select target letters, branch starters, core words, and key concepts from curriculum content areas. Keep these targets in mind, as you are modeling with Lily Bruce and presenting choices of writing topics, sentence starters, and activities. The more cohesive we are in our modeling, the less work Lily Bruce will have to do to learn from us.

<table>
<thead>
<tr>
<th>Week of</th>
<th>Target Letters: For use across activities (letter-name, letter-sound, alphabet song, alphabet book read aloud)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9/12/19</td>
<td>L and G</td>
</tr>
<tr>
<td>9/19/19</td>
<td>I like this (4s)</td>
</tr>
<tr>
<td>9/26/19</td>
<td>I want (S)</td>
</tr>
<tr>
<td>10/3/19</td>
<td>I want!</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Week of</th>
<th>Target Branch Starters: For planning feedback on follow-up from Communication Circle, etc.</th>
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<tbody>
<tr>
<td>9/12/19</td>
<td></td>
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<td>10/3/19</td>
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<table>
<thead>
<tr>
<th>Week of</th>
<th>Sentence Starters of the Week: For use in close reading and predictable short writing</th>
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<tbody>
<tr>
<td>9/12/19</td>
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<td>9/19/19</td>
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<tr>
<th>Week of</th>
<th>Curriculum Concept Topics: What is the class studying for science, social studies, etc.</th>
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<tbody>
<tr>
<td>9/12/19</td>
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<th>Week of</th>
<th>Vocabulary</th>
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<td>L and G</td>
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</table>

What’s our job?

"The role of the teacher, therapist, or aide is to facilitate independence, active engagement, and support for problem solving, NOT to ‘get it right.’"

- Linda Burkhart, Mary-Louise Bertram, and Dale Gardner-Fox, CTG 2014
Cori’s Big Take-Aways So Far...

* The ways Lily Grace learns aren’t as different as I was led to believe.

* Her success has everything to do with what we believe is possible and how we support her autonomy and self-determination.

* Communication, literacy, and inclusion are possible. A full life is possible.

* We had to learn the keys to supporting Lily Grace – and problem-solving access – and integrate them into everything we do.

Know that for families...

* The road is hard.

* It’s a messy path.

* We want you as partners.

* We make mistakes ALL THE TIME – and you’re allowed to make mistakes, too!

* We need you to truly see our child.

It’s so worth it!

A full life...

Lily Grace is an AAC User!

We know our daughter so much better than we ever did before.

She has a lot to say!
She has a lot to say!
Here's what Lily Grace had to say to me when it was time for me to give her medicine.

Taking Grandma to the airport to fly back home...
“fun please”

Visiting the Komodo Dragon at the Toronto Zoo...
“look komodo ask let’s pretend hug”

After boarding the Magical Express to Disney World...
“I think I think favorite”
When she’s just hanging out with friends and family...

“I think awesome”

“look fun”

A full life...

Lily Grace attends her neighborhood school in a general education classroom.

Lily Grace’s classmates’ contributions to her one-page profile.

A full life...

• Gorgeous friendships

• Gorgeous friendships with other AAC users
A full life...

Lily Grace is making really exciting progress with literacy.

Dictated with AAC

Youtube search for Sesame Street videos

"sesate"

Remember...

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Thank you!

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