

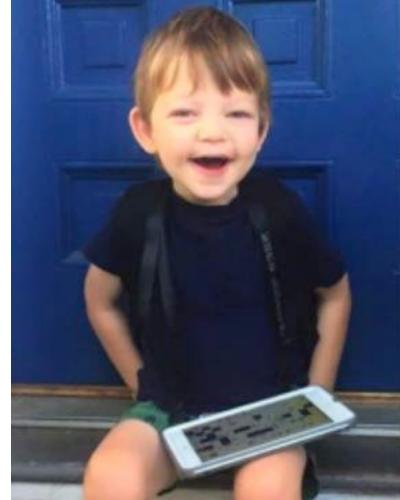
# A Synthesis of Current Research in Augmentative and Alternative Communication Practices for Individuals with Angelman Syndrome Kaitlyn A. Clarke & Janice C. Light

#### Introduction

- Angelman Syndrome (AS) is a genetic disorder that occurs in approximately 1 in 15,000 births (Angelman Syndrome Foundation, n.d.).
- The primary cause of AS is the deletion of bands 11-13 on the long arm of the maternally inherited 15<sup>th</sup> chromosome (Clayton-Smith & Laan, 2003), while other cases of AS are caused by specific defects in imprinting of the UBE3A gene, the replacement of the maternal copy of UBE3A by a second paternal copy, or other unknown origins (Clayton-Smith & Laan, 2003; Jolleff et al, 2006).
- AS is characterized by global developmental delays, little or absent speech, motor disorder—such as ataxia, intellectual disability, hyperactivity, and Seizures (Jolleff et al, 2006).
- Individuals with AS' expressive language skills are characterized by limited speech, typically with fewer than five words (Weltman & Weiman, 2016).
- Individuals with AS display stronger comprehension of spoken language than their production (Alvares & Downing, 1998; Weltman & Weiman, 2016).
- Given their phenotypical and developmental profiles, individuals with AS can be characterized as having complex communication needs (CCN). They often

require the use of augmentative and alternative communication (AAC).

 There is limited research on the use of AAC with individuals with AS to improve communication skills.



#### Purpose

- The primary goals of this synthesis are: (a) review and synthesize current research in the field of AAC as it relates to AS;
  - (b) identify strengths and gaps in the current research;
  - (c) determine clinical implications for the use of AAC with individuals with AS.

#### Methods

#### **SEARCH**

#### Databases:

EBSCO (Academic Search Complete), ERIC, PsychInfo, PubMed, Linguistics and Language Behavior Abstracts (LLBA), and Pennsylvania State University library

#### Search term categories

"Angelman syndrome", "AAC", "augmentative communicat\*"

**Author and Ancestry Review** 

#### **INCLUSION CRITERIA**

- Peer-reviewed scholarly journal
- Research participants diagnosed with AS
- Study outcomes were related to AAC use
- Experimental studies, qualitative reports from caregivers, or review of clinical data

#### DATA EXTRACTION AND CODING

- Study authors and design
- Participant age/gender
- Context
- Type of AAC
- Intervention/training
- Target measure/DV
- Gain score
- PND/TauU
- Certainty of evidence

#### Results

The systematic search identified 3 quantitative and 9 qualitative studies (11 studies total)

#### Quantitative Studies

#### Participants ranged in age from 21 months to 10 years

**PARTICIPANTS** 

- Three males, two females (n=5).
  - 40% two years and under (n=2) 60% nine years and older (n=3).

**INTERVENTION CONTEXT** 

40% in a preschool setting

20% in the home (n=1)

#### **Unaided AAC:** Gestures

- enhanced natural gestures

#### **TYPES OF AAC** Aided AAC:

- graphic symbols
- vocal output device
- speech generating devices
- PECS, picture boards, and object

#### **INTERVENTION CHARACTERISTICS**

- Aided and unaided AAC
- 60% in the school setting

- Prompting
- Modeling
- Structured enhanced
- natural gesture instructional protocol.

#### **DEPENDENT VARIABLES**

- increased requests for preferred items
- increased initiations with clear intentions
- increased spontaneous use of ENG.

### **Qualitative Studies**

#### **IDENTIFIED THEMