



He doesn't communicate, I just know what he wants: The complexity of communication for people with intellectual disabilities

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Myth busting

Some people with intellectual disability don't communicate

Communication is more than words

Using signs or a picture communication system makes people lazy

Communication occurs through any means available

Perseverative or echolalic speech is non-communicative

Communication and conversations are participatory

People with intellectual disability usually understand more than they express

Communication is multi-dimensional

Asking yes/ no questions is a good strategy when communicating with people with limited speech or communication

Conversations are based on interactional "rules"

Some people with intellectual disability don't communicate

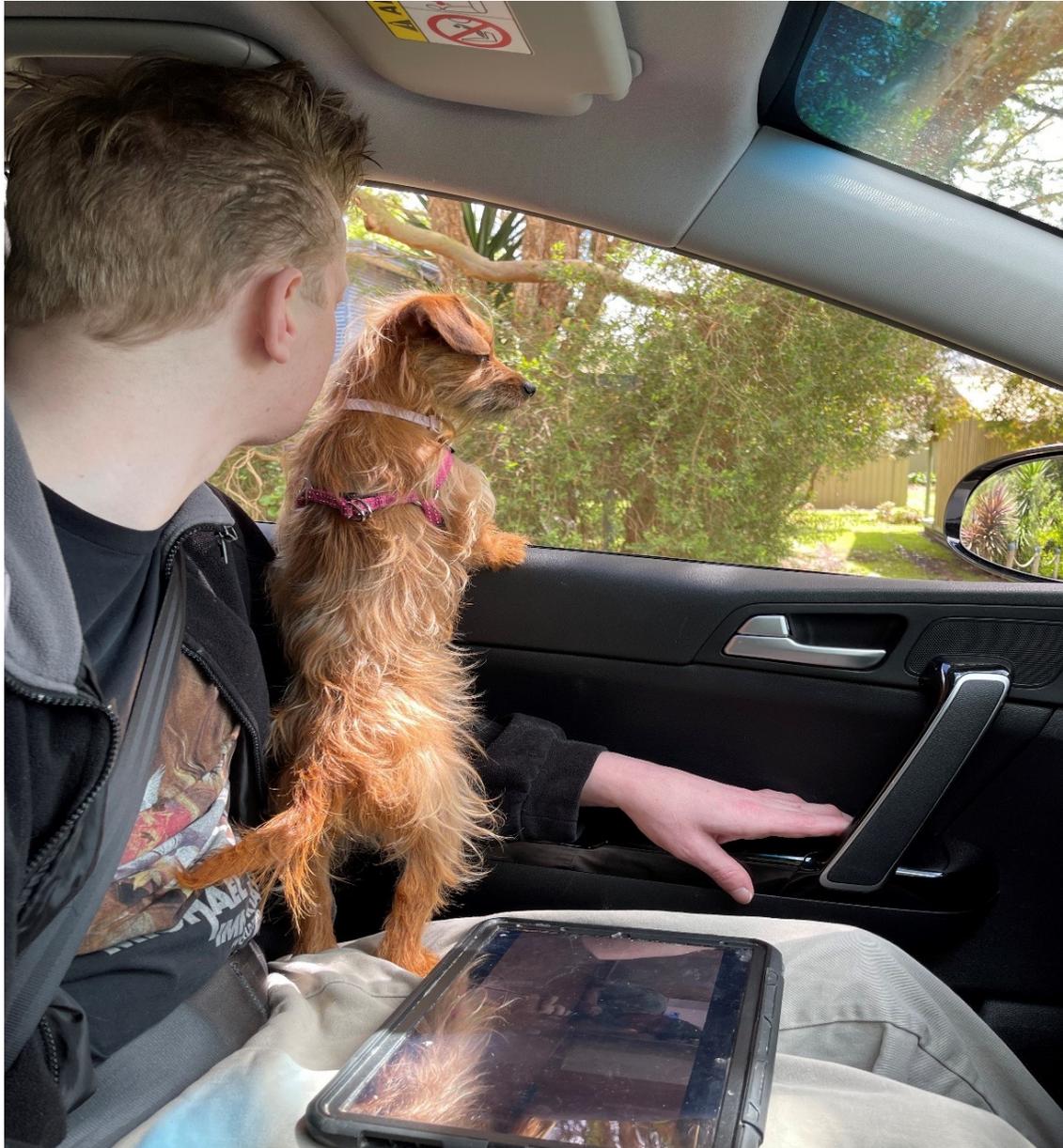
Communication is more than words



The Richness of Complexity







Our recent week at the beach together. His iPad is everything to him: Communication (Proloquo2Go), sharing news (Day One journal), independent entertainment (Youtube), and hobby (photography). Its always with him (except at the actual beach!)

