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Evidence-based approaches to working on communication with children and adults with profound ID: challenges and opportunities

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Overview:

- Communication as a human right.
- An inclusive definition of communication.
- People with profound intellectual disability (ID)
- Development of early communication
- Communication assessments for people with profound ID.
- Evidence-based early communication intervention strategies.

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Communication is a Human Right

- This position is supported by
  - Article 19 of the Universal Declaration of Human Rights,
  - by academics (e.g. Sen, 2015),
  - by researchers and practitioners (e.g. McLeod, 2018) and
  - by people with communication disabilities and their supporters (e.g. Murphy et al., 2018).
- Many people with complex needs, including those with profound intellectual disabilities, are not able to exercise this right, because they have not had the opportunity to develop or use their communication skills.
- AAC, in its various forms, can give access for many to this basic human right.

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What is Communication? An Inclusive Definition

'Communication is about two or more people working together and coordinating their actions in an ongoing response to each other and the context'

(Bunning, 2009, p.48)

'Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or non-linguistic forms, and may occur through spoken or other modes.'

www.asha.org/policy/GL1992-00201.htm

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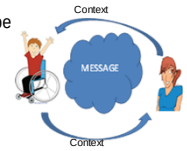
Advantages of these definitions for early communicators and for people using AAC

- **All children and adults must be thought of as communicators.**
- The roles of 'sender' and 'receiver' become blurred.
- Communication is a joint effort and messages may be co-constructed by two or more communication partners.
- The importance of the communication context is recognised.



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Children and Adults with Profound ID

Cognitive development that is very low or untestable, and increased likelihood of:

- Visual impairment (van Splunder et al. 2006) and hearing impairment (Kerr et al., 2003),
- Severe motor impairments (van Timmeren et al., 2016),
- Limited or no comprehension of speech, and communication at pre-symbolic or proto-symbolic levels (e.g. Dhondt et al., 2020; Iacono et al., 2009),
- Multiple health problems including epilepsy (van Timmeren et al., 2017),
- Fluctuating arousal levels (Guess et al., 2002)
- Chronic pain (Beacroft & Dodd, 2009).

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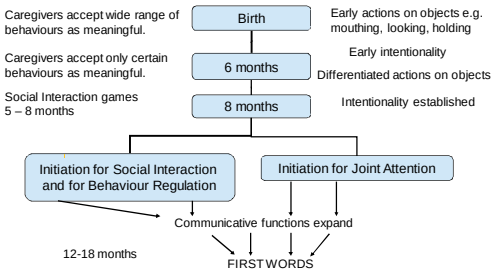
How communication develops – 1 (see e.g. Bruner, 1975)



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From Contingency Awareness (CA) to Intentionality

- CA: the awareness of an association between two events; the relationship between a specific *cause* or *action* and an *effect* (O'Brien et al., 1994).
- In England, this level is required for accessing specialist AAC services.
- Leads to Intentionality: the realisation that *you* can have an effect on the environment – and how.
- Achieved around 4-6 months in typical infants, presumably as a result of repeated chance experiences (J.S. Watson, 1966).
- Being treated as a communicator may lead on to Intentional Communication; using another person to make something happen.

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Secondary Motivational Impairment or Learned Helplessness

- Probably the most important thing you will ever learn!

WHY?

- Failure to acquire intentionality means a lack of awareness that one can have an effect on the world.
- Can cause a progressive reduction in attempts to engage with objects and people.
- May be associated with increased self-involvement or self-stimulatory behaviour.

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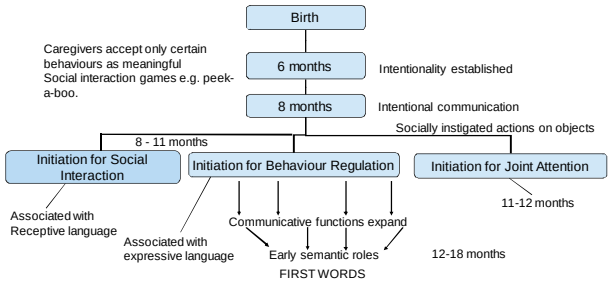
How communication develops – 2 (Crais et al., 2004, Stewart et al., 2021)



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Implications of this account of development

- Communication develops through both **cognitive** and **social-interactive** routes.
- Communication develops in small, identifiable steps
- Opportunities for supporting development along these steps can come from both social and cognitive areas.
- The development of intentionality is a significant step.
- Communication partners play a very important role.
- Progress towards/in AAC draws on both world knowledge (cognition) and on interest and skill in interacting with others (social).

