Understanding the complexity of communication in people with intellectual disabilities

Teresa Iacono, Ph.D.
La Trobe Rural Health School, Bendigo, Victoria, Australia
Remembering Penny

PUSSY’S ON THE ROOF!!!
Bloom & Lahey (1979)
Effective & Efficient Communication
The Complexity of Imitation

- Social-cognitive understanding and social motivations influence what young children copy:
  - Understanding of others’ goals and intentions
  - Ability to collaborate with others by sharing goals and reading others’ communicative intents towards oneself
  - One’s own social and instrumental goals at the moment

(Carpenter, 2006)
Possible Functions of Echolalia

• Immediate
  o Turn-taking
  o Labelling
  o Answering ‘yes’
  o Requesting (often mitigated)
  o Responding to high arousal states
  o Rehearsing
  o Self-regulating (occurring with motor activity)

• Delayed
  o Turn-taking
  o Verbal completion
  o Labelling
  o Protesting
  o Requesting
  o Calling
  o Affirming
  o Directing
  o Responding to an association
  o Self-directing (with motor activity)
  o Rehearsing
  o Non-interactive labelling

Prizant & Wetherby, 1981
Echolalia in Autism

- Increasing productive language skills (McEvoy, Loveland & Landry, 1988)
- Increasing Receptive language skills (Robert, 1989; 1999)
Down syndrome – oversimplifying the complex?


1. Mental age = Comprehension = Production
2. Mental age = Comprehension > Production
3. Mental age > Comprehension > Production
Down Syndrome Language

Comprehension

Vocabulary

Syntax
Early Asynchronies
Readiness for Language...

- Intentional Communication Acts – Symbolic Language
- ICA – “an event in which the child directed a motoric and/or vocal act toward the adult and awaited a response from the adult” (Wetherby et al., 1988, p. 241)
- Threshold productions of approximately 1 per minute signal readiness to transition to symbolic communication in the form of spoken words (McCathren, Warren, & Yoder, 1996; Warren & Yoder, 1998)
ICAs in Children with Down Syndrome

- Delays in prelinguistic development
- Reliance on gestures
- Chan & Iacono (2001) – observed 3 girls with Down syndrome (17-19 months) over 3 months in structured and unstructured sessions
Children with Down syndrome
Transition to Symbols

Emergence of Words

Rate of ICA

Sessions

ASID, 2012
When Speech is not Available

- Deficits in speech have the potential to impact on language learning
  - Reduced communication attempts and opportunities for learning?
  - Increased frustration resulting in problem behaviours?
  - Reduced complexity of the messages attempted?

Miller & Leddy, 1998
It’s not just a struggle to develop language, but also to hold onto it

- Do people with intellectual disability lose language skills as they age?

Iacono, Torr & Wong (2010)

- Cross sectional study of 59 adults (31 males) aged 19 – 58 (mean = 38); 10 with confirmed or suspected Alzheimer’s disease
- Expressive language of those who could engage in narratives or conversations single words to extended and complex sentences.
- After accounting for the effect of Alzheimer’s disease and non-verbal cognition, only expressive language and auditory short term memory were found to decrease with age ($r = -0.26, p<.05$)
Whispering Jack

• What happens for some adolescents and adults with Down syndrome that causes speech skills to drop off?
Understanding Complexity

Form

Effective & Efficient Communication

Mental Health

Physical Health

Content

Use
Driver’s for Effective and Efficient Communication

Intersubjectivity/
Reciprocity of interactions
McLean & Snyder McLean (1978); Bruner (1972); Werner & Kaplan (1963)

Relations with others result in
the emergence of individual consciousness – culture
becomes a part of each person’s
nature (Vygotsky, 1934/1987)
“It will take the child a year to start talking, but on every day of that year a variety of language-related mechanisms will inch their way toward efficient action.”

*John Locke, 1994, p. 2*

“Social relations or relations amongst people genetically underlie all higher functions and their relationships.”

*Len Vygotsky, 1981*
When the Parts Don’t Come Together

Social Interactions remain core
Understanding Complexity

Understanding of how best to enhance social interaction, communication and/or language in people with intellectual disabilities who may do it differently comes from detailed and prolonged engagement with them in social contexts.
Using any Means Possible

• Iacono, Carter & Hook (1998)
  o Challenged the applicability of published criteria to demonstrate intentional communication
  o Ability to co-ordinate attention between person and referent in the face of significant and multiple disabilities
When communication is hard work!
Using any Means Possible

• Interactions between children with disability (Down syndrome; Cerebral Palsy) and their mothers and siblings
  o What communicative behaviours do mothers and siblings respond to?