Jane Tracy (2021, personal communication)

Using signs or a picture communication system makes people lazy: Communication occurs through any means available

...one day [Vincent] attached a real tea bag to the [shopping]list, in lieu of having a picture

Iacono et al. (2013, p. 397)

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)



Using signs or a picture communication system makes people lazy:

Communication occurs through any means available

Perseverative speech is non-communicative

Communication and conversations are participatory

So if I'm here and she wants attention it'll be "Dad, Dad, Dad" and it really won't stop until you go up there, and she'll say "sit, sit, sit" and you sit there for a while. Then she'll say "talk, talk, talk." So you sit down and say "what do you want to talk about" and she'll go "talk," and you go "what do you want to talk about and she'll go "talk." I say "do you want to talk about school" and then I'll say something like "Katie's a good friend" and she'll go "friend."

Johnson et al. (2010, p. 181)

People with intellectual disability usually understand more than they express: Communication is multi-dimensional

Miller (1981) – profiles of language in children with Down syndrome

1. Mental age = Comprehension = Production
2. Mental age = Comprehension > Production
3. Mental age > Comprehension > Production

Oversimplification?

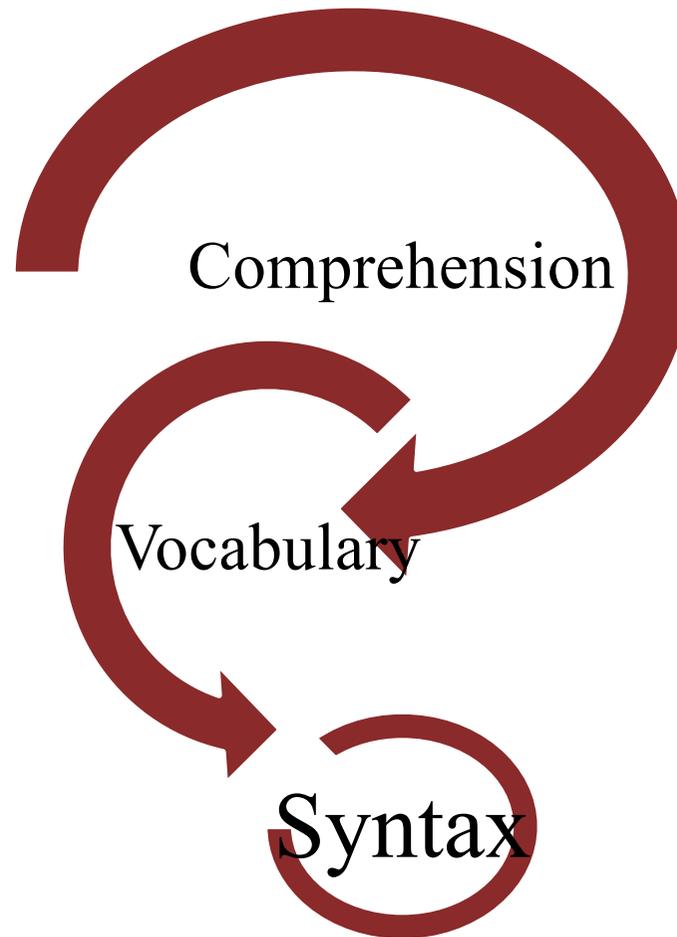
Difficulties in identifying communication stages of people with intellectual disability who are not using “language”

William's Syndrome

Spared Verbal ability in the presence of intellectual disability (i.e., better language than expected for mental age)

Content-free speech ~ *Cocktail Party Speech* (Udwin & Yule, 1990)

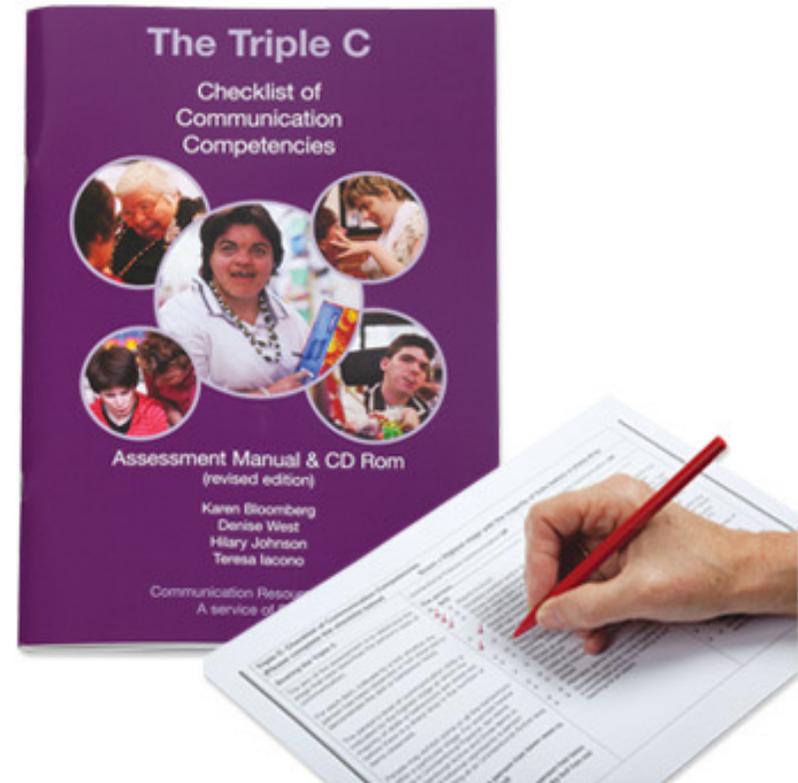
Down Syndrome Language



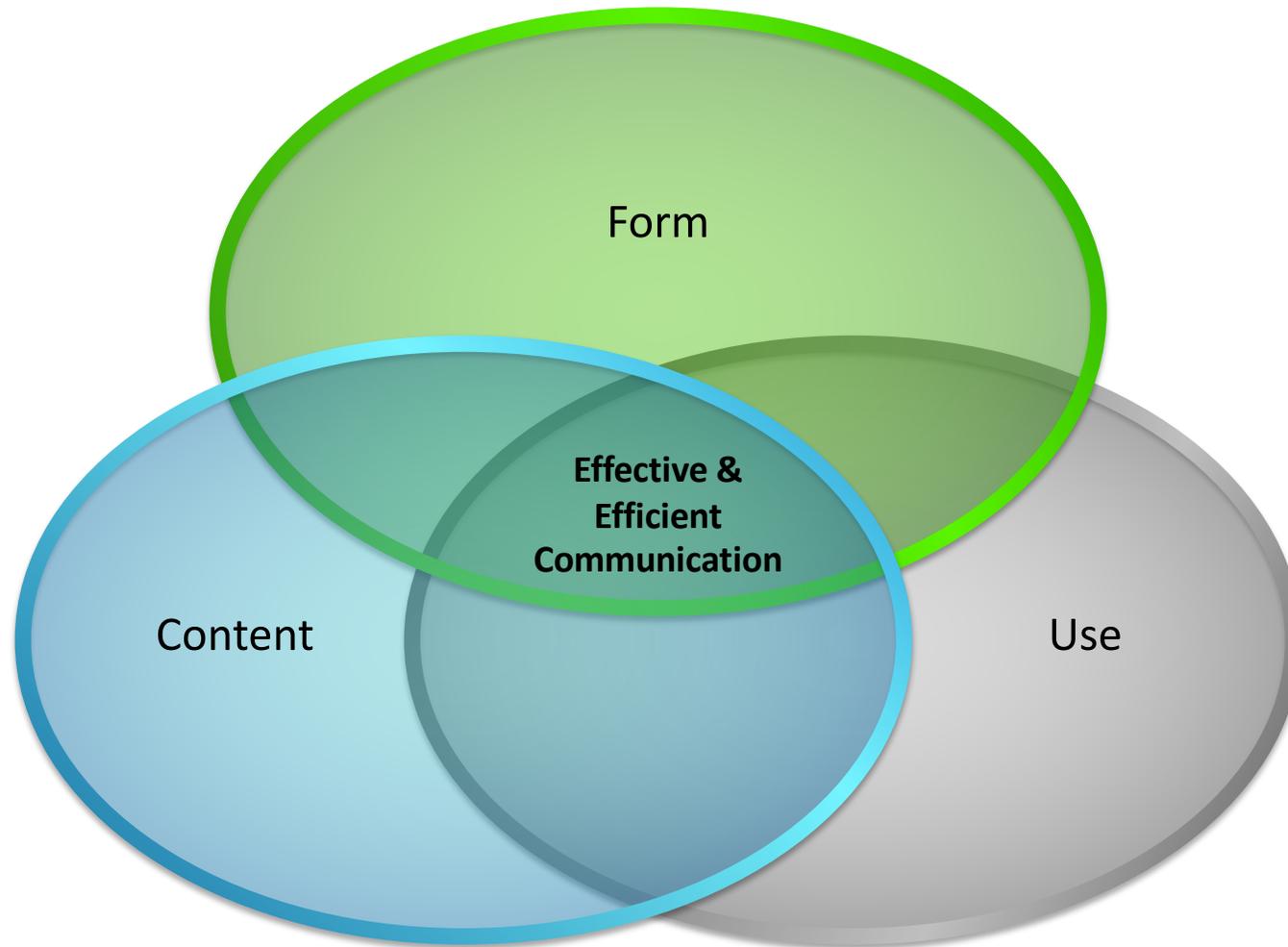
Assessing the communication of adults with severe intellectual disability: Triple C – Checklist of Communication Competencies

- Administered by speech pathologist (usually observing the person too) to families and or support workers; interpreted and recommendations generated by speech pathologist
- Semi-structured interviewing allowing the SP to gather further information about the person (e.g., hearing, vision, epilepsy) – part of it is building a consensus understanding the person
- Stages of communicative/cognitive development
 - Unintentional (passive)
 - Unintentional (active)
 - Intentional informal
 - Symbolic (basic)
 - Symbolic (established)

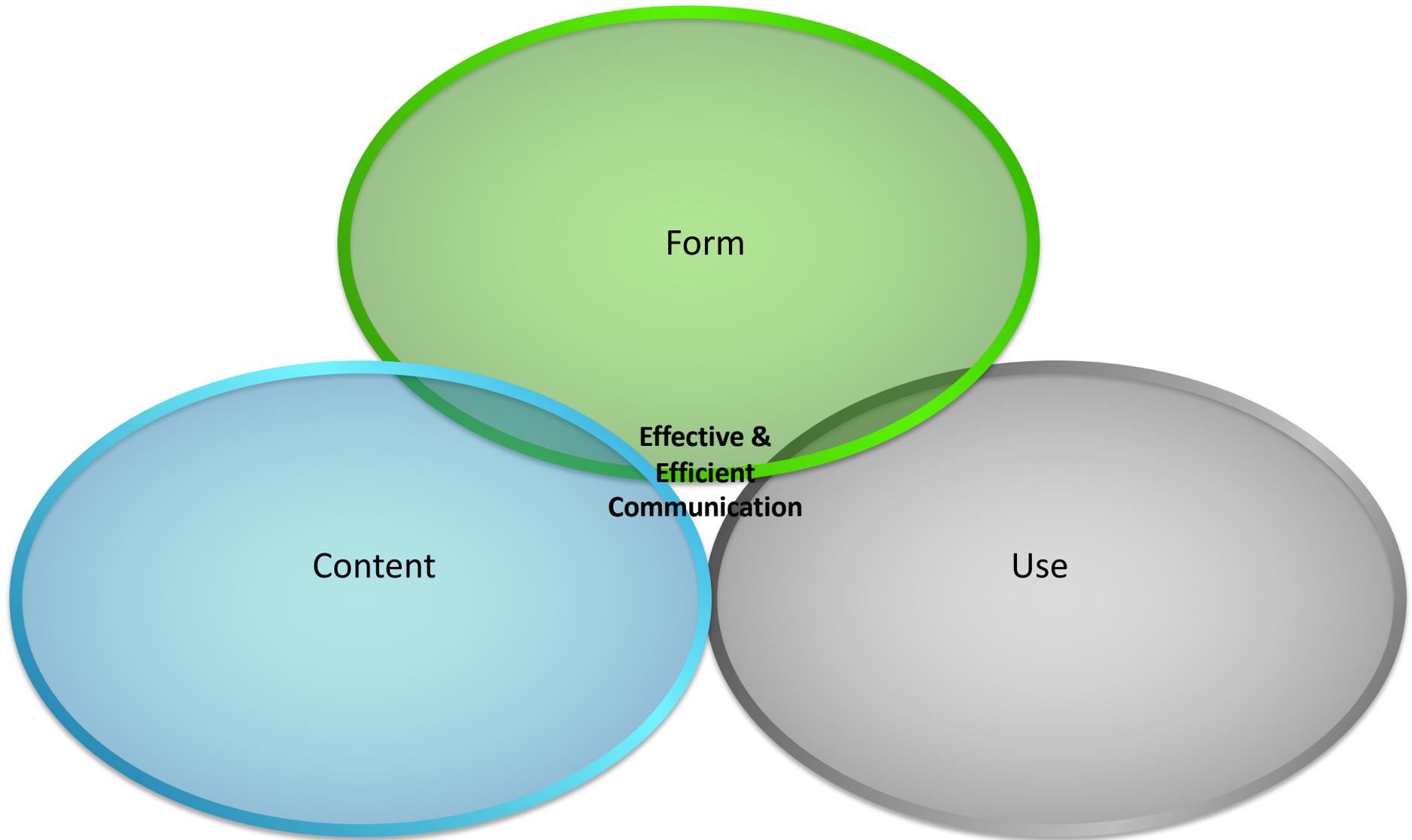
Research to demonstrate construct validity (Iacono et al., 2005; 2009)

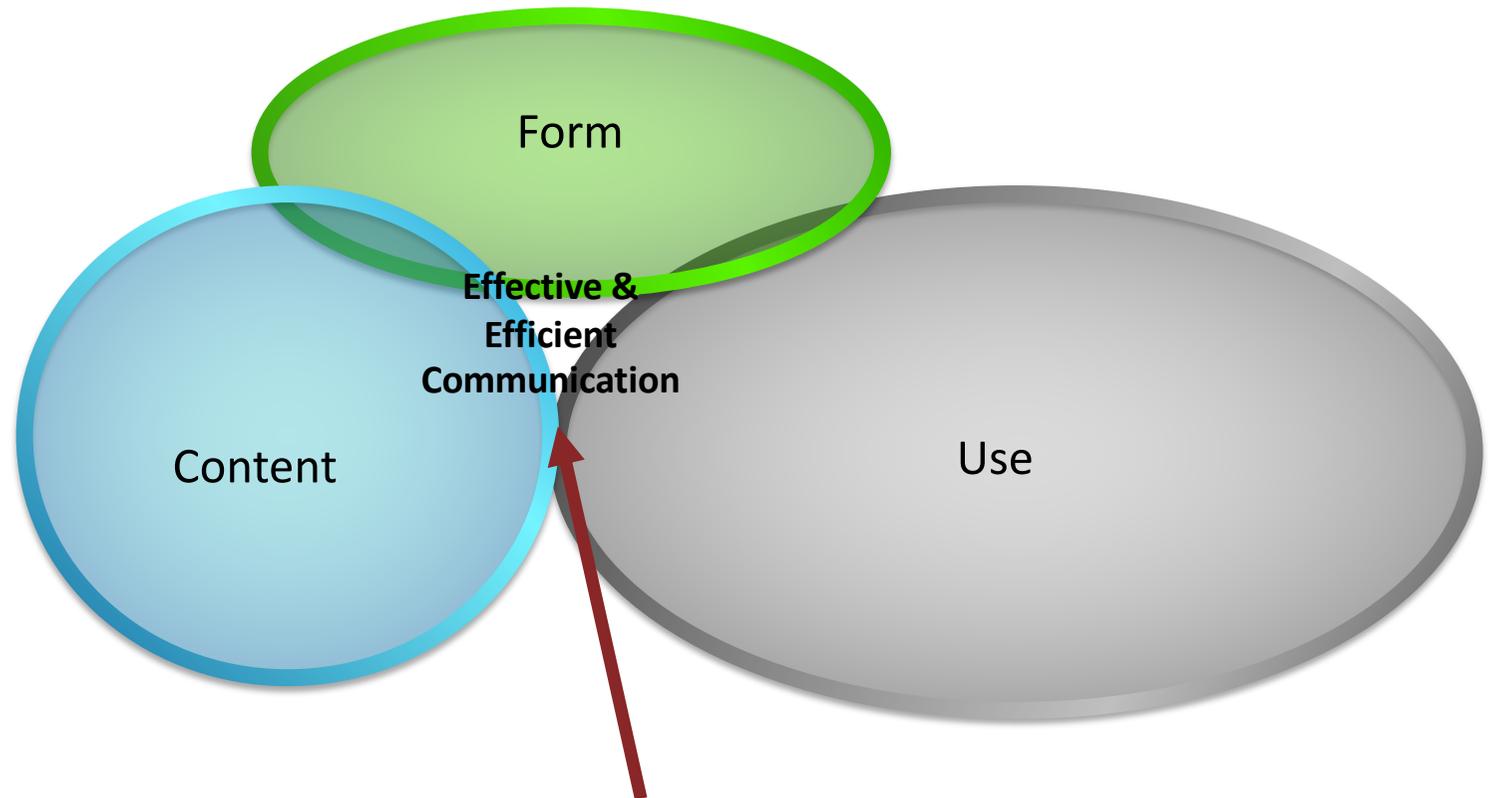


Communication is a multidimensional construct



Bloom & Lahey (1979)

