

Development of Emotional Competencies in Children with Complex Communication Needs: Implications for Practice and Research

Sarah Blackstone¹, Krista Wilkinson², Jen Thistle²
with Gabriela Rangel³, Dale Epstein⁴, & Jacob Feldman²

¹ Augmentative Communication, Inc

² The Pennsylvania State University

³ Centro de Apoyo Tecnológico para la Comunicación y el Aprendizaje

⁴ University of North Carolina – Chapel Hill

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Why should we care about fostering and supporting emotional competence in users of AAC?

- AAC professionals/families are members of teams providing a range of services to children with CCN
- A “participation model” of services emphasizes that:
At the core of understanding a person’s functioning is an understanding of that person’s ability to participate in essential and desired activities/routines within his or her natural environments...” (Wilcox & Woods, 2011, p. 365)
- Emotional competence and language/communication are intricately linked aspects of human development that contribute to this goal
- Fostering emotional competence therefore enhances participation outcomes.

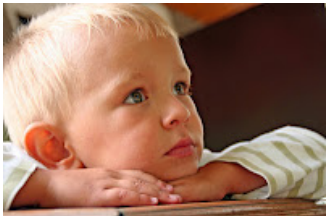
Who would benefit from an enhanced focus on fostering emotional competence and participation?

- The development of emotional competencies has a developmental trajectory that begins at birth and continues throughout life
- Individuals of any age would therefore benefit from analysis of emotional competencies and the supports that promote them
- Our focus today will be children with CCN between the ages of 0-10 years, in order to begin the conversation
- However, children grow up and the issues facing adolescents, young adults, and older adults warrant future attention

What are the general outcomes that emotional competence can help support?

Emotional Competence – the ability to identify and respond to one's emotions, is critical for....

Basic readiness for learning (aka homeostasis): over- or under-arousal of any sort is a state that is not conducive for learning to occur



Development of social relationships with single individuals (friendships) as well as with groups (peer group membership)



Acquisition of skills needed for self-regulation and context-appropriate behaviors



Self-determination and self-advocacy to enhance independence during transitions to adulthood/maturity



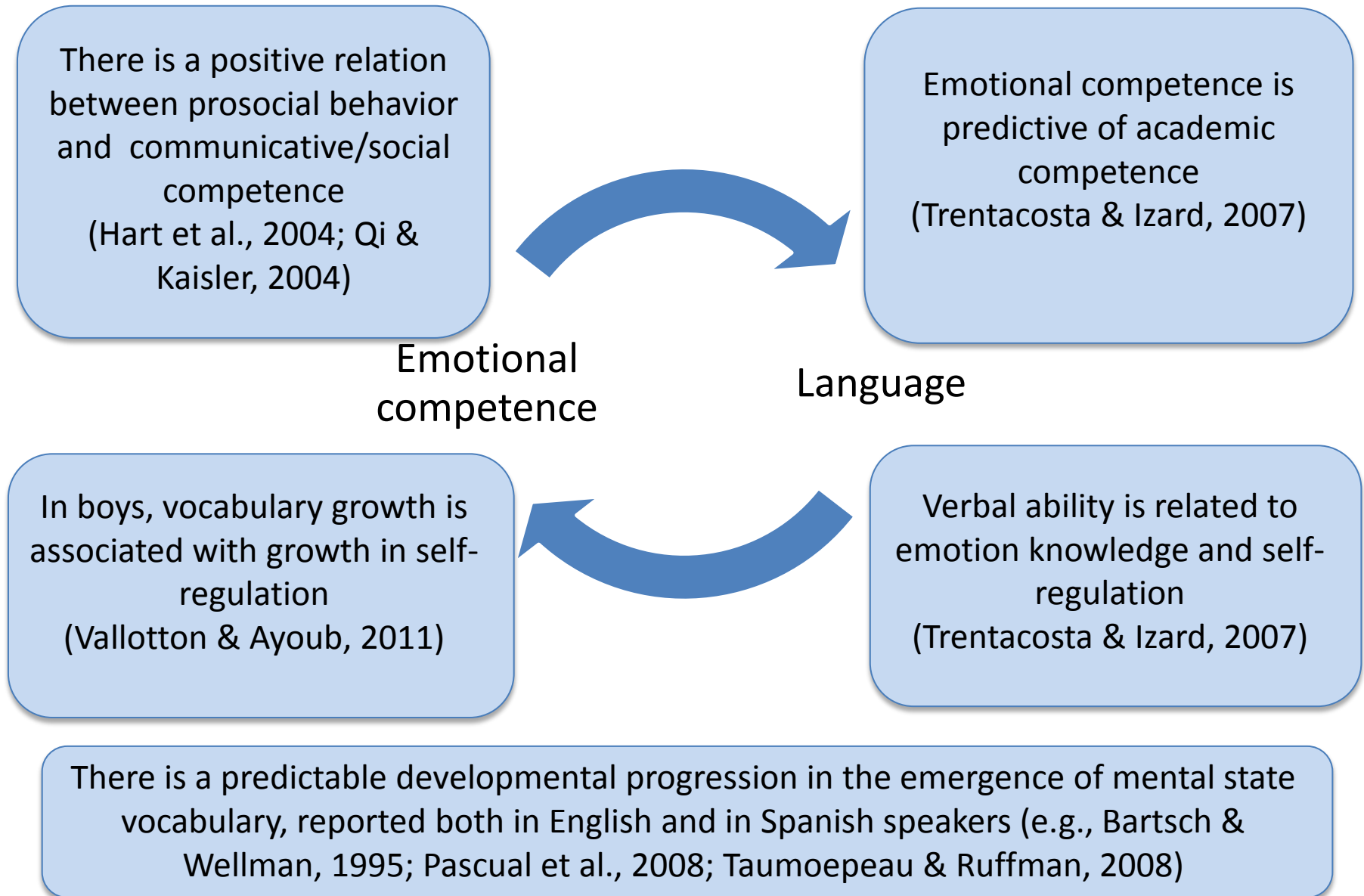
Self-Advocacy

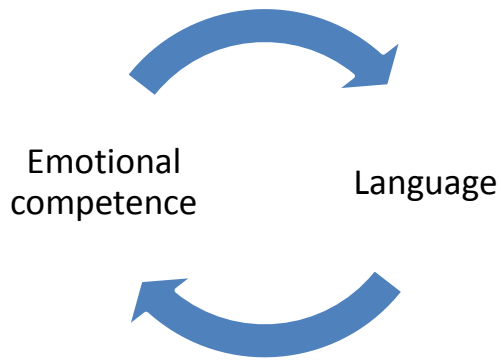
The History of People with Disabilities Deciding for Themselves



http://www.museumofdisability.org/advocacy_self_1800s.asp

In typical development, language learning and emotional growth are bi-directional...





One particularly salient relation between emotion and language is in the form of “private speech” or self-talk....

- Winsler et al, 2003, reported that compared to children who rely on audible private speech, children whose private speech is covert/internalized (inaudible)
 - Show fewer problems of self-regulation and behavioural control
 - Are rated as more social
 - Are viewed by parents as having better social skills
- However, private speech is frequently observed during challenging tasks at every age, and may help delay extreme emotional responses (Cole, Armstrong & Pemberton, 2010)

What about children with disabilities?

- Very little work has been done
- Virtually all of the work that has been done has been with children using spoken modes of communication
- We do know a little about specific language impairment:
 - Children with SLI also have difficulty labeling and responding to others' emotions (Brinton et al., 2007)
 - Children with SLI, especially boys, are rated by teachers as lower on some – BUT NOT ALL – aspects of emotion regulation using a standardized instrument (Brinton et al., 2002)
 - The combination of emotion challenges together with language difficulty explained almost half of the variance in social reticence measures (Fujiki et al., 2004)

What about children with disabilities?

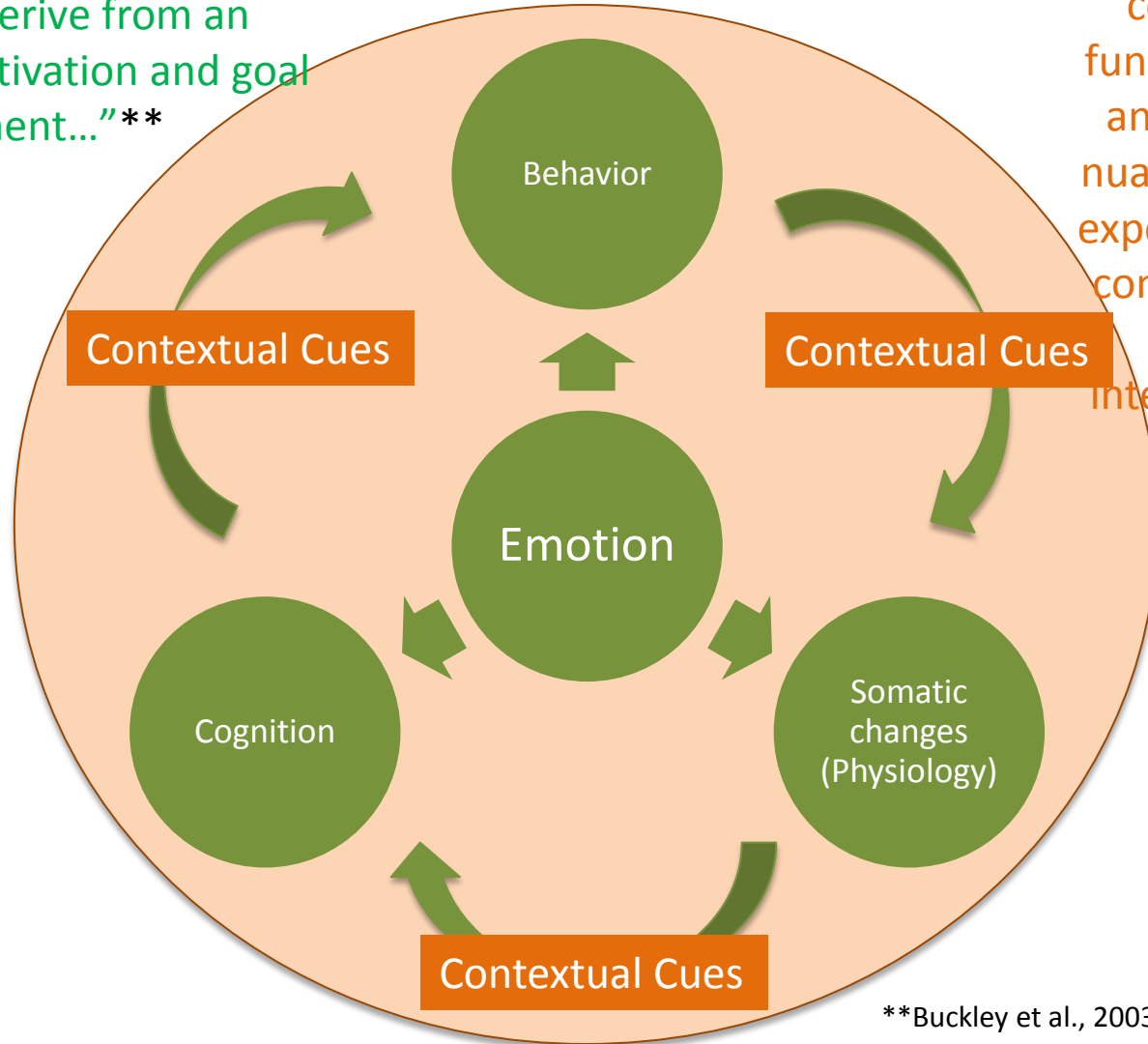
- This topic has also been addressed in the SCERTS model for enhancing socio-emotional abilities in children with autism spectrum disorders (ASD)
 - SC = social competence;
 - ER = emotion regulation;
 - TS = transactional support
- Children with ASD show difficulties with arousal and, consequently, emotion regulation (e.g., Prizant et al., 2003)
- The SCERTS model has a growing evidence base for its effectiveness (Prizant et al., 2010), further supporting the critical relationship between communicative competence and emotional competence

What drives development of emotional competence?

Two complementary theories....

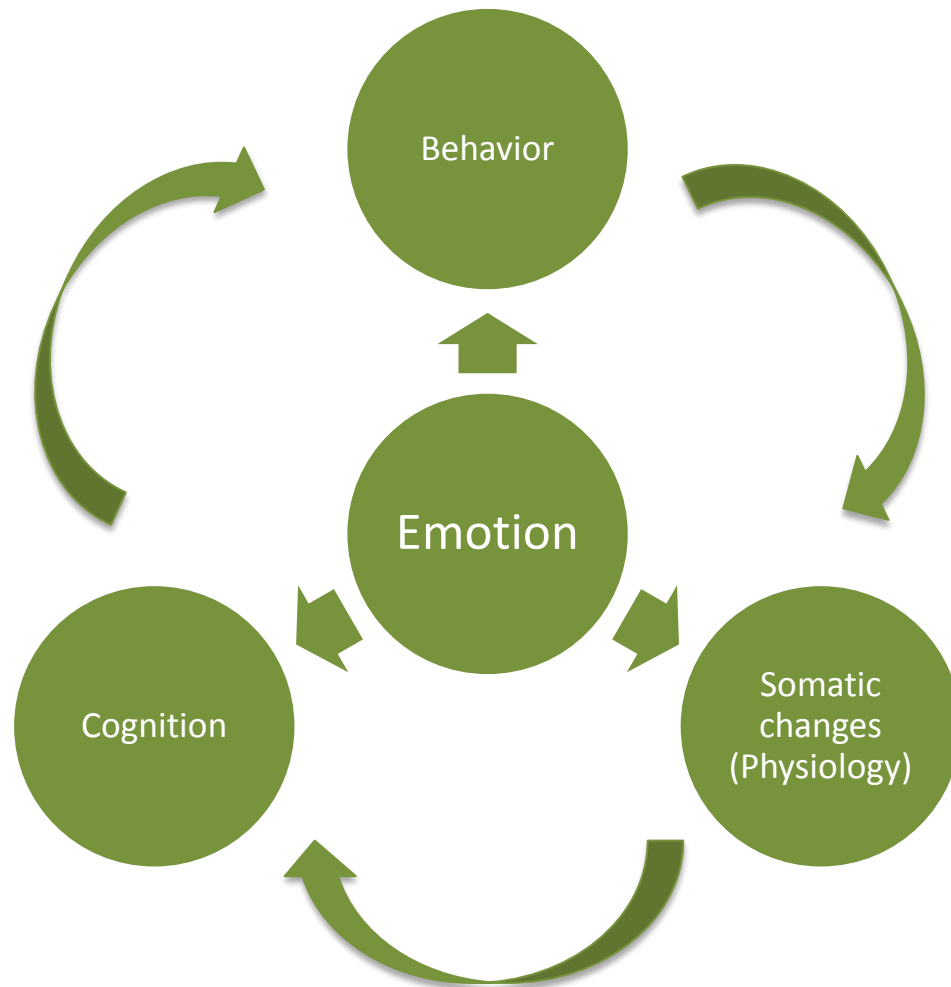
Functionalist model (Campos et al): “maintains that emotional responses derive from an individual’s motivation and goal attainment...”**

Social constructivist (Saarni et al.)
“complements the functionalist position and maintains that nuances in emotional experience are due to contextual cues that influence our interpretation of the situation...”



**Buckley et al., 2003

First, let's consider the contributions of the functionalist approach...



“Any eliciting event can produce a multiplicity of emotions...

“As Sroufe (1996) noted, it is the meaning of the event, and not its physical composition, that determines the emotion...” p.378

Event = encountering a spider



I just stepped on it by mistake....

remorse



Hahaha..hahaha...
I'm on this side of
the window and
you're not.....

gloating



It's dangling from
the ceiling above
my bed...!!!!

fear



Eeeew, I just
found it on my
dinner plate....

disgust



Yeah, yeah, yeah...
I can tell that's
plastic....

boredom

the nature of the significance determines the **QUALITY** of the emotion.

Is the event...

- irrelevant?
- positive?
- stressful?

Emotion = the process of registering the significance of a physical or mental event, **as the individual construes the significance**

The degree of the perceived significance determines the **MAGNITUDE** of the emotional response, as well as its urgency



fear

Calvin considers spiders to be scary – and this is a particularly big one

Significant event, perceived as stressful, resulting in a large magnitude of negative emotion



boredom

But when Calvin realizes the spider is plastic, the emotion generated changes as does its behavioral manifestation. The nature of the event is reclassified from “stressful” to “irrelevant,” and the magnitude decreases...

