Speech and Language Therapy interventions and AAC in Rett Syndrome

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Association Française du Syndrome de Rett
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Rett Syndrome

Communication difficulties	• Speech production • Expressive and receptive language
Motor difficulties	• Muscle tone • Hand use • Scoliosis
Fluctuating attention level	
Stereotyped behaviors (Ferreira & Teive, 2020; Neul et al., 2010)	• Hand mouthing • Clapping, wringing hand
Medical conditions, sensorial	• Epilepsia, scoliosis,... • Oral sensitivty, bruxism, swallowing difficulties

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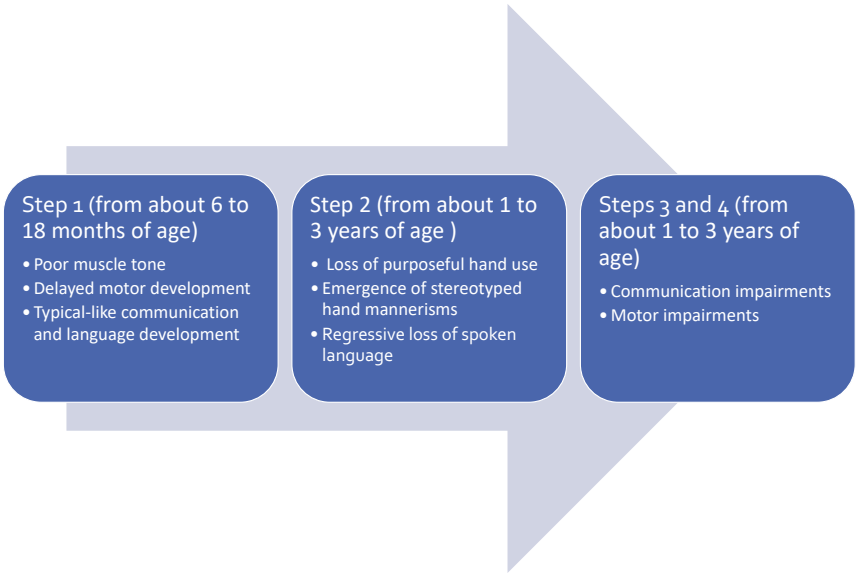
Rett Syndrome

Heterogeneity

Developmental stages



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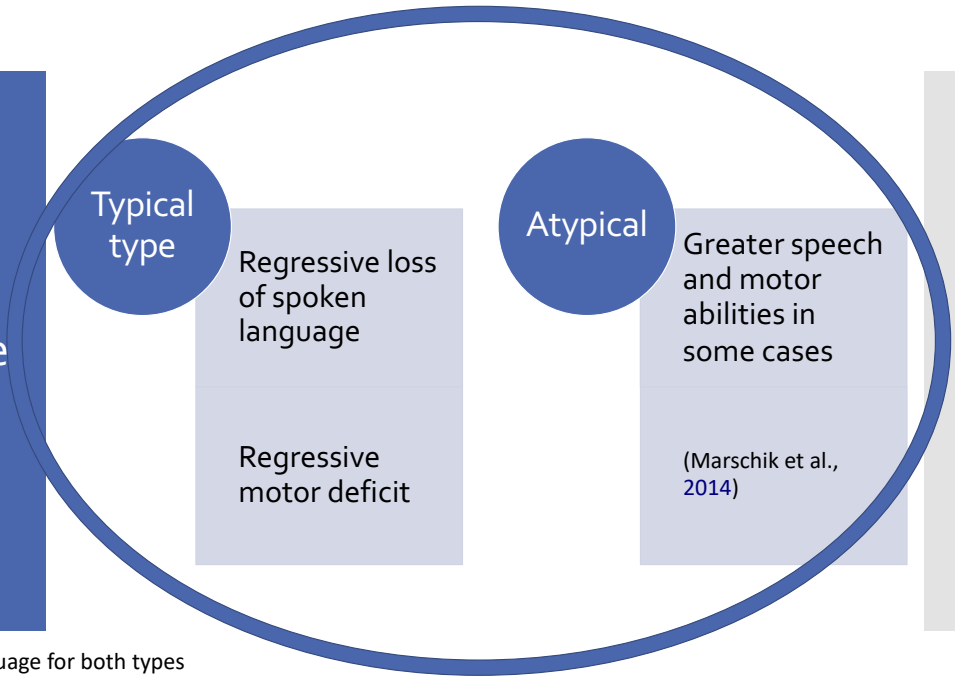
Heterogeneity

Rett Syndrome types (Operto et al., 2019)



Regressive loss of spoken language for both types
(Bartolotta et al., 2011; Hagberg, 2002; Marschik et al., 2014; Neul et al., 2014).

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Rett Syndrome

Which intervention?

- Relevance of SLT interventions
- Communication is a right (CRPD, UNO, 2006)
- Evidence-based practices (Sigafoos et al., 2023)
- AAC is a major treatment priority (Larriba-Quest et al., 2020)

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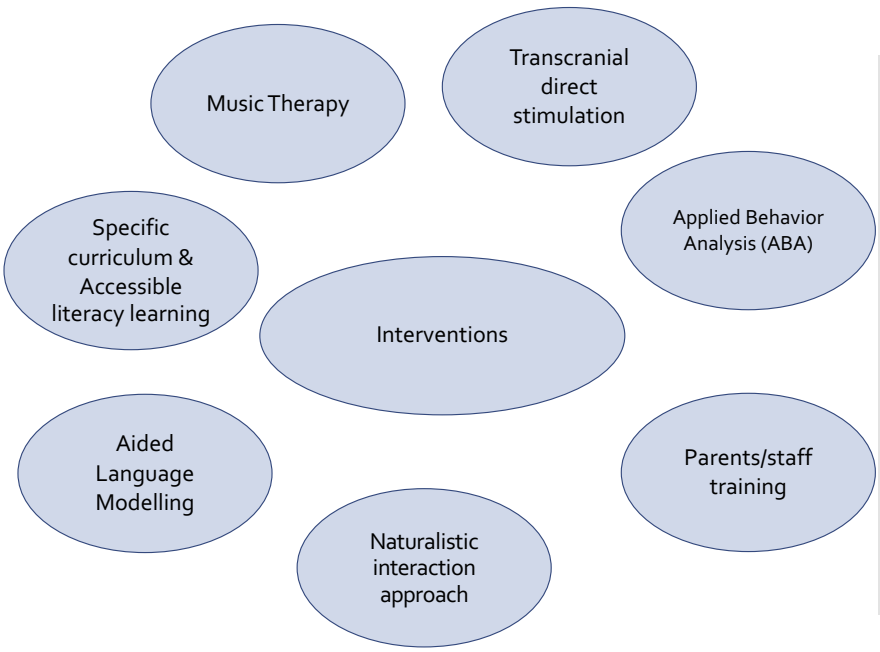
Rett syndrome

What kind of intervention?