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Condition-related challenges

- Communication development can be affected differently by different disabilities:
  - Visual and hearing difficulties affect feedback from actions.
  - Cioni et al. (1993); cerebral palsy (CP) and the associated difficulties with movement and action have an effect on cognition
  - Bjorgaas et al. (2012); communication difficulties in young children with CP and associated with mental health challenges.
  - Sievers et al. (2018); establishing Initiations for Joint Attention is challenging for children with Autism Spectrum conditions.
  - Stewart et al 2021: In typically developing children, frequency of gestures is a predictor of language acquisition. Should we pay more attention to how children with developmental disabilities convey ISI, IBR & IJA?

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Assessment of Early Communication

- If we are assessing *pre-verbal* communication, does the language of the assessment, e.g. Swedish, English, Hindi, matter?
- What aspects of communication are we trying to assess?
- Most communication assessments assume children's development will follow a broadly typical trajectory – can we assume this will be true?
- Because our learner's communication can be idiosyncratic, a familiar person should be involved in the assessment and assessment should be carried out over time.

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Assessments of Early Communication - 1

Routes for Learning (Welsh Govt, 2020)
hwb.gov.wales/curriculum-for-wales/routes-for-learning
- Assesses early cognition and communication up to joint attention and early symbolic functioning
- Free online materials and guidance, including video examples

Communication Matrix (Rowland, 2011, 2013) https://communicationmatrix.org
- Swedish versions for parents and professionals available at
- https://communicationmatrix.org/Content/Translations/2010ParentCMSwedish.pdf
- https://communicationmatrix.org/Content/Translations/2010ProfessionalCMSwedish.pdf
- Assesses **expressive** communication 0-24 month level

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Assessments of Early Communication - 2

Affective Communication Assessment (Coupe et al., 1985; Coupe-O'Kane & Goldbart, 1995)
- complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/m08p020b.html
- Explores pre-intentional communication and transition to intentional communication in detail.

Preverbal Communication Schedule (Kiernan& Reid, 1987; Smidt, 2017)
- Revised version available at www.mosaiccommunication.com.au/pvcs
- Assesses communication behaviours and functions up to early words, signs and symbols.

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From early development and assessment to intervention strategies

Communication develops through both cognitive and social routes; so opportunities for early intervention and preparing for AAC draw on support for cognitive *and* social development.

- Evidence-based approaches to support early cognitive development
- Evidence-based approaches to support the development of social interaction
- Evidence-based early communication interventions

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Contingency awareness and Intentionality

Cause & effect activities can teach learners that their actions have consequences.

This learning is pleasurable (Raab et al., 2009).

It can be achieved through "no tech" and "light tech" activities, including experience of activating single switches:

e.g. by action or sound (Lancioni et al, 2006a & b; 2009, Roche et al, 2015)
- to operate a CD player, a fan or toy,
- to make or to convey a choice or
- to gain social contact

Intentionality can be a step towards intentional communication and AAC.

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Practical strategies for developing intentionality 1

Opportunities to affect and control the environment do not require expensive equipment.

There are many "no tech" experiences that give learners feedback on their actions.
- Playing with water or other responsive media
- Making a mobile move
- Hitting a drum or gong
- "Bobo" dolls

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Promoting the development of intentionality 2

Mainstream technologies also offer opportunities for experience of controlling the environment e.g.:

- Piano keyboard apps
- Sensory light box app (starts with cause & effect, but with options for small onward steps) www.youtube.com/watch?v=ioYkK_i6XDo www.youtube.com/watch?v=ihMSw8BIXF4

Specialist technology includes:

- Microswitch controlled vibration pad, toys, music etc.

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Evidence for switch-based interventions

- Roche et al. (2015) systematic review: 18 studies, results "consistently positive."
- Study design: Single Case Experimental Designs, typically 1-8 participants.
- Most were conducted by Lancioni and colleagues.
- Few evaluations in naturalistic settings; exceptions –
  - Classrooms: Barber (2000); Ware & Thorpe (2006)
  - Family home: Singh et al. (2003)
- Switch-based approaches could be more widely used by practitioners in the UK (Goldbart et al., 2014; Mansell, 2010).
- What about Sweden?

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Social development: practical considerations

- Importance of contingent, positive, responsive communication partners (e.g. Warren et al., 2010)
- Consistent, responsive and sensitive communication partners enhance quality of life (Goldbart & Caton, 2010, Hostyn & Maes, 2009)
- and provide enjoyable interactions with others (Ware & Healey, 1994)
- One challenge is TIME:
  - Should interaction "sessions" be timetabled or spontaneous?
  - Can we integrate interaction opportunities into everyday routines? (Not easy: Samuel et al., 2008; Warren et al. 2010)
  - (How) can we make time for learner-led interactions?

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Social development & interaction: Issues

Challenges:

- Many studies report impact on communication partners but not necessarily on learners.
- Systematic reviews e.g. Hutchinson & Bodicoat (2015), Wood & Standen (2021) find few high quality studies (&/or poor reporting).
- Studies with classroom staff and in adult services are affected by practical issues e.g. learner illness, staff turnover, little long term follow-up.
- Few studies on parent intervention: Exception - Rensfeldt Flink et al. (2020); training positively valued and some evidence of increased parental responsiveness.

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Social development & interaction: Evidence-based approaches

- Intensive Interaction (see next slide)
- Objects of Reference (see later slide)
  - Only two evaluations with mixed findings, but widely used in the UK and related to other sensory or object cueing approaches.
- Service development approaches:
  - Creating Contingency-sensitive Environments (Ware, 1994) – management support influences intervention success.
  - OIVA (Koski et al., 2010; 2014) – sustainable change requires management support. Changing staff attitudes is important.
  - Ways to Communicate (Granlund & Olsson, 1990) / Picture It (Bloomberg et al., 2003) – some positive changes in both staff and learners.

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Intensive Interaction (Nind and Hewett, e.g. 1998; 2006)

- Based on the highly responsive, individualised interactions between babies and caregivers.
- Aim: to promote social communication, enjoyment of interaction and enhance learner's sense of agency.
- May change staff responsiveness outside sessions.

- Focus on fundamentals of communication, e.g. taking turns, sharing personal space, understanding and using: eye contact, facial expression, physical contact, nonverbal communication, vocalisation.
- Evaluations mainly SCED e.g. Leaning & Watson, 2006; Samuel et al, 2008.
- Service wide evaluations reporting change in staff views and behaviour only – Clegg et al., 2018; Firth et al., 2008.
- Systematic review by Hutchinson & Bodicoat (2015): Some evidence of effectiveness, but more research needed.

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Objects of Reference

- Objects used to represent actions, events or people to support communication, e.g. a cup for a drink.
- Aim for increased awareness of the link between the objects and actions, events, people, etc.
- Used to tell the learner what is going to happen next, e.g. spoon for lunch, water for a bath.
- Progression to use by the learner to convey wants, needs and preferences.
- Linked with visual timetables and to symbolic AAC.
- Only two evaluations (Jones et al., 2002; Harding et al., 2011) with mixed findings.

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Conclusions

- Everyone can communicate!
- Cognitive development and social interaction are both important for developing communication and underpin use of AAC.
- Appropriate ways to assess early communication in children and adults with profound ID are available.
- Several intervention approaches support the development of early communication preparing for use of AAC but more research on their effectiveness is needed.
- Research with this group is not easy (Granlund & Wilder, 2006; Maes et al., 2020) but is important to support practice.

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Questions and discussion

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