Responses can be at the “secondary” level as well. The secondary level allows the child to have control over the response and a choice among the possible alternatives.

Secondary responses:

- How can I face it?
- What can I do?
- Will I be efficient?

The secondary responses may be very different...

.... Or they may be the same:

I will run away

I will touch it

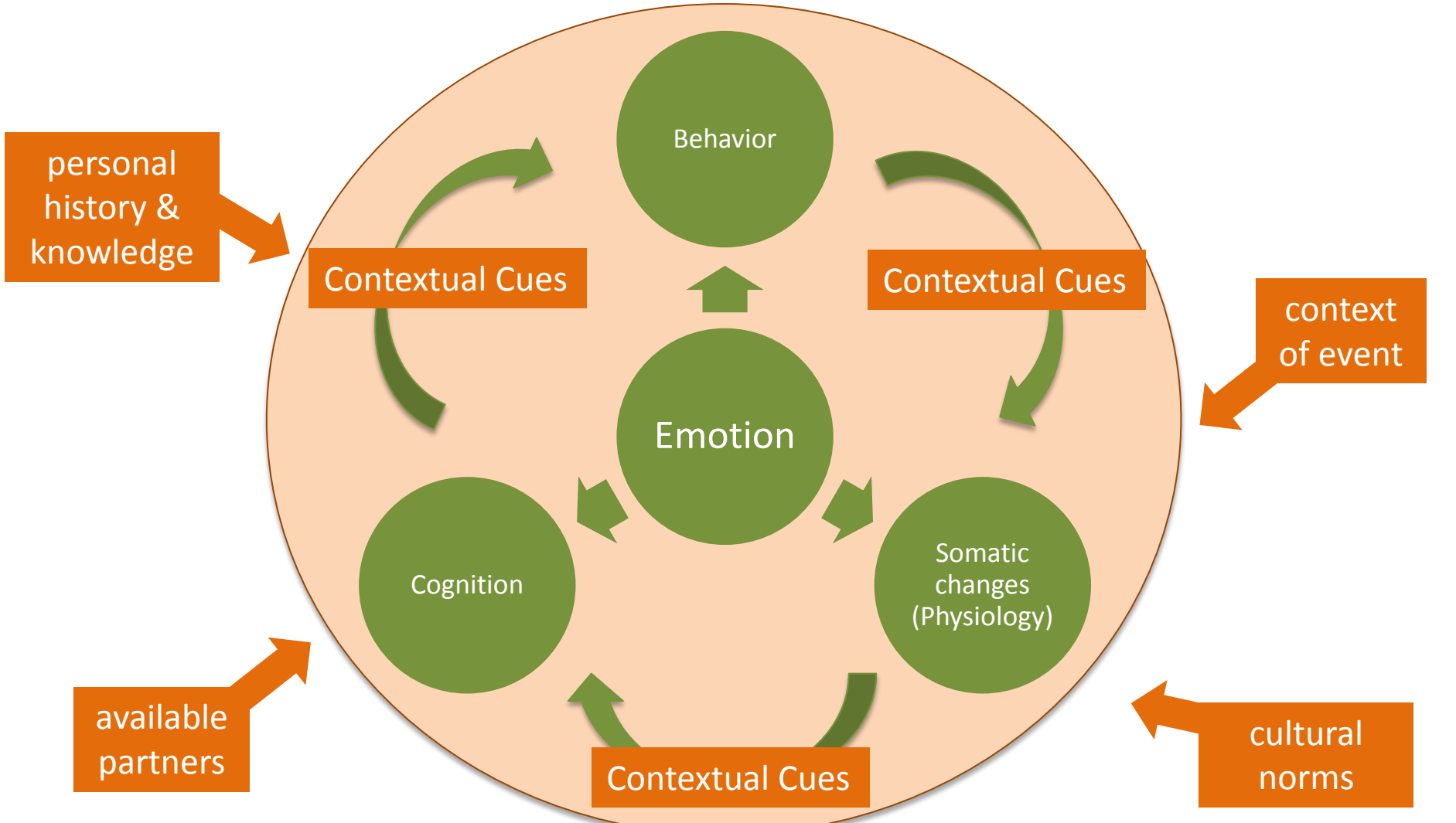
I will step on it....



fear

boredom

Now, let's consider the contributions of the complementary social constructivist approach...



Take-away messages from social-constructivist model:

- Competence emerges within a **social and cultural framework** of experiences
- How individuals deal with emotion varies widely (social, cultural, familial, experience, factors).
- The degree to which someone can access language/communication tools and use them effectively to interact and “self-regulate” will affect their development of emotional competence.

Development of emotional competence is an integrated process that has three characteristics:

Characteristic #1: It has a **developmental sequence**

Characteristic #2: Within this developmental sequence, **specific skills/elements** are acquired by the child

Characteristic #3: Acquisition of these skills and resulting emotional competence are strongly influenced by partner scaffolding, that is, emotional competence is a **caregiver supported process** that does not develop/mature without that input.

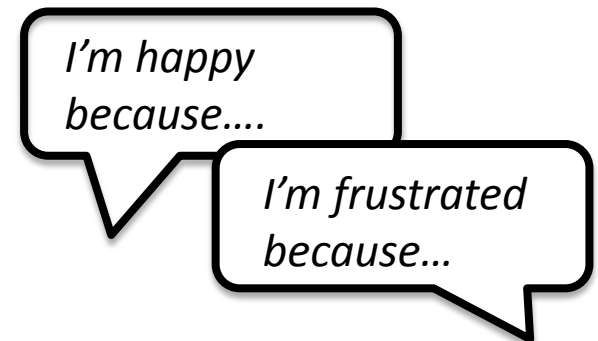
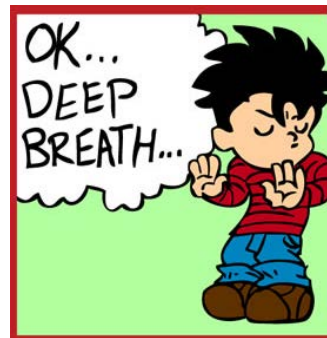
Characteristic #1: The developmental sequence



1. Emotions occur without awareness, and are expressed without language

2. Behaviors are interpreted by caregivers as emotional expressions

3. Behaviors are gradually mediated by social, cultural, and linguistic norms



6. Emotional competence ultimately requires a "theory of mind"

5. Emotional competence involves communication with self ("private speech")

4. Increasingly, emotional competence requires use of language

Characteristic #2: Elements/skills develop to support it (Western framework; Saarni et al 1999)

Step 1. Awareness of one's own emotions

Step 2. Ability to discern/understand the emotions of others

Step 3. Ability to use the vocabulary of emotion and expression

Step 4. Capacity for empathic involvement

Step 5. Ability to differentiate internal subjective emotional experience from external emotional expression

Step 6. Capacity for adaptive coping with aversive emotions and distressing circumstances

Step 7. Awareness of emotional communication within relationships

Step 8. Emotional self-efficacy in accord with one's moral sense

Characteristic #3: The role of the caregiver

In both functionalist and social constructivist theory, caregivers provide the structure to help children learn how to respond to events, and, importantly, to help modify the process of experiencing the emotion and responding behaviorally in a socially/culturally acceptable way



By 1 year of age it has transitioned into verbal scaffolds provided by a parent.... “You’re feeling upset.. Sit down and take some deep breaths...” Another good example: “Use your words...” – Saarni steps 2-3



As the child experiences these scaffolded opportunities, s/he begins to internalize the concepts and vocabulary, and can begin to apply them herself and others - Saarni steps 3-6

Advanced language provides meta-linguistic skills for self-reflection and self-efficacy - Saarni steps 3-6



At first, this scaffolding is nonverbal – soothing, patting, singing – Saarni step 1

What does all of this matter for users of AAC?

If we can provide users of AAC with the tools to learn about and regulate their emotions, we open up all of the positive opportunities resulting from emotional competences

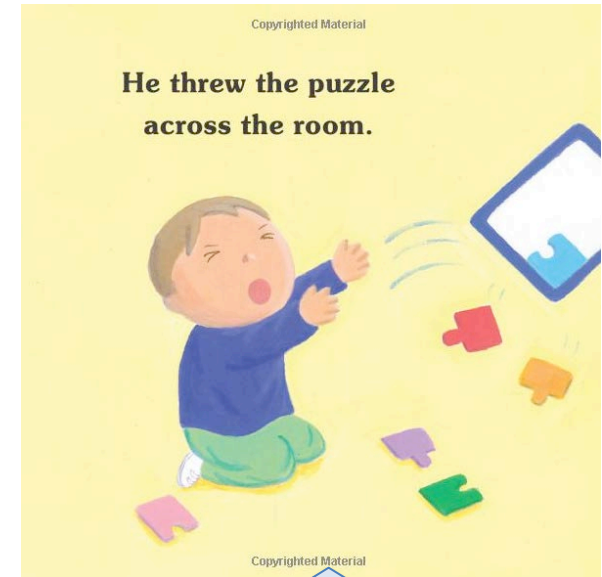
BUT...

When we fail to attend to emotion development in people with CCN, we fail also to provide them the means to access the many positive benefits associated with emotional competence that we have just outlined

What are the challenges in developing emotional competence in folks with CCN?

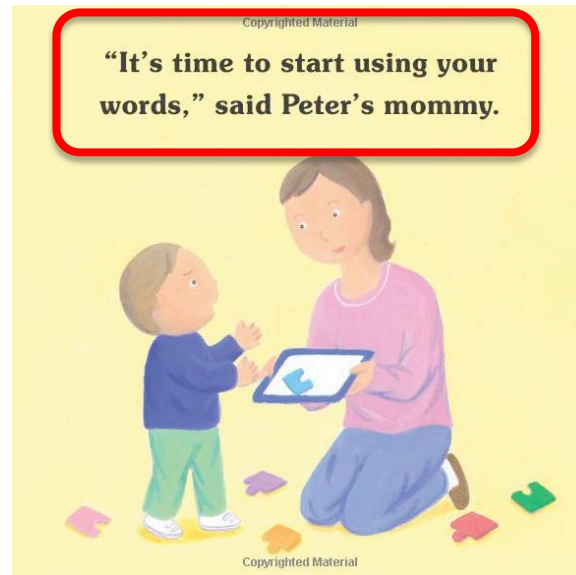
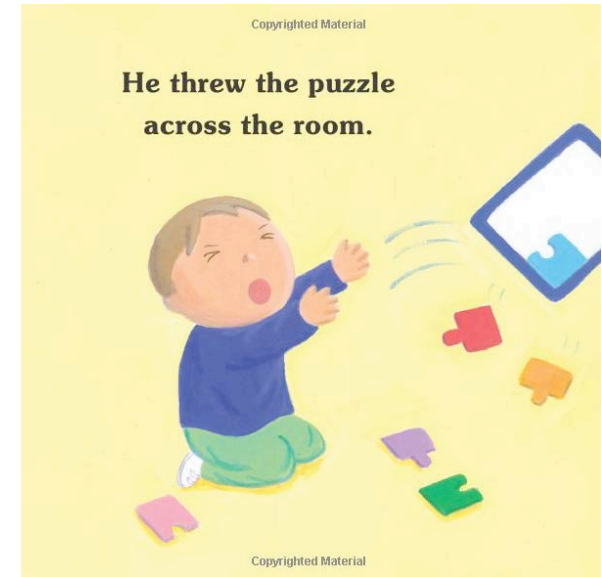
- Challenges facing the child
 - Difficulty communicating using language
 - Difficulty expressing emotions because of physical/motor/cognitive challenges
 - Difficulty interacting...with people and the environment
- Challenges introduced by/in the environment
 - Partners misinterpret gestures, facial expression
 - Partners ignore or overlook expressions of emotion
 - Partners not aware of the need to address emotional development
 - Focus is on physical care, equipment issues, social roles
 - Myths about AAC and users of AAC
 - Technology limitations (how does one “shout”?)

An example of how the integrated process of emotional competence relates to users of aided AAC



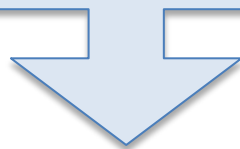
This is commonly referred to in our field as “challenging” behavior

Our responses are typically to punish or to replace the behavior, rather than to use it as an opportunity to develop independent emotional competence



Remember -- By 1 year of age it has transitioned into verbal scaffolds provided by a parent.... "You're feeling upset.. Sit down and take some deep breaths..." Another good example: "Use your words..." – (Saarni steps 2-3)

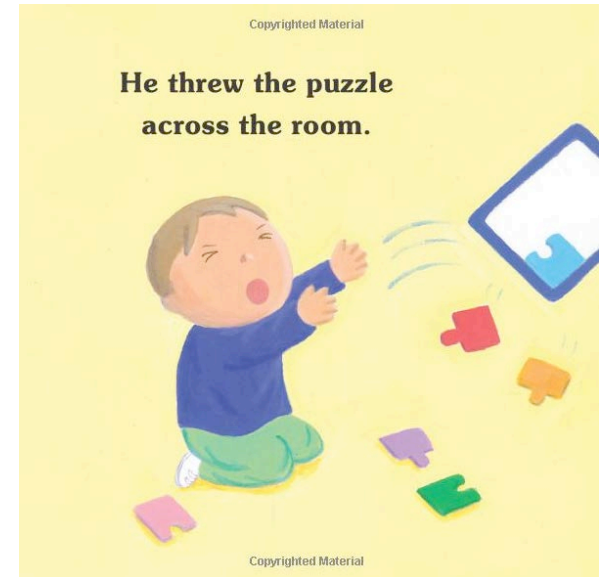
We often see caregivers using **oral** speech to offer these strategies – but how many boards that you are aware of have the means for the partner to model this phrase **USING AN AIDED symbol?**



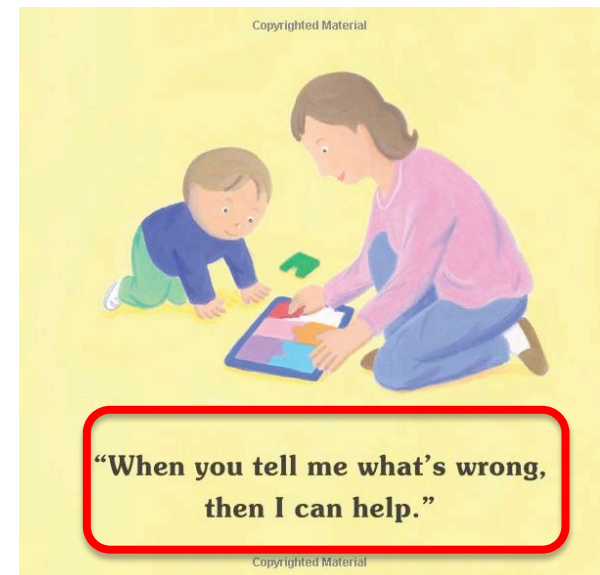
But without the aided symbol, the input will necessarily be oral only. If the child has difficulty understanding oral speech, then the input will be limited in its effectiveness because of the modality



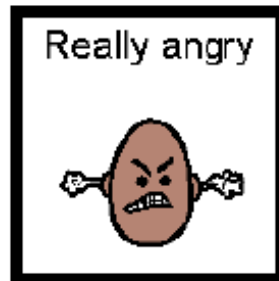
Furthermore, without the aided symbol the child has no means of using his AAC system to engage in private speech – again, we are leaving the process of private speech up to the oral mode, which is likely not to be optimal for the child



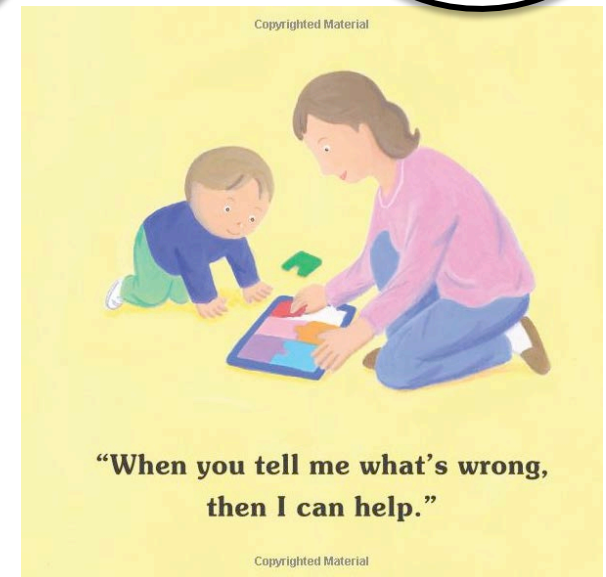
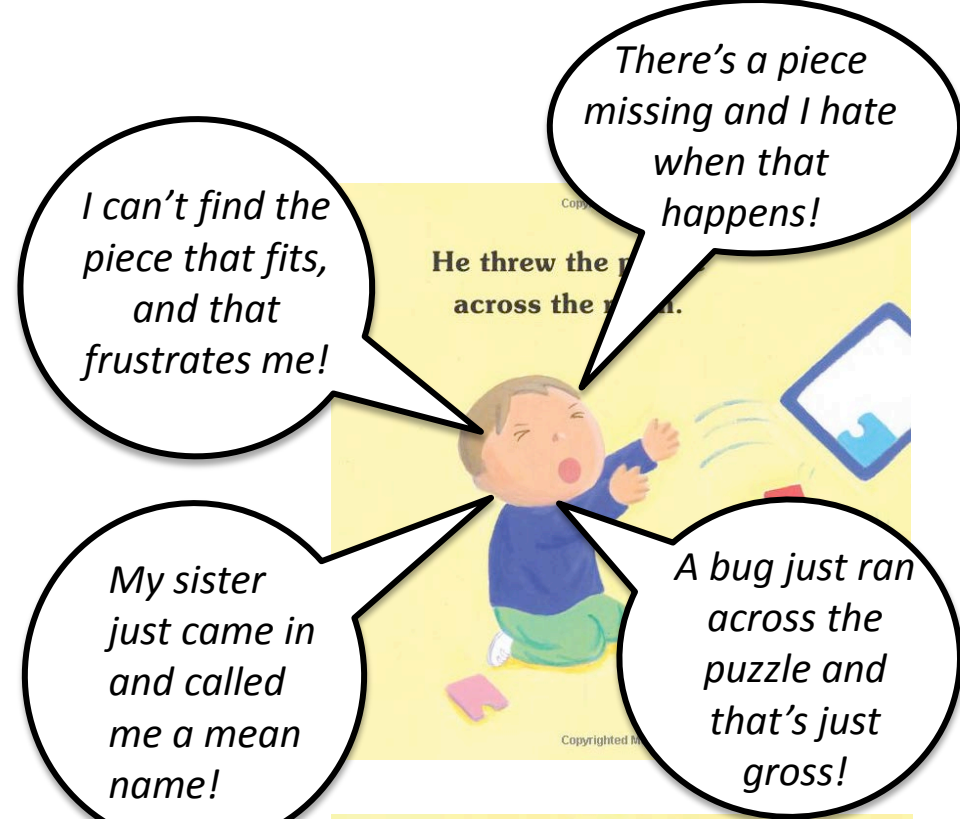
Remember: As the child experiences these scaffolded opportunities, s/he begins to internalize the concepts and vocabulary, and can begin to apply them herself and others (Saarni steps 3-6)



If the only thing a child using AAC has access to is a board that contains labels for emotions, the only thing he will be able to communicate is the label for his emotion (“really angry”) – which in this case, is already fairly obvious



Furthermore, the board contains no way to talk about the possible “secondary response” alternatives to the throwing which is the current response to the emotion

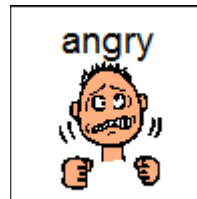


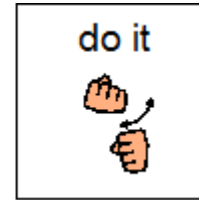
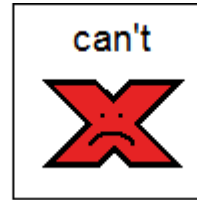
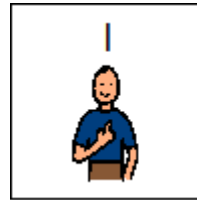
So, what are the key elements of AAC to support emotional competence?

- Symbols representing a **variety of emotions** should be available on the board (which many of us already do), but the symbol could also have a **navigation function** that leads to the next two elements →
 - Inclusion of **“because” statements** – this allows for the “tell me what’s wrong” OR “tell me what’s right” to be added to the basic emotion label
 - Symbols that represent **strategies for responding** to emotions (take a deep breath) should be added AND USED BY THE PARTNERS – this allows for input but also the ability of the child to begin to manage his/her own emotions

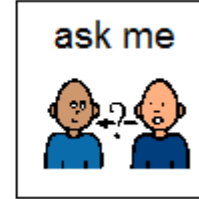
For Instance:

- Symbol for an emotion leads to a pop up that allows for identification of the eliciting emotion and talking about secondary responses

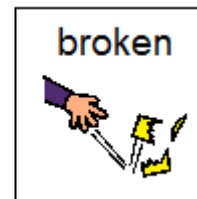
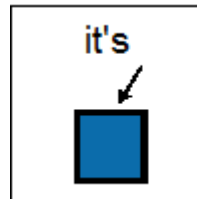




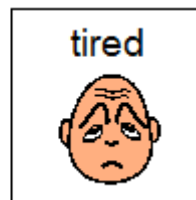
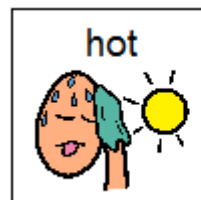
Frustration over
difficult task



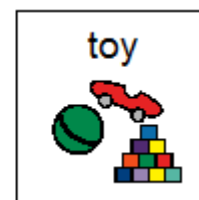
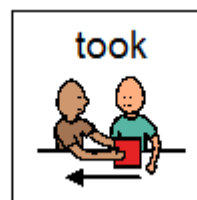
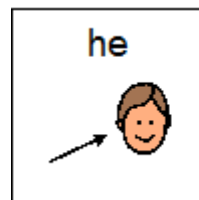
Feeling **ignored**, left
out



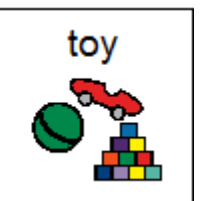
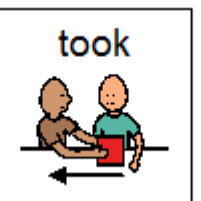
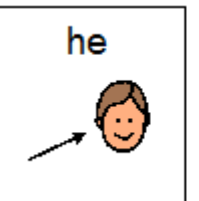
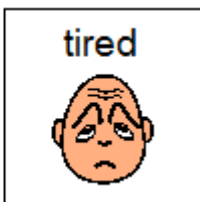
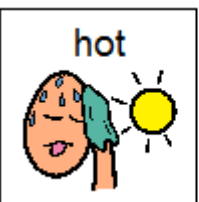
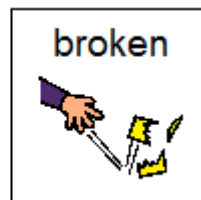
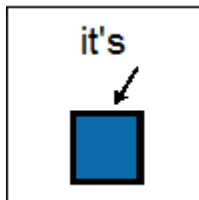
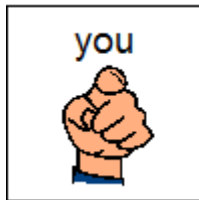
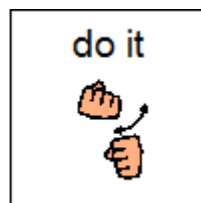
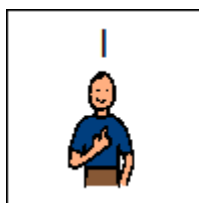
Disappointment



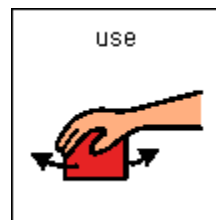
Feelings influenced
by internal state



Feelings influenced
by others' actions



We also want to make sure to include additional vocabulary to allow for partner support and, ultimately, self-regulation by child:



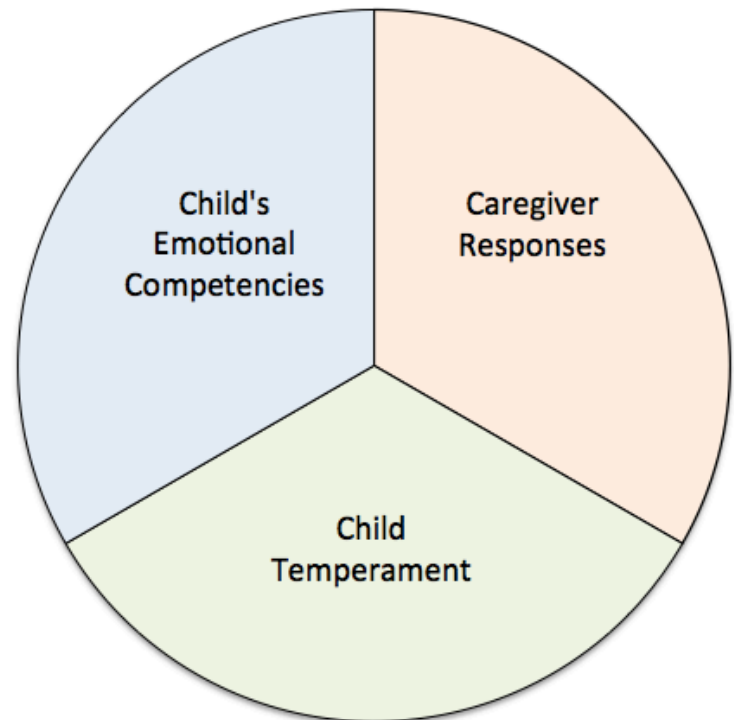
A possible tool for supporting developing emotional competencies in children with CCN (ages 0-10)

PURPOSE OF TOOL

- Raise awareness of the importance of emotional development
- Encourage mindful interventions that support emotional development

STRUCTURE OF TOOL

- Assesses three areas....



Questions about child's emotional competencies

Early Developing Emotional Competencies: Children with Complex Communication Needs

Name of individual:

Examiner:

D.O.B.:

Informant(s):

Date of interview :

Social circle(s) :

Methods of Emotional Expression Available to Individual with Complex Communication Needs (check all that apply)

- ☐ facial expressions ☐ vocalizations ☐ symbols/text on non-electronic communication display ☐ writing
☐ body postures ☐ speech ☐ symbols/text on simple AAC device ☐ other methods
☐ gestures ☐ manual signs ☐ symbols/text on synthesized speech device
☐ symbols/text on mobile device/computer with apps/software_____

QUESTIONS ABOUT INDIVIDUAL WITH COMPLEX COMMUNICATION NEEDS

1. Which emotions/feelings does individual currently express? (Ekman, Friesen, & Ellsworth) (Parrott, 2001) INDICATE ALL THAT APPLY.

PRIMARY EMOTIONS	OFTEN	SOMETIMES	RARELY	NOT SURE	SECONDARY/TERTIARY EMOTIONS (examples)	OFTEN	SOMETIMES	RARELY	NOT SURE
Affection/Love					Adoration				
Anger					Irritation/Frustration Rage Jealousy/Envy				
Sadness					Disappointment Shame Neglect				
Fear					Horror Nervousness				
Surprise					Excitement Amazement				
Joy/happiness					Cheerfulness Delight				
Disgust					Contempt Revulsion				

COMMENTS:

Questions about child's emotional competencies

2. How does the individual currently express these emotion/feelings? Please check all that apply and give examples.	<input type="checkbox"/> Facial expressions <input type="checkbox"/> Body postures <input type="checkbox"/> Gestures <input type="checkbox"/> Vocalizations <input type="checkbox"/> Other _____	EXAMPLES using nonlinguistic behaviors				
	<input type="checkbox"/> Speech <input type="checkbox"/> Manual signs <input type="checkbox"/> Symbols/text on non-electronic communication display <input type="checkbox"/> Symbols/text on simple AAC device <input type="checkbox"/> Symbols/text on synthesized speech AAC device <input type="checkbox"/> Symbols/text on mobile device/ computer with apps/ software <input type="checkbox"/> Writing <input type="checkbox"/> Other _____	EXAMPLES using linguistic behaviors				
3. How many DIFFERENT words/symbols/signs does individual use to express emotion/feelings?	<input type="checkbox"/> None (if selected, please go to #6) <input type="checkbox"/> Less than 5 graphic symbols/words/signs <input type="checkbox"/> 6 to 10 graphic symbols/words/signs <input type="checkbox"/> 11 to 20 graphic symbols/words/signs <input type="checkbox"/> More than 20 graphic symbols/words/signs <input type="checkbox"/> More than 50 graphic symbols/words/signs					
Please give examples of words/graphic symbols/signs used.						
4. Does individual express emotion using language (words/graphic symbols/signs) <u>a</u> across multiple contexts?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE	
b) <u>in</u> ways that multiple communication partners understand ?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE	
5. Does individual require prompting to label his/her own emotions using language?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE	
Give examples of types of prompts used.						
6. Does individual seem to recognize the emotions of others?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE	
Please give an example.						

Questions about child's emotional competencies

7. Does individual label/make comments about" the emotions of others?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
Please give an example.					
8. Does individual show empathy for others?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
How does individual demonstrate empathy?					
9. Does individual enjoy books/stories that express emotion?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
Please give example of book/story.					
10. Can individual create short narratives (written or spoken) that describe emotion/feelings?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
Please give an example.					
11. How does individual handle emotional extremes?					
a. Please describe how individual handles 'positively charged situations' (e.g., birthday party, doing something special, going to favorite store)?					
b. Please describe how individual handles situations that are negatively "charged" (e.g., fire drill, not getting what he/she wants, being frightened)?					
c. Does individual calm easily?	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
ADDITIONAL COMMENTS					

Questions about how caregivers respond to emotion



QUESTIONS ABOUT CAREGIVERS/PRIMARY COMMUNICATION PARTNERS

1. Please respond to the following statements by agreeing or disagreeing. Please feel free to comment.

	AGREE	DISAGREE	COMMENT
a. Parents/caregivers freely express both positive and negative emotions.			
b. Parents/caregivers tend to keep expressions of emotion to themselves			
c. Parents/caregivers have clear expectations about how children should express their emotions.			
d. Parents/caregivers encourage the individual to express his/her emotions.			
e. Parents/caregivers provide access to vocabulary so individual can express his/her emotions.			

2. In general, how do parents/primary caregivers display emotion? Check PRIMARY methods they rely on.

☐ facial expressions ☐ talk openly about feelings ☐ body posture ☐ gestures ☐ become physically aggressive ☐ escape from situation
☐ vocalizations ☐ talk about how others feel ☐ manual signs ☐ write about feelings ☐ artistic expression ☐ other _____

2b. Specifically, how do caregivers typically express the following emotions?

☐ Love/affection _____ ☐ Anger _____ ☐ Sadness _____
☐ Fear _____ ☐ Surprise _____ ☐ Happiness _____
☐ Anxiety _____ ☐ Frustration _____ ☐ Other _____

3. Do caregivers talk to the individual about

	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
a. <u>the individual's</u> emotions?					
b. <u>their own</u> emotions?					
c. <u>other people's</u> emotions?					
d. <u>emotions</u> related to books/ movies /DVD/TV shows, etc.					

EXAMPLES

4. Do caregivers seem to recognize when the individual is expressing emotion?

	OFTEN	SOMETIMES	RARELY	NO	NOT SURE
a. Which emotional expressions may not be recognized?					

Questions about how caregivers respond to emotion

5. Do caregivers encourage and support the individual to express his/her emotions using language?	OFTEN	SOMETIMES	RARELY	NOT APPLICABLE
EXAMPLES				
6. Do caregivers sometimes choose to ignore the individual's emotional expressions?	OFTEN	SOMETIMES	RARELY	NOT SURE
a. Which emotions are ignored? For what reasons are they ignored?				
7. Do caregivers use strategies to help the individual regulate his/her emotions?	OFTEN	SOMETIMES	RARELY	NOT SURE
EXAMPLES				
8. Do caregivers feel the individual has "behavior problems?"	OFTEN	SOMETIMES	RARELY	NOT SURE
EXAMPLES				
9. Do caregivers use strategies to help the individual "gear themselves up" for difficult or challenging situations/tasks.	OFTEN	SOMETIMES	RARELY	NOT SURE
EXAMPLES				
10. Do caregivers use strategies to help the individual "calm down" after difficult or challenging situations.	OFTEN	SOMETIMES	RARELY	NOT SURE
EXAMPLES				

Questions about the child's temperament



QUESTIONS ABOUT TEMPERAMENT/BEHAVIORAL CHARACTERISTICS <small>Caspi & Shiner (2008),</small>					
1. How would you describe the individual's temperament? Please check all that apply.		<input type="checkbox"/> happy <input type="checkbox"/> shy <input type="checkbox"/> pessimistic <input type="checkbox"/> considerate <input type="checkbox"/> reserved <input type="checkbox"/> outgoing <input type="checkbox"/> charismatic <input type="checkbox"/> distractible <input type="checkbox"/> angry <input type="checkbox"/> aggressive <input type="checkbox"/> irritable <input type="checkbox"/> persistent (tenacious) <input type="checkbox"/> sad <input type="checkbox"/> optimistic <input type="checkbox"/> fearful <input type="checkbox"/> stubborn <input type="checkbox"/> other _____			
2. Does individual seem to enjoy being with others?		OFTEN	SOMETIMES	RARELY	NOT SURE
Please give example(s).					
3. Does individual enjoy physical contact (hugs, sitting close to, etc.)					
a. <u>with</u> family members?		OFTEN	SOMETIMES	RARELY	NOT SURE
b. <u>with</u> other adults?		OFTEN	SOMETIMES	RARELY	NOT SURE
c. <u>with</u> peers?		OFTEN	SOMETIMES	RARELY	NOT SURE
Please give examples.					
4. Does person show strong attachment to parents/ caregivers		OFTEN	SOMETIMES	RARELY	NOT SURE
Please give examples.					
5. Does individual express fear of strangers and/or unfamiliar situations?		OFTEN	SOMETIMES	RARELY	NOT SURE
Please give examples.					
6. Does individual have temper tantrums?		OFTEN	SOMETIMES	RARELY	NOT SURE
Please describe					

Questions about the child's temperament

Describe how <u>caregivers</u> react during a temper tantrum.				
7. Does individual exhibit self-injurious behaviors?				
	OFTEN	SOMETIMES	RARELY	NOT SURE
Please describe				
Describe how <u>caregivers</u> react when child exhibits self-injurious behaviors.				
8. Is the individual aggressive toward others?				
	OFTEN	SOMETIMES	RARELY	NOT SURE
Please describe				
Describe how <u>caregivers</u> react when child is aggressive toward others.				

Application of the tool: Two case studies

Now we're going to show you how we have filled out the tool for two case studies, so you can get a sense of how it might work

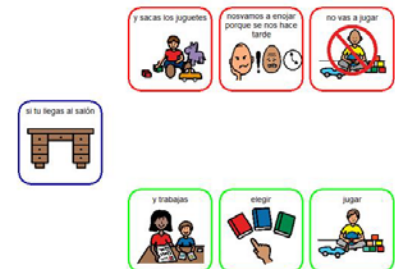
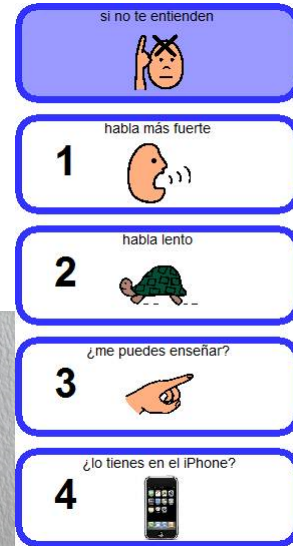
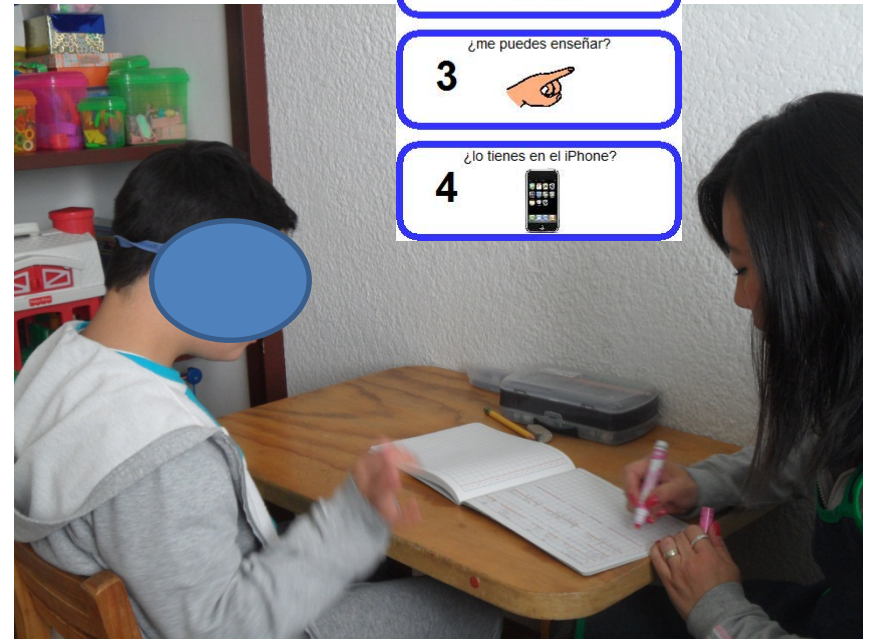
Ximena

- Age – 2 years old
- DOB – 7-19-10
- Cerebral Palsy (Severe)
- Lives with family
- PT, feeding (just had G-tube inserted),
- Being introduced to AAC tools/strategies



Santi

- Age 12
- DOB – 10-9-99
- Down syndrome
- Attends CATIC - school and therapies
- Uses manual signs, visual supports, pacing board, contingency maps, iPad, iPhone



Answers to Child Questions:

Methods of Emotional Expression Available to the client (all that apply)

METHOD	Ximena	Santi
Facial expressions	✓	✓
Vocalizations	✓	✓
Body postures	✓	✓
Gestures		✓
Speech		✓
Manual signs		✓
Writing		✓
Symbols/text on non-electronic communication display		✓
simple AAC device		✓
synthesized speech device		
mobile device/computer with apps/software		✓
Other methods		

Answers to Child Questions:

Which emotions/feelings does client currently express?
(Indicate all that apply)

(Ekman, Friesen, & Ellsworth) (Parrott, 2001)

Primary emotions

PRIMARY EMOTIONS	OFTEN	SOMETIMES	RARELY	NOT SURE
Affection/Love	√ √			
Anger	√	√		
Sadness	√	√		
Fear		√		√
Surprise		√	√	
Joy/happiness	√	√		
Disgust		√		
COMMENTS:				

Secondary emotions

Adoration

√ √ Irritation/Frustration

√ Rage

√ Jealousy/Envy

√ Disappointment

Shame

Neglect

Horror

√ Nervousness

√ √ Excitement

Amazement

Cheerfulness

Delight

Contempt

Revulsion

√ Other: **confusion**

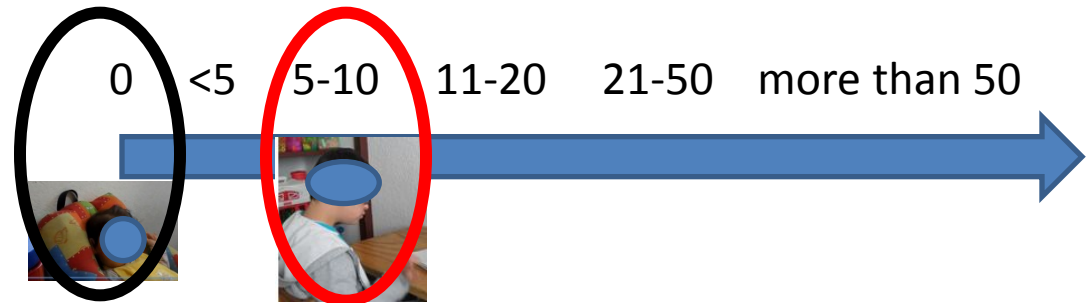
Answers to Child Questions:

How Does Child Currently Express Emotion?