(Sigafoos et al, 2023)

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Rett syndrome

What kind of intervention?

- Literature review (Sigafoos et al., 2023)
  - 16 articles
  - 100 participants from 3 to 47 years of age.
- SGD
  - Stasolla et al., 2014
  - Wandin et al., 2021
- Microswitch
  - Simacek et al., 2017, 2011
  - Byers et al., 2015.
- Eye-gaze controlled AAC device (Wandin et al. 20201)
  - Core Words
- Literacy & Meditated reading learning approach
  - Feuerstein et al. (1988)
- Limited effects of musicotherapy on communication

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Decision-making

- SLPs representations Im Sweden (Rensfeldt Flink et al., 2022a)
  - 90 SLPs
  - CAA recommandée par les orthophonistes
  - Critères de décision:
    - Child characteristics
    - Social networks

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Effects of AAC

- Literature review (Amoako & Hare, 2020)
- Lack of research in communication interventions
- 13 studies, N=60
- 11 are about communication.
- 8 about symbols or microswitch:
  - 1 about PECS and SGD (Stasolla et al., 2014)
  - 1 gaze control (Hetzroni, Rubin, & Konkol,2002)
  - 1 SGD (Simacek et al., 2016)
  - 2 with-micro switch(Stasolla and Caffo, 2013, Lancioni et al., 2014)

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Effects of AAC

- Literature review (Amoako & Hare, 2020)
- Positive effects :
  - Making choice (Stasolla, F., Perilli, V., Di Leone, A., Damiani, R., Albano, V., Stella, A., & Damato, C., 2015)
  - Requests (Simacek, J., Reichle, J., & McComas, J. J. , 2016)
  - Literacy (Fabio, Castelli, Marchetti, & Antonietti, 2013)
  - Attention (Fabio, Giannatiempo, Oliva, & Murdaca, 2011)
  - Adaptative behaviors (à l'aide de contacteurs) (Stasolla & Caffo, 2013)
  - Stereotypies (Stasolla et al., 2014)

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Rett Syndrome

What kind of intervention?

- Individuals with the preserved speech variant of Rett syndrome might be more responsive to speech-mode interventions (Sigafoos et al., 2023)?
- Little research on the impact of intervention on the developmental trajectory of individuals with Rett syndrome.
  - An interesting line for future research would be to investigate whether it is possible to preserve more speech in persons with atypical Rett syndrome through early intensive speech therapy.
- the stage and type of Rett syndrome are generally not consistently reported (Sigafoos et al., 2023: p. 1)

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Life span

- Lack of research with adults (Maratsos, 2008)
- Positive outcomes for all studies but one
- Potential value of providing communication intervention to the adult population (Matson et al., 2008)

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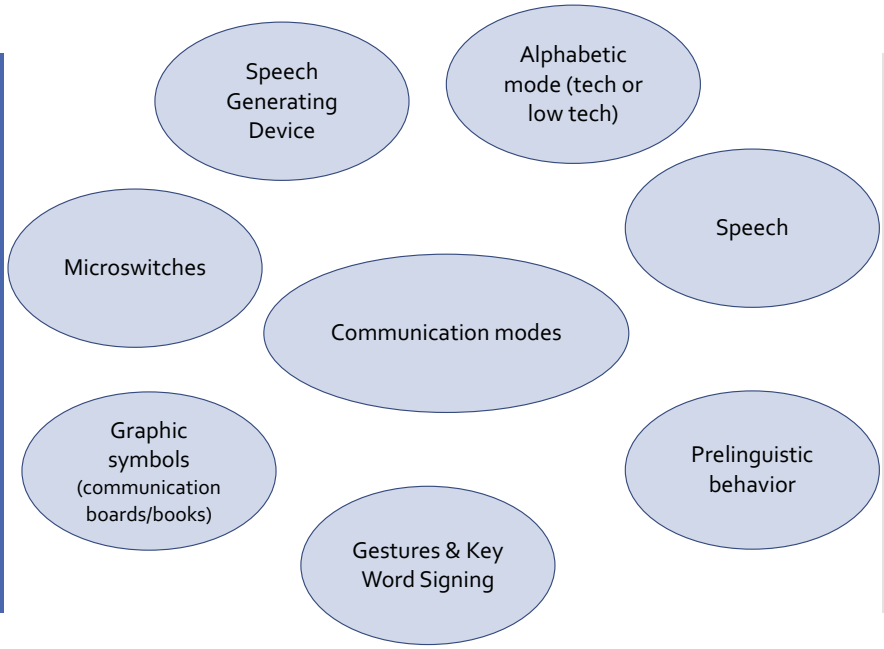
Communication modes



(Sigafoos et al, 2023)

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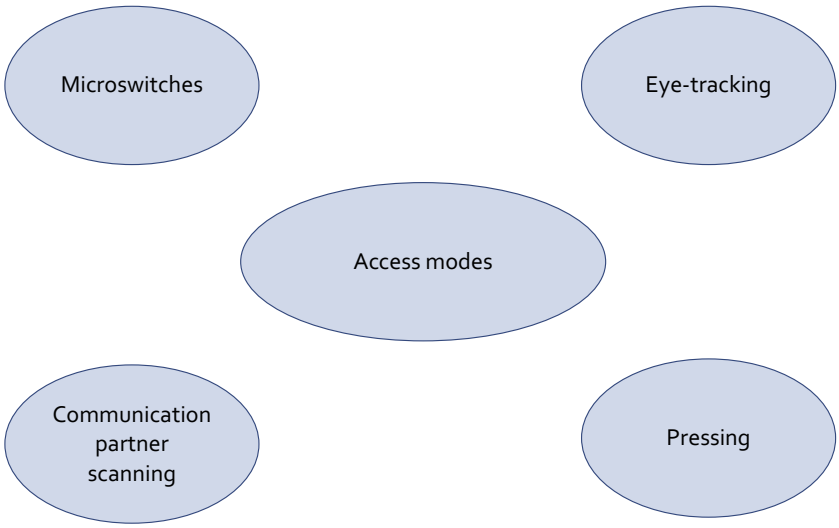
Access modes