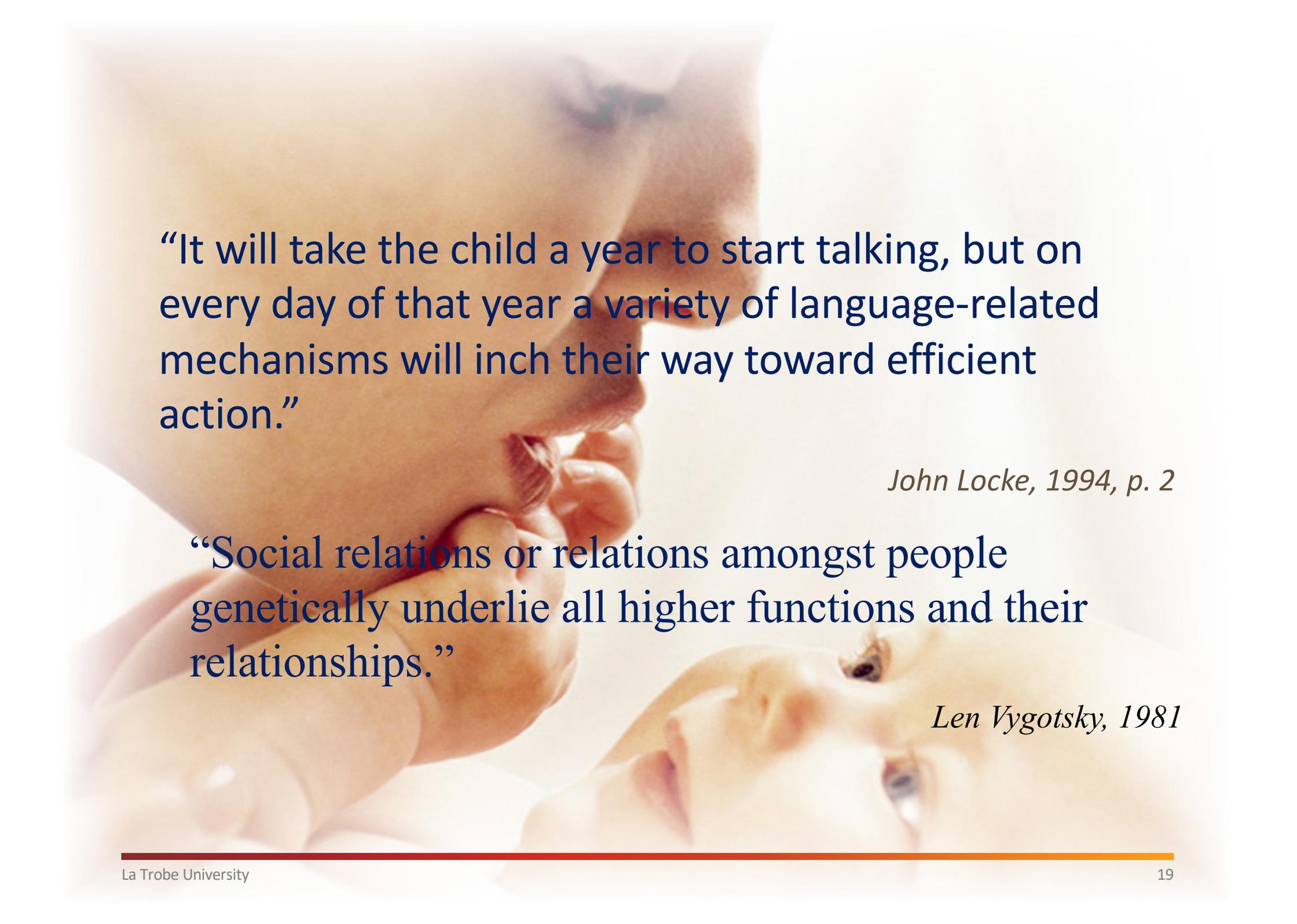




Greater reliance on an observant and responsive communicative partner

When it Doesn't Come Together

Social Interactions remain core



“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



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)

Asking yes/ no questions is a good strategy when communicating with people with limited speech or communication: Conversations are based on interactional “rules”

Grice’s conversational maxims

- 1. The maxim of quantity**, be as informative as you can, giving enough but not too much information.
- 2. The maxim of quality**, be truthful; don’t give false information or information not supported by evidence
- 3. The maxim of relation**, be relevant; says things that are pertinent to the discussion.
- 4. The maxim of manner**, try to be as clear, as brief, and as orderly as you can and avoid obscurity and ambiguity

Asking yes/ no questions is a good strategy when communicating with people with limited speech or communication: Conversations are based on interactional “rules”

Is there a belief that people with intellectual disability who engage in conversation break these maxims (general rule of conduct)?

Do people with intellectual disability say “yes” to “yes/no” questions – ie., do they acquiescence to please the questioner? Or do they respond via any means available to them?

Work of Rapley, Finlay, Antaki and colleagues has brought into question this belief (based on work of Sigelman and colleagues in the 1980s) through a series of studies in which conversational analysis has been applied to conversational samples, such as between researchers or support workers and adults with intellectual disabilities

Rapley & Antaki (1996)

Explored “acquiescence” in adults with intellectual disability participating in a Quality of Life questionnaire

Data were from 8 interview transcripts

Conversational Analysis

Detailed transcription and qualitative analysis of conversational samples

A key principle:

“people in an interaction achieve their meaning by actively using each others’ expectations about what comes after what in the normal sequence of talk”

(Rapley & Antaki, 1996, p. 211)

Rapley & Antaki (1996) – Pseudo-aquiescence

Code: MT/MR/JW

- 322 I d'you ↑feel out of ↓place (..) > out an' about in < ↓social (..) situ↓ations
- 323 AN → n[o:
- 324 I [Anne? (..) never?
- 325 AN no
- 326 I sometimes?
- 327 AN ↓°no°
- 328 I or usually
- 329 AN → ↑some↓times I ↑do:
- 330 I yeah? (..) ok we'll ↑put a two down for that one then (*sniff*)

The reformulation of the response

Rapley & Antaki (1996) – Pressure to change answers

Code: HB/MR/TT

138 I yeah?
139 (3 sec)
140 .hh ↑are there people living with ↓you who (.) who (.) who ↓bother you (.)
141 sometimes (..) or hurt you or: (.) [m-
142 BO [↑no
143 → I make you ↑angry or [(pes↓ter you) (.) no? (1 sec) ↑so ↓y-
144 BO [↓n:o
145 I y' ↑like the people you live ↓with
146 BO yes:
147 I yeah?
148 (2 sec)

The reformulation by the interviewer – changing the polarity of the question, but the response in essence remains the same

Finlay & Antaki (2012)

Ways in which disability support staff transform questions in order to solicit an adequate reply – thereby fulfilling the interactional goal of the question

Data from videos for an ethnographic study (~30 hours)

Conversational analysis

Questions were used by staff for

1. Clarification of communication – trying to determine the meaning of a behaviour
2. Assess a person's choice or preference (e.g., questionnaires, decisions about current activities)
3. Initiation or pursuit of a physical activity – person's readiness to begin or willingness to continue or end an activity
4. Giving advice or making suggestions – e.g., a better way of doing something
5. Encouraging reflection and/or social participation – e.g, participate in a conversation or provide information about a current activity

Finlay & Antaki (2012)

Failed questions

1. Not formatted for the question
 - No response
 - Yes/no question results in neither
 - Unrelated to the topic
2. Questioner felt the answer was inadequate

Finlay & Antaki (2012)

Example Extract

Extract 5. A-VD04-9.30

1. Jill: Damien [what would you like to do now would you like to go to
2. the toilet?
3. Damien: [*looks at her with smile*]
4. Damien: [*appears to make no response*]
5. Jill: [*laughs*] Damien (.) would you like to go to the toilet?
6. Damien: mmn [*turns head away*]
7. Jill: huh? (.) yes or no?
8. Damien: [*head sways*] mmn [*turns head away*]
9. Jill: Tell me (.) coffee's all gone (3.0) coming to the toilet? (2.0) yes?
10. Damien: [*looks at her, then sways head, looking to left and right*]
11. Jill: yes?
12. Damien: [*looks away, smiles, lets head fall, looking at table*] nnhh
13. Damien: [*looks up, then away, then up, then away, grinning*]
14. Jill: shall we go to the toilet Damien?

Extract 5. A-VD04-9.30

Then about 25s later, offers and alternative to the toilet

Jill: Shall we go to the toilet or do you wanna go and watch the television?

Do repeat questions facilitate communication?

Basic sentence structure

- *You want an apple*

(Subject + Verb + Object)

What happens to the sentence structure when we use a question?

- *Do you want an apple?*

(Verb to do + Subject + Verb + Object)

Typical follow up questions....

- What do you want? Do you want an apple? Or do you want a banana? You like apples, don't you?

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.

Other Complexities

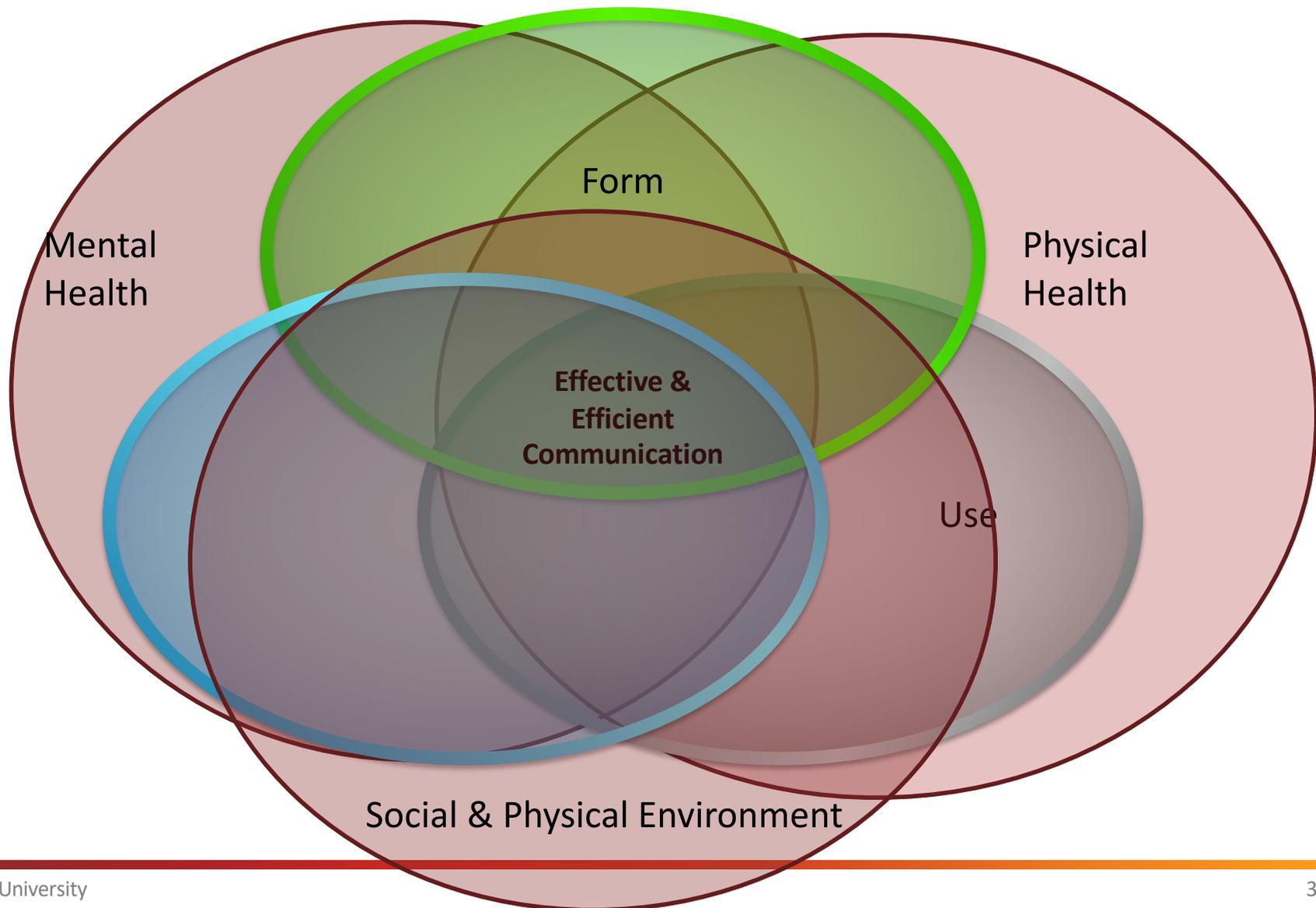
What does it mean to lack intentional communication according to criteria beyond one's sensory, physical and/or intellectual capacity?

What does it mean to have some symbolic language, but not sufficient to sustain language development?

What are the long term implications of problems in one or more of the areas of form, content or use?

How do we respond to interaction with people with profound intellectual disability so that we ensure social connection and avoid risk of ignoring that person altogether or, thinking we know “what they want”?

Understanding Complexity



The Symbolic but not Quite Linguistic Plateau

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

Hilary Johnson (2012)

Using Whatever Means Possible ...

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)

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Subtle Behaviour as Communication

People in the environment may not notice or view unconventional behaviours as being communicative, resulting in

- Learned Helplessness whereby the person stops trying and becomes very passive, no longer trying to interact with others.

OR

- Challenging Behaviours, whereby they modify and intensify their behaviours in order to get a response, and thereby experience some effect on their social environment or have their needs and wants met.

When symbols are not the medium

Affect attunement in communicative interactions between adults with profound intellectual disabilities and support workers (Sheridan Forster, 2011)

“...the immediate recasting of the emotional-behavioural state of one person by another person, using emphasised behaviours” (Forster & Iacono, 2014, p. 1106)

“**Effort and attention example:** P21 gazing at DSW drops head to right then raises it and DSW raises her eyebrows then nods down” (Forster & Iacono, 2014, p. 1115)

Take aways

Focus on the social interaction – its not just what you say

Direct communication to the person

Minimise questions

Use complete sentences, reducing to simple phrases or single words when options are being given or to direct understanding

Use and make available all modalities

Give opportunities to initiate

Watch, listen, wait, respond

Learn to be comfortable with long pauses



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Thank you

With thanks to Nick and Jane

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