2. How does the individual currently express these emotion/feelings?

- Facial expressions
- Vocalizations
- Body postures
- Gestures
- Speech
- Manual signs
- Writing
- Symbols/text on non-electronic communication display
- Simple AAC device
- Synthesized speech device
- Mobile device/computer with apps/software
- Other methods

3. How many DIFFERENT words/symbols/signs does individual use to express emotion/ feelings?



Santi - sad, angry, happy, nervous, fear (using body language, aac device, writing)
At first, he tries to say it verbally, then signs or draws. But if people don't understand him, he uses his Ipad or cell phone (with Tap to Talk or other app)

Answers to Child Questions:

	Often	Some- times	Rarely	No	Not sure
4. Does individual express emotion using language (words/graphic symbols/signs) a) across multiple contexts? b) In ways that are recognizable to multiple partners	✓			✓	
5. Does individual require prompting to label his/her own emotions using language? Examples		✓		✓	
6. Does individual seem to recognize emotions in others? Examples	✓				✓
7. Does individual label the emotions of others? Examples		✓		✓	
8. Does individual show empathy for others? Examples	✓			✓	

Answers to Child Questions:

	Often	Some- times	Rarely	No	Not sure
9. Does individual enjoy books/stories that express emotion? Examples					✓✓
10. Can individual create short narratives (written or spoken that describe emotions/feelings? Examples				✓✓	

11. How does individual react during “emotionally charged” situations? Positively charged.....
Negatively charged....

Answers to Caregiver Questions:

QUESTIONS ABOUT CAREGIVERS/PRIMARY COMMUNICATION PARTNERS

1. Please respond to the following statements by agreeing or disagreeing.
Please feel free to comment.

	AGREE	DISAGREE	COMMENT
a. Parents/caregivers freely express both positive and negative emotions.	√ √		
b. Parents/caregivers tend to keep expressions of emotion to themselves	√	√	
c. Parents/caregivers have clear expectations about how children should express their emotions.		√ √	
d. Parents/caregivers encourage the individual to express his/her emotions.	√ √		
e. Parents/caregivers provide access to vocabulary so individual can express his/her emotions.	√	√	

Answers to Caregiver Questions:

2. In general, how do parents/primary caregivers display emotion?

Check PRIMARY methods they rely on.

- facial expressions ✓✓
- body posture ✓✓
- gestures ✓✓
- Vocalizations ✓✓
- manual signs ✓
- talk openly about feelings ✓✓
- Talk about how others feel ✓✓
- become physically aggressive ✓
- escape from situation ✓
- write about feelings ✓✓
- artistic expression
- other _____

Specifically, how do caregivers typically express the following emotions?

Love/affection _____

Anger _____

Sadness _____

Fear _____

Surprise _____

Happiness _____

Anxiety _____

Frustration _____

Other _____

Answers to Caregiver Questions:

3. Do caregivers talk to the individual about	OFTEN	SOME TIMES	RARELY	NO	NOT SURE
a. the individual's emotions?	✓	✓			
b. their own emotions?		✓	✓		
c. other people's emotions?		✓✓			
d. emotions related to books/ movies /DVD/TV shows, etc.		✓	✓		
EXAMPLES					

Answers to Caregiver Questions:

	Often	Some- times	Rarely	No	Not sure
4. Do caregivers seem to recognize when the individual is expressing emotion?	✓✓				
5. Do caregivers encourage and support the individual to express his/her emotions using language?		✓		✓	
6. Do caregivers sometimes choose to ignore the individual's emotional expressions?	✓ crying	✓			
7. Do caregivers use strategies to help the individual regulate his/her emotions?	✓ Not working	✓			
8. Do caregivers feel the individual has "behavior problems?"	✓		✓		
9. Do caregivers use strategies to help the individual "gear themselves up" for difficult or challenging situations/tasks.	✓				✓
10. Do caregivers use strategies to help the individual "calm down" after difficult or challenging situations	✓	✓			

Answers to Temperament Questions:

1. How would you describe the individual's temperament? Please check all that apply.	<input checked="" type="checkbox"/> <input type="checkbox"/> happy <input checked="" type="checkbox"/> <input type="checkbox"/> shy <input type="checkbox"/> <input type="checkbox"/> pessimistic <input type="checkbox"/> <input type="checkbox"/> considerate <input checked="" type="checkbox"/> <input type="checkbox"/> reserved <input type="checkbox"/> <input type="checkbox"/> outgoing <input checked="" type="checkbox"/> <input type="checkbox"/> charismatic <input checked="" type="checkbox"/> <input type="checkbox"/> distractible <input type="checkbox"/> <input type="checkbox"/> angry <input type="checkbox"/> <input type="checkbox"/> aggressive <input type="checkbox"/> <input type="checkbox"/> irritable <input checked="" type="checkbox"/> <input type="checkbox"/> persistent (tenacious) <input type="checkbox"/> <input type="checkbox"/> sad <input checked="" type="checkbox"/> <input type="checkbox"/> optimistic <input type="checkbox"/> <input type="checkbox"/> fearful <input checked="" type="checkbox"/> <input type="checkbox"/> stubborn <input type="checkbox"/> <input type="checkbox"/> other __frustrated__			
2. Does individual seem to enjoy being with others? Describe.	OFTEN	SOMETIMES <input checked="" type="checkbox"/>	RARELY <input checked="" type="checkbox"/>	NOT SURE
3. Does individual enjoy physical contact (hugs, sitting close to, etc.) Examples				
a. with family members?	OFTEN <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	SOMETIMES	RARELY	NOT SURE
b. with other adults?	OFTEN <input checked="" type="checkbox"/> (if familiar)	SOMETIMES	RARELY <input checked="" type="checkbox"/>	NOT SURE
c. with peers?	OFTEN <input checked="" type="checkbox"/>	SOMETIMES	RARELY <input checked="" type="checkbox"/> never	NOT SURE

Answers to Temperament Questions:

	OFTEN	SOME-TIMES	RARELY	NO	NOT SURE
4. Does individual show strong attachments to parents/caregivers? Example.	✓ ✓				
5. Does individual express fear of strangers and/or unfamiliar situations? Example.	✓ ✓				
6. Does individual have temper tantrums? Example. How does caregiver/others react?	✓	✓			
7. Does individual have self-injurious behaviors? Example				✓	✓ Can't do it
8. Is individual aggressive toward others?				✓	✓

General goals

- Increase use of vocabulary that expresses emotion, both by the children and their partners
- Increase understanding of emotion in self/others and different responses to circumstances
- Increase capacity for adaptive coping with aversive emotions and distressing circumstances...emotional regulation

Specific Strategies

Input to child

- Well informed communication partners
- *Reading a range of stories
- Watching Movies/TV shows & talking about them
- Talking about events
- Setting up opportunities to hear other people with disabilities talk about their experiences
- Encouraging teachers to include reference to emotion in their lessons
- Using gestures, aided input, etc. that provide child with access to a rich vocabulary of emotion
- Contingency maps
- Schedules
- Social Stories

Output from child

- Supports for drawing
- Supports for writing
- Gesture dictionary
- Dramatic play scenarios
- Access to diverse emotion symbols and conversations about feelings using “because” statements (see Slide #29)
- Easy access to sounds on devices that can express emotions
- Emotion wheels
- Opportunities to “talk about” write about emotionally charged events, including use of aided input and self-talk concerning “strategies” (see Slide #30)
- Scales/thermometers, Social groups
- Talking about stories/movies/TV shows/activities at school/home/community that have generated emotions

Brief summary - Ximena

- Just 2 yo, severe motor limitations
- No access to language and emotional expression (developmentally okay)
- Parents very frustrated with crying. Tool helped understand emotional issues

Example: Goals and strategies

Ximena

GOALS

- Increase awareness of emotions in self and others
- Understand and use vocabulary of emotion to express feelings

SAMPLE STRATEGIES

- Use daily routines to provide input about emotions (hers/others). Teach specific vocabulary using body/symbols.
 - Love, anger, sad, frustrated, surprise
- Consult with psychologist to manage persistent crying
- Comment on emotions during favorite book reading using body (signs) and symbols
- Introduce songs on Ipad..as happy song; sad song; angry song, etc.
- Use symbols when talking about emotion (signs, on Etran, Ipad, etc.)

Brief Summary - Santi

- 12 yo. Attending comprehensive program at CATIC
- Intervention multi-focused
- Being encouraged to express emotion using variety of options
- Behavior has dramatically improved
- Family more aware of importance of addressing emotional development

Next Steps

WORKING GROUP

- Pilot Test Tool ->
Focus on children with CCN
from 1 to 10 years
(developmental levels)
- Make it available to those who
want to participate in field
test.
- Modify tool based on results
- Post slides on [www.aac-
rerc.com](http://www.aac-
rerc.com) and
www.augcominc.com

ISAAC PARTICIPANTS

- Ask questions/give feedback
(fill out papers)
- Email if want to participate
in pilot test