(Sigafoos et al, 2023)

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Assistive Technology

- Develop the agency in context (Lancioni et al., 2022)
  - Cause and effect (Lancioni et al., 2003)
  - develop children's indice of happiness
- Micro-switch with vocals (Lancioni et al., 2001)

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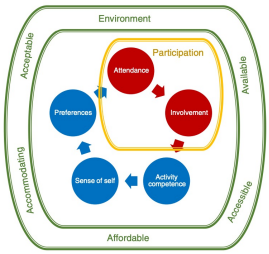
Participation and engagement

- Participation restriction
  - *"limited resources, combined with a mechanical, unimaginative care culture and slight ambition or means to find out what a good life might mean for a particular individual with very limited means to express his or her dreams, wishes, hopes and desires."* (Vehmas et al, 2021, p. 2-3)
- Participation



The participation concept:
Attendance: defined as 'being there' and measured as frequency of attending, and/or the range or diversity of activities in which an individual takes part.
Involvement: the experience of participation while attending, including elements of motivation, persistence, social connection, and affect.

Related concepts:
Activity competence: the ability to execute the activity being undertaken according to an expected standard.
Sense of self: intra-personal outcomes of participation related to confidence, satisfaction and self-esteem.
Preferences: the opportunity to choose and to be able to undertake activities that are meaningful or valued.

Environmental dimensions:[3]
Availability: objective provision of activities or services.
Accessibility: ability (or perceived ability) to access the activity or situation.
Affordability: financial, time, energy, and other resource constraints to attending.
Accommodability: the ability of the situation to be adapted or modified.
Acceptability: the person's acceptance of the situation, and other people's acceptance of the individual in the activity setting.

(Imms et al., 2016)

- Engagement and participation (Alant, 2016)

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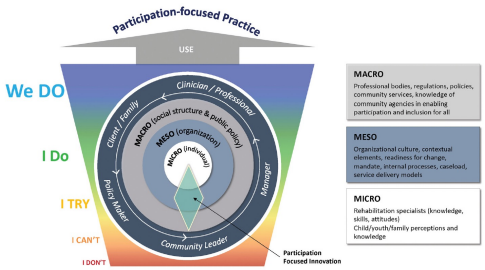
Participation and engagement

- Interventions
  - Work everyday life situations (Imms, 2020)
  - make participation possible in her·his social context (King et al., 2020).
- Cultural change and collaboration between stakeholders



(Anaby et al., 2022 : 1749)

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AAC

- Multimodality (Cress & Marvin 2003, Harding et al. 2011)
  - One modality can have an effect on others (Dunst et al., 2011)
  - Various modes can be used in context (Simacek et al., 2018):
    - Objets 3D (22% des cas), pictograms (15,3%), CGD(40,7%) ou des Microswitch (50,8%).
- Modality Sampling (Johnston et al., 2012)

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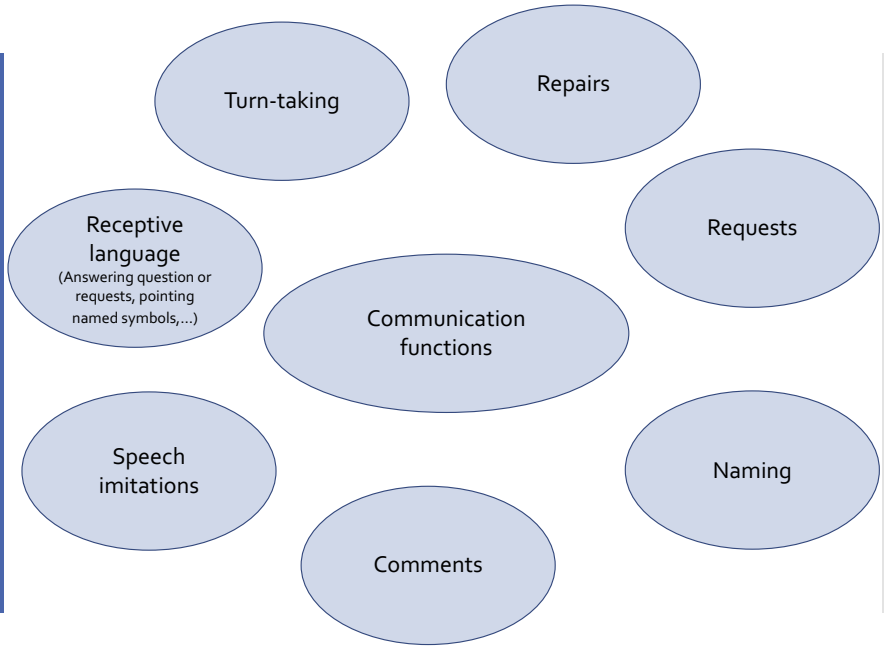
Communication functions & interaction management



(Sigafoos et al., 2023)

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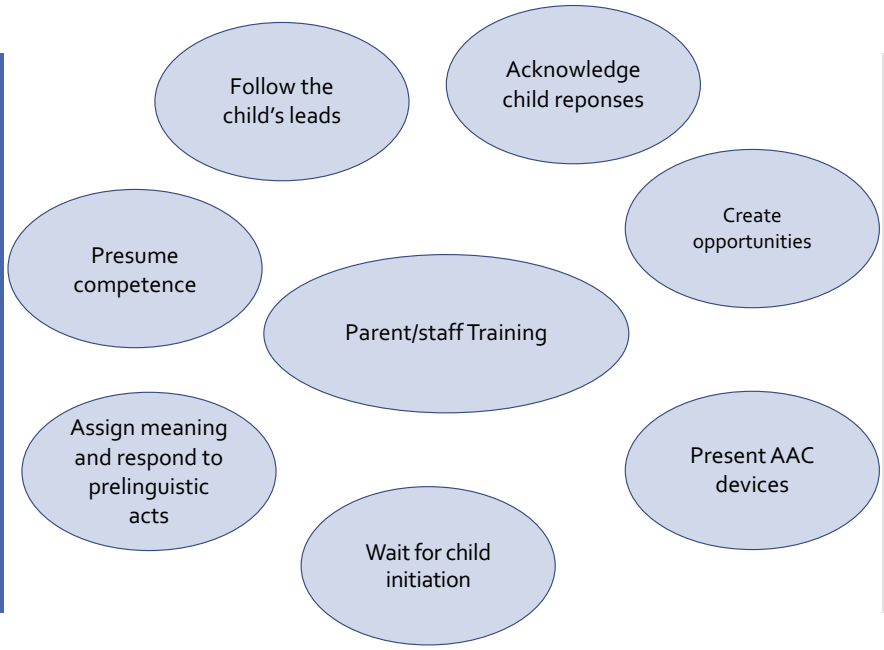
Parent/staff training

Communication partners



(Sigafoos et al, 2023) study 2, 15

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Communication partners

- Communication quality of children varies regarding communication partner way to communicate (Hostyn & Maes, 2009, Van Keer et al., 2017)
- Communication partners have to be implicated in CAA interventions (Van keer & Maes, 2016)
  - ➢ They can stimulate AAC devices use in context
- Training of the parents
  - not sufficient (Piškur et al., 2017)
- Program of training for parents of children with S/PIMD for Communication Partner in Sweden (Rensfeldt Flink et al., 2022b)

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Indicators of communicative intent

- Observation
  - Indicators of communicative intent (Bunning, 2009)
    - Alternating eye gaze
    - Clear waiting for a response
    - Active seeking of proximity
    - Systematic variation in behaviour
    - Persistance and intensity of behaviour
  - Singh et al. (2015)
    - Team observation
    - Communication opportunity
- Co-producing knowledge (Nind & Strnadová, 2020)
  - Nicola Grove : co-constructing stories, in story telling

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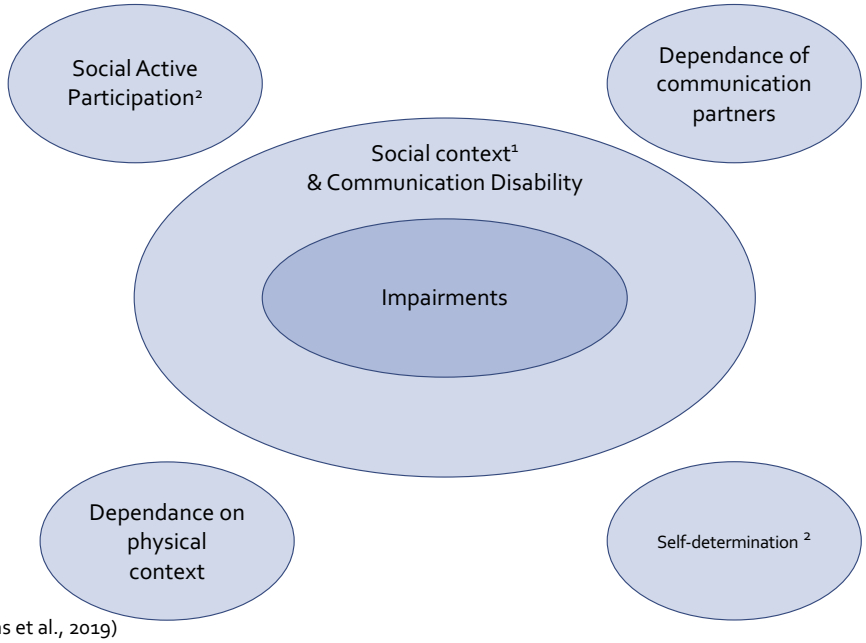
Communication disability



¹ Disability Creation Process (Fougeyrollas et al., 2019)

² Convention on the Rights of Persons with Disabilities (CRPD, UNO, 2006)

³ Kamstra et al. (2017)

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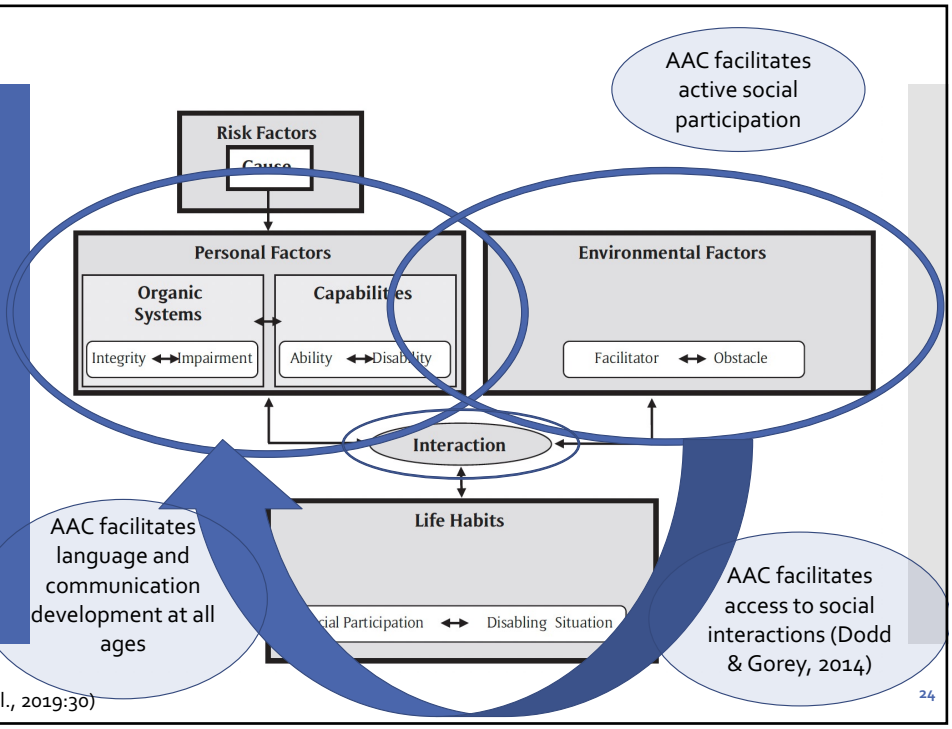
AAC & Disability Creation Process (Fougeyrollas et al., 2019)



(Fougeyrollas et al., 2019:30)

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AAC goals

Communication Accessibility

- Understandability of messages directed to the person
- Active social participation in interactions

Language and communication development

- Through all life-span

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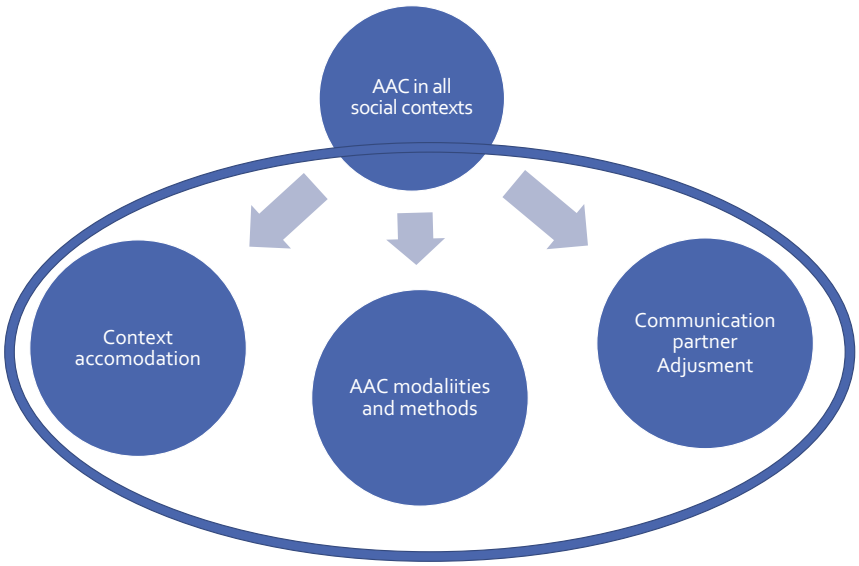
What is AAC?



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Factors predicting AAC outcomes for ASD children

(Meta-analysis Sievers et al., 2018, 2020)

- Communication partner level of knowledge
- Perception and representation about AAC benefits
- Modelling from Communication Partners
- Speech & Language Therapy Intensity

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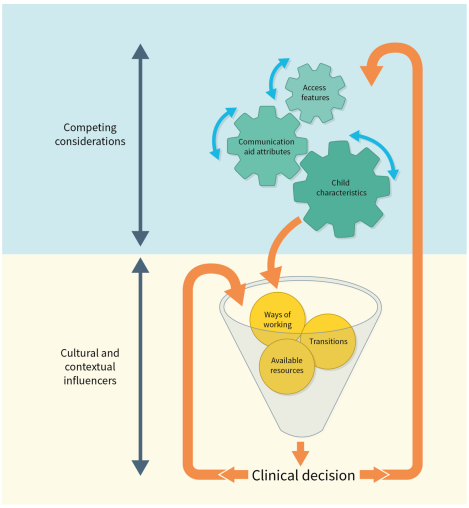
Decision-making

I-ASC Explanatory Model

(Lynch & Murray, 2019, 2023),

- **Identifying Appropriate Symbol Communication Aids for Children who are non-speaking: Enhancing clinical decision-making (I-ASC, Lynch & Murray, 2019, 2023)**



(Lynch & Murray, 2023: 13)

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AAC Modes

Goals

Key Word Signing & PODD	Socio-developmental approach, modelling, first words & first words combinations in context, Comprehension support, communication functions aquisition
PECS	Initiation & request
Microswitch	Cause & effect training & first words
Visual scenes (Holyfield et al. 2019a & b)	Contextual 'Just-in-Time' interventions, first interactional and referential abilities
Icons position-centered grid systems (Dukhovny & Thistle 2019) (Minspeak & LAMP Approach)	Robust vocabulary access, Quick utterances production, syntactically and morphologically complete
Icons size-centered grid systems (Dukhovny & Zhou 2016) (Proloquo2Go, TD Snap,…)	Robust vocabulary access, Utterances production, syntactically and morphologically complete

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AAC Modes

Cognitive & Motor Habilities

Key Word Signing	Memory recall abilities / Imitation & Motor abilities
Pictures	Picture understanding/Discrimination, Motor ability to grasp or point
Microswitch	Motor ability to press / Cause & Effect
Visual scenes (Holyfield et al. 2019a & b)	Episodic memory
Icons position-centered grid systems (Dukhovny & Thistle 2019) (Minspeak & LAMP Approach)	Memory recall abilities Learning through motor planning abilities / Navigation
Icons size-centered grid systems (Dukhovny & Zhou 2016) (Proloquo2Go, TD Snap,…)	Icons understanding/Discrimination / Navigation

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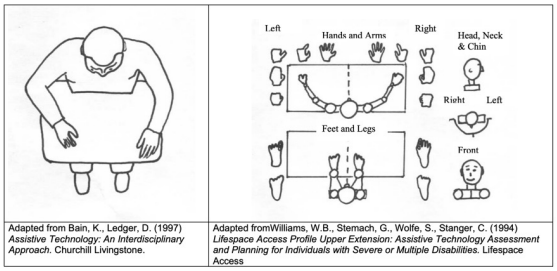
Physical context setting

- Position of AAC tools
  - Assessment
  - Motor abilities
  - Visual field



Adapted from Bain, K., Ledger, D. (1997) *Assistive Technology: An Interdisciplinary Approach.* Churchill Livingstone.

Adapted fromWilliams, W.B., Stemach, G., Wolfe, S., Stanger, C. (1994) *Lifespace Access Profile Upper Extension: Assistive Technology Assessment and Planning for Individuals with Severe or Multiple Disabilities.* Lifespace Access

(https://acecentre.org.uk/)

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Transdisciplinarity

Speech & Language Therapists
- Expertise on language and communication development and disorders
- Assessment of language and communication
- Communication and language rehabilitation methods

Occupational therapists
- Assessment and rehabilitation of motor abilities, body position, functional movements, body posture, auxiliar tools implementation

Psychologists
- Cognitive, adaptative and attention assessment

Special educators & teachers
- Intervention through the daily activities and routines
- Daily observation and assessment

Vision specialists & orthoptists
- Vision assessment, communication tools with contrasts and textures

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Collaboration

(Uthoff et al., 2021)

& cf. Binger et al. (2012)

(Uthoff et al., 2021, p.2)

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AAC assessment tools

- Communication Matrix (Rowland, 2012)
- Social Network (Blackstone, 2004)
- Routes For Learning (Welsh Government, 2014)
- FIATS-AAC (Ryan et al., 2018)

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Pragmatics Profile

(Martin, Small & Stevens, 2017)

- **The Pragmatics Profile for people who use AAC (Martin, Small & Stevens, 2017)**
  - https://acecentre.org.uk/resources/pragmatics-profile-people-use-aac
  - Grid for an interview with communication partners
  - Assessed topics:
    - Context & motivations
    - Reasons to communication & Reactions to communication (Communication Functions)
    - Participation in conversation

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FIATS-AAC (Ryan et al., 2018)

- **Family Impact of Assistive Technology Scale for Alternative and Augmentative Communication (FIATS-AAC) (Ryan et al., 2018)**
  - Survey for parents
  - Children from 3 to 18 years-old
  - 13 measured dimensions
  - Based on the International Classification of Functioning, Disability and Health for Children and Youth (WHO, 2007)
  - 89 statetements with Lickert scale with 7 points
- 7 Child's characteristics
  - Behaviour
  - Communication, social versatility
  - Doing activities, Education
  - Autonomy, Contentment, self-reliance
- 6 Family-related characteristics
  - Caregiver relief
  - Family roles

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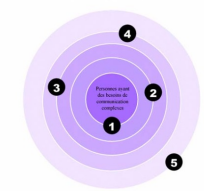
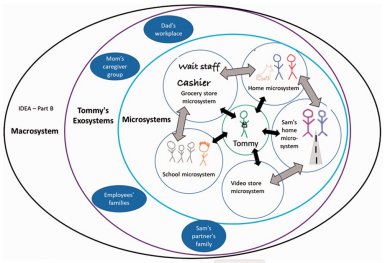
Communication partners- & Family-centered approaches

- **Social Networks (Blackstone, Hunt Berg, 2003)**
  - https://www.attainmentcompany.com/social-networks-package



1. Family
2. Friends
3. Acquaintances
4. Paid workers
5. Unfamiliar communication partners

- **Family-centered Approach**
  - (Coburn et al., 2021: 233)



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A work-in-progress

A Transdisciplinary collaborative platform

AAC HIVE

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AAC HIVE Online grid

Master Thesis at University of Neuchâtel

in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in italian (Ferrari & Giang, 2023)

Observer	Social context	Activity	Date
Parents	Home	Play	
Teacher	Classroom	Meal	
Terapist	…	Shared reading	
…		…	

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AAC HIVE Online grid

Master Thesis

in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in italian (Ferrari & Giang, 2023)

Modality	Communication Function	Dialogue Position
Key Word Signing	Request	Self-initiation
Speech	Comment	Answer
Picture	Question	Repetition
SGD	Naming	Partial prompting

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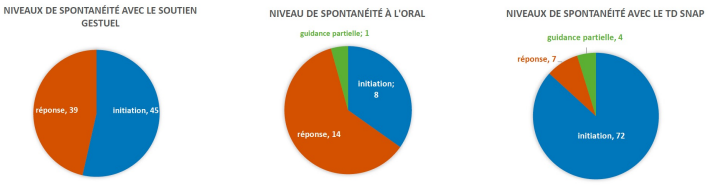
AAC HIVE Online grid

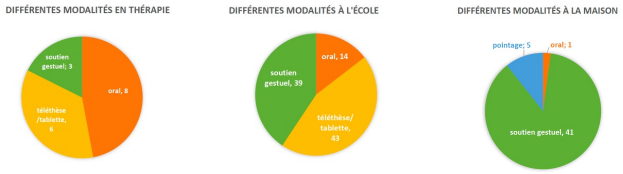
Examples of results

Position in dialogue in each modality



(Boyer & Gross, 2022: 116)

Modality in each context



(Boyer & Gross, 2022: 114-115)

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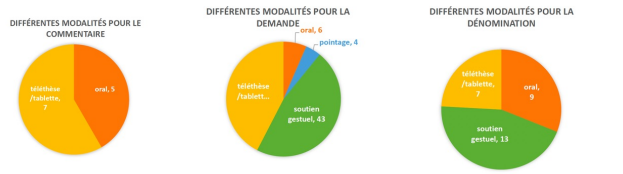
AAC HIVE Online grid

Examples of results

Position in dialogue in each communication function

(Boyer & Gross, 2022: 118)

AAC modality in each communication function



(Boyer & Gross, 2022: 114-115)

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AAC HIVE Online survey

AAC user characteristics

Online grid

in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in Italian (Ferrari & Giang, 2023)

- Diagnosed disorder and AAC modalities
- Communication functions
  - Requesting, refusing, call attention,…
- Lexical and syntactic level
- Sensorial specificities
- Preferred activities or/and sensorial stimulations
- Type of plays
- Level of comprehension

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Online survey

AAC user characteristics

Online grid

in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in Italian (Ferrari & Giang, 2023)

- Communication fonctions
- Turn-taking and conversation habilities for:
  - Self- or other- initiated initiations or clsings of …
    - Conversations
    - turns
    - topics
  - Self- or other- initiated initiations of repairs

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Online survey

Communication Partner Characteristics

Master Thesis
in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in Italian (Ferrari & Giang, 2023)

- Level of familiarity of the communication partner
- Self assessment of
  - the level of knowledge about AAC, i.e. tools & methods *
  - The representations about AAC
- Needs of training and of indirect intervention
- Communication partners communication AAC user directed speech characteristics:
  - Modalities
  - Open vs. closed questions
  - Level of modelization with AAC tools*
  - Offered opportunities of communication
  - Time adjustments

* Lickert scale with 7 levels

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Online survey

Communication Partner Characteristics

Master Thesis
in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in Italian (Ferrari & Giang, 2023)

- Familiarity with the AAC User
- Knowledge about AAC, i.e. tools & methods *
- Representations about AAC
- Needs of training and of indirect intervention
- How they interact with the AAC User
  - Modalities
  - Open vs. closed questions
  - Level of modelling with AAC tools*
  - Offered opportunities of communication
- Time & pause

* Lickert scale with 7 levels

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Online survey

AAC User characteristics

Master Thesis
in French (Bayle, 2020, Pagnier, 2020, Vacher, 2021, Boyer & Gross, 2022, Müller & Pierre, 2023)

in Italian (Ferrari & Giang, 2023)

- Sensorial specificities
- Preferred activities or/and sensorial stimulations
- Level of comprehension
- Conversation abilities
  - Self- or other- initiated closings of conversations, turns or topics
  - Self- or other- initiated repairs

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Some comments

- Heterogenity of characteristics of people with Rett Syndrome regarding communication
  - Patient-centered approach
- SLT and CAA
  - Goal: participation in social contexts
  - collaboration between stakeholders
    - Observations
    - Goals setting
  - Training of stakeholders
- A tool is necessary to
  - facilitate collaborative among stakeholders
  - share observations for assessment
  - By-pass geographical or agenda barriers allowing non-synchrone collaborations
  - facilitate team organization, trainings and training needs identification

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Thank you for your attention

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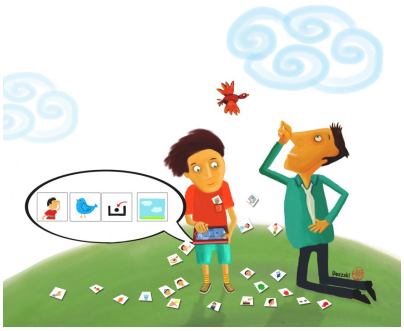
Any question?



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References

Ainsworth, M. K., Evmenova, A. S., Behrmann, M., & Jerome, M. (2016). Teaching phonics to groups of middle school students with autism, intellectual disabilities, and complex communication needs. Research in Developmental Disabilities, 56, 165–176. doi:10.1016/j.ridd.2016.06. 001

Amoako, AN, Hare, DJ. (2020)Non-medical interventions for individuals with Rett syndrome: A systematic review. *J Appl Res Intellect Disabil*. 2020; 33: 808–827. https://doi.org/10.1111/jar.12694

Auer, P., & Hörmeyer, I. (2017). Achieving intersubjectivity in augmented and alternative communication(AAC): Intercorporeal, embodied and disembodied practices. In: Meyer C, Streeck J, and Jordan S (eds). Intercorporeality: Emerging socialities in interaction. Oxford: University Press, pp. 323–60.

Bartolotta, T. E., & Remshifski, P. A. (2013). Coaching communication partners: A preliminary investigation of communication intervention during mealtime in Rett syndrome. Communication Disorders Quarterly, 34(3), 162–171. doi:10.1177/1525-740112453165

Bean, I. (2011). *Switch Progression Road Map*. Inclusive Technology. http://www.inclusive.co.uk/Lib/Doc/pubs/switch-progression-road-map.pdf.

Byiers, B. J., Dimian, A., & Symons, F. J. (2014). Functional communication training in Rett syndrome: A preliminary study. American Journal on Intellectual and Developmental Disabilities, 119(4), 340–350. doi:10. 1352/1944-7558-119.4.340

Blackstone, S.W., & Hunt Berg, M- (2003). Les réseaux sociaux. Un inventaire de la communication pour les personnes ayant des besoins de communication complexes et leurs partenaires. Augmentative Communication Inc. (http://www.constance-lethbridge.qc.ca/CRCL_WEB/datas/Fichiers/crcl_160.pdf).

Boyer, M. & Gross, L. (2022). Élaboration et passation de moyens d'évaluation collaborative et dynamique auprès des partenaires de communication d'enfants utilisateur·trice·s de moyens de Communication Alternative et Améliorée. Mémoire de Master de Logopédie non publié. Université de Neuchâtel.

Bunning, K. (2009). Making sense of communication. In J. Pawlyn & S. Carnaby (Eds.), *Profound intellectual and multiple disabilities: Nursing complex needs* (pp. 46–61). Wiley Blackwell.

Clarke, M.T., Sargent, J, Cooper, R, Aberbach, G., McLaughlin, L., Panesar, P., Woghiren, A., Griffiths, T., Price, K., Rose, C., Swettenham, J. (2020). Development and Testing of the Eye-pointing Classification Scale for Children with Cerebral Palsy. *Disability and Rehabilitation*, 1-6. https://doi.org/10.1080/09638288.2020.1800834.

Coburn, K. L., Jung, S., Ousley, C. L., Sowers, D. J., Wendelken, M., & Wilkinson, K. M. (2021). Centering the family in their system: a framework to promote family-centered AAC services. *Augmentative and Alternative Communication*, *37*(4), 229-240. https://doi.org/10.1080/07434618.2021.1991471 .

Dukhovny, E. & Zhou, Y. Y. (2016): Effects of icon size and location on speed and accuracy of SGD access. Augmentative and Alternative Communication, 32(4), 241-248.

Dukhovny, E. & Thistle, J. J. (2019). An exploration of motor learning concepts relevant to use of speech-generating devices. Assistive Technology, 31(3), 126-132.

50

References

Ferreira, M. G., & Teive, H. A. G. (2020). Hand stereotypies in Rett syn- drome. Pediatric Neurology Briefs, 34(0), 2. doi:10.15844/pedneurbriefs- 34-2

Fougeyrollas, P., et al. (2019). The Disability Creation Process Model: A Comprehensive Explanation of Disabling Situations as a Guide to Developing Policy and Service Programs. Scandinavian Journal of Disability Research, 21(1), 25–37. DOI: https://doi.org/10.16993/sjdr.62.

Hagberg, B. (2002). Clinical manifestations and stages of Rett syndrome. Mental Retardation and Developmental Disabilities Research Reviews, 8(2), 61–65. doi:10.1002/mrdd.10020

Hostyn I, Maes B. (2009). Interaction between persons with profound intellectual and multiple disabilities and their partners: a literature review. *J Intellect Dev Disabil.* 34(4): 296–312.

Holyfield, C., Caron, J. G., Drager, K. & Light, J. (2019a): Effect of mobile technology featuring visual scene displays and just-in-time programming on communication turns by preadolescent and adolescent beginning communicators. International Journal of Speech-Language Pathology, 21(2), 201-211.

Holyfield, C., Caron, J. G. & Light, J. (2019b): Programing AAC just-in-time for beginning communicators: the process. Augmentative and Alternative Communication, 35(4), 309-318.

Julien, H. M., Parker-McGowan, Q., Byiers, B. J., & Reichle, J. (2015). Adult interpretation of communicative behavior in learners with Rett syn- drome. Journal of Developmental and Physical Disabilities, 27(2), 167– 182. doi:10.1007/s10882-014-9407-z

Jullien, S. (2020). Le choix des moyens de Communication Alternative et Améliorée (CAA). Le cas des communicateurs émergents. Tranel, 73:27-47. http://www.unine.ch/files/live/sites/tranel/files/Tranel/73/27-48_Jullien_def-1.pdf

Jullien, S. (2021). Soutenir la communication des personnes polyhandicapées: les moyens de CAA. Revue Suisse de Pédagogie Spécialisée, 3, 30-.36.

Kamstra, A., van der Putten, A. A. J., Post, W. J., & Vlaskamp, C. (2015). Informal social networks of people with profound intellectual and multiple disabilities: relationship with age, communicative abilities and current living arrangements. *Journal of applied research in intellectual disabilities : JARID*, *28*(2), 159-164. https://doi.org/10.1111/jar.12115

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References

Kamstra, A., van der Putten, A. A., & Vlaskamp, C. (2017). Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands. *Journal of intellectual disabilities : JOID*, *21*(2), 158-174. https://doi.org/10.1177/1744629516653037

Lancioni, G. E.; Singh, N. N.; O'Reilly, M. F.; Sigafoos, J.; Alberti, G.; Campodonico, F. et al. (2022) Everyday Technology to Help People with Intellectual and Other Disabilities Access Stimulation via Functional Motor Responses and Improved Body Posture. In : Developmental neurorehabilitation, vol. 25, n° 1, p. 59–67. DOI: 10.1080/17518423.2021.1989513.