Susheel Singh (2012)
## Example of coded transcript

<table>
<thead>
<tr>
<th>Utterance/Behaviour</th>
<th>I/R</th>
<th>Function</th>
<th>Modality</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wow, baby (Takes a doll from the box and shows it to C).</td>
<td>MI</td>
<td>Naming</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ahhh!!! (Looks at doll and then at M and then back at doll, while vocalizing excitedly and reaching for the doll).</td>
<td>ICA-CR</td>
<td>Request</td>
<td>Vocalization, Eye gaze, Diectic gesture (reach)</td>
<td></td>
</tr>
<tr>
<td>(Gives the doll to C)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Picks up a comb and combs the dolls hair)</td>
<td></td>
<td></td>
<td>Symbolic Play</td>
<td></td>
</tr>
<tr>
<td>Give the baby a drink (puts a cup in front of C)</td>
<td>MI</td>
<td>Request action</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ahhh (Takes cup and throws it away)</td>
<td>CA-CR</td>
<td>Protest</td>
<td>Vocalization, Motor action</td>
<td></td>
</tr>
<tr>
<td>No, don’t do that.</td>
<td>MR</td>
<td>Negation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Singh (2012)*
## Modalities of Communicative Acts and Intentional Communicative Acts

<table>
<thead>
<tr>
<th>Mother-child</th>
<th>Sibling-child</th>
<th>Triadic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DS</strong></td>
<td><strong>CP</strong></td>
<td><strong>DS</strong></td>
</tr>
<tr>
<td>2. Gestures</td>
<td>2. Facial ex</td>
<td>2. Gestures</td>
</tr>
</tbody>
</table>

Singh (2012)
When Symbolic Skills Don’t Lead to Linguistic Development

Social interactions and processes that underpin positive relationships for people with severe intellectual disability and limited symbolic communication skills.

Hilary Johnson (2012)
Hilary’s Central Participants

• The Challenges of Describing their Communication

• Receptive language
  o From non-testable to a receptive language age of 5 years

• Expressive language
  o Sandra - Speech of < 100 single words. A limited number of two-word phrases used repetitively (e.g., mum happy, dad happy). Uses 10 Key word signs
  o Colin - Uses <30 Key word signs. Can initiate interactions by pointing to photos
  o Eric - Uses < 10 spoken words. Uses > 100 Key word signs. Can use photos/pictures to share requests or comments
Eric went up to a staff member and finger spelled B to the staff as he was waiting for Betty to come back from a program. The staff member did not recognize the sign so Eric went and took a picture, a photo of Betty from the wall, and showed it to the staff. She promptly replied I don’t know, but she’ll be back.

(FN/E/4)

Johnson et al. (2011)
For a Range of Uses

Having fun and hanging out

The other day he was sitting in the chair and he looked at me and laughed ‘bam way mama’ and I went ‘yam bad yamma’ and we did that for 4 min both laughing … he knew it was nonsense. (EF4)

Johnson et al. (2012, p. 5)
ST PAUL'S UNITING CHURCH

NO COMMUNICATION

NO RELATIONSHIP
Tristan’s “Thumbs Up”
Some of Tristan’s Expressions

Anticipation  Cranky  Concentration

Cheeky  Mischievous  Happy
When symbols are not the medium

Affect attunement in communicative interactions between adults with profound intellectual disabilities and support workers

Sheridan Forster (2011)
Affect Attunement

“The use of cross modal means to recast affect expressions to share meanings”

Forster (2011, p. xi)
Complexity of Coding
Affect Attunement

<38.0>((Linda (L) enters the lounge room. Daphena (D) is seated on the floor with a cushion playing with the clothing protector around her neck))
<38.6>L: >hey ninni< (0.8)
>whatcha doin-< ((grabs another big cushion from behind Daphena and places it on the floor))
<43.1>D: ur:
<43.7>L: >°hey hey got your cushion°<
<43.8>D: ((grasps cushion with right hand and pulls it to right side, pats right hand down on cushion))
<46.4>D: uuh- ur
<48.4>L: >here it is:<> sniff
<49.1>L: ((places wash bucket of objects on cushion in front of D))
<49.9>D: ur° (places hand in the bucket to objects, looking a objects, grabs bit of red fabric and lifts to forehead level)
<51.5>L: °yeah°(flips bit of fabric out of the bucket)
<52.1>L: (grabs squeaky piranha toy)
<52.3>L: squeak: squeak-squeak-squeak squeak::<
D: (strips red fabric with left hand, right hand holding up above head level)
An Example

• Participant in his 50s with Cerebral Palsy, profound intellectual disability; blind in one eye. Long term epilepsy with deteriorating health.

(Forster, 2012)
Revisiting Complex Communication Needs

- Affect Attunement
- Unconventional Signals
- Delayed/ asynchronous development
- Reliance on any and all means and modes

Responsive Social Environment
TIME

Rich
Rewarding
Reciprocal
Interaction
Complex from Whose Perspective?
Enjoying the Richness of Complex Communication
The Richness of Complexity
thank you

Penny
Jeffrey Chan
Susheel Singh
Sheridan Forster
Hilary Johnson
Maria and Tristan
Jane, Nick and their family