Larriba-Quest, K., Byiers, B. J., Beisang, A., Merbler, A. M., & Symons, F. J. (2020). Special education supports and services for Rett syndrome: Parent perceptions and satisfaction. Intellectual and Developmental Disabilities, 58(1), 49–64. doi:10.1352/1934-9556-581.49

Lynch, Y., & Murray, J. (2023). The I-ASC Explanatory Model as a Support for AAC assessment planning. In M. M. Smith (Ed.), *Clinicial cases in Augmentative and Alternative Communication* (pp. 12-26). Routledge.

Lynch, Y., Murray, J., Moulam, L., Meredith, S., Goldbart, J., Smith, M., Batorowicz, B., Randall, N., & Judge, S. (2019). Decision-making in communication aid recommendations in the UK: cultural and contextual influencers. *Augmentative and Alternative Communication*, *35*(3), 180-192. https://doi.org/10.1080/07434618.2019.1599066

Matson, J. L., Dempsey, T., & Wilkins, J. (2008). Rett syndrome in adults with severe intellectual disability: Exploration of behavioral character- istics. European Psychiatry : The Journal of the Association of European Psychiatrists, 23(6), 460–465. doi:10.1016/j.eurpsy.2007.11.008

Marschik, P. B., Vollmann, R., Bartl-Pokorny, K. D., Green, V. A., van der Meer, L., Wolin, T., & Einspieler, C. (2014). Developmental profile of speech-language and communication functions in an individual with the preserved speech variant of Rett syndrome. Developmental Neurorehabilitation, 17(4), 284–290. doi:10.3109/17518423.2013.783139

Martin, S., Small, K., and Stevens, R. 2017. The Pragmatics Profile for People who use AAC (First Published 26 Sep 2017). Available at:https://acecentre.org.uk/resources/pragmatics-profile-people-use-aac/.

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References

Mesibov, G., & Howley, M. (2003). Accessing the Curriculum for Pupils with Autistic Spectrum Disorders: Using the TEACCH Programme to Help Inclusion (1st ed.). Routledge. https://doi.org/10.4324/9781315097664

Neul, J. L., Kaufmann, W. E., Glaze, D. G., Christodoulou, J., Clarke, A. J., Bahi-Buisson, N., Leonard, H., Bailey, M. E. S., Schanen, N. C., Zappella, M., Renieri, A., Huppke, P., & Percy, A. K. (2010). Rett syndrome: Revised diagnostic criteria and nomenclature. Annals of Neurology, 68(6), 944–950. doi:10.1002/ana.22124

Neul, J. L., Lane, J. B., Lee, H.-S., Geerts, S., Barrish, J. O., Annese, F., Baggett, L. M., Barnes, K., Skinner, S. A., Motil, K. J., Glaze, D. G., Kaufmann, W. E., & Percy, A. K. (2014). Developmental delay in Rett syndrome: Data from the natural history study. Journal of Neurodevelopmental Disorders, 6(1), 20. doi:10.1186/1866-1955-6-20

Rensfeldt Flink A, Åsberg Johnels J, Broberg M, et al. (2022b) Examining perceptions of a communication course for parents of children with profound intellectual and multiple disabilities. Int J Develop Disability, 68(2):156–167.

Routes for Learning Advisory Group. (2020) Routes for Learning: Guidance. Welsh Government.

Rowland, C. (2013) Communication MAtrix. https://communicationmatrix.org/Content/Translations/Matrice_de_communication.pdf.

Sievers, S. B., Trembath, D., & Westerveld, M. (2018). A systematic review of predictors, moderators, and mediators of augmentative and alternative communication (AAC) outcomes for children with autism spectrum disorder. Augmentative and Alternative Communication, 34(3), 291–229. 10.1080/07434618.2018.1462849.

Sievers SB, Trembath D, & Westerveld MF. (2020). Speech-Language pathologists' knowledge and consideration of factors that may predict, moderate, and mediate AAC outcomes. J Autism Dev Disord, 50(1):238–249.

Sigafoos, J., Roche, L., O'Reilly, M. F., Lancioni, G. E., & Marschik, P. B. (2023). Updated systematic-narrative review on communication intervention in Rett Syndrome: 2010–2022. *Augmentative and Alternative Communication*, 1-15. https://doi.org/10.1080/07434618.2023.2215864

Simacek, J., Reichle, J., & McComas, J. J. (2016). Communication intervention to teach requesting through aided AAC for two learners with Rett syndrome. Journal of Developmental and Physical Disabilities, 28(1), 59–81. https ://doi.org/10.1007/s10882-015-9423-7

Singh, S.J., Iacono, T., & Gray, K.M. (2015). Interactions of pre-symbolic children with developmental disabilities with their mothers and siblings. International Journal of Language and Communication Disorders, 50, 202-214.

Townend, G.S., Bartolotta, T.E., Urbanowicz, A., Wandin, H., Curfis, L.M.G. (2020). Directives de communication du syndrome de Rett: Manuel pour les thérapeutes, les éducateurs et les familles. Centre d'expertise Rett Pays-Bas-GKC, Maastricht, NL, NL, et Rett syndrome.org, Cincinnati, OH..

UNO (2006). Convention on the Rights of Persons with Disabilities. https://www.ohchr.org/fr/instruments-mechanisms/instruments/convention-rights-persons-disabilities

Van Keer I, Colla S, Van Leeuwen K, et al. (2017). Exploring parental behavior and child interactive engagement: a study on children with a significant cognitive and motor developmental delay. Res Dev Disabil, 64:131–142.

Uthoff, S. A. K., Zinkevich, A., Boenisch, J., Sachse, S. K., Bernasconi, T., & Ansmann, L. (2021). Collaboration between stakeholders involved in augmentative and alternative communication (AAC) care of people without natural speech. *J Interprof Care*, *35*(6), 821-831. https://doi.org/10.1080/13561820.2020.1860918

World Health Organization. (2007). International classification of functioning, disability and health: children and youth version: ICF-CY. World Health Organization. https://apps.who.int/iris/handle/10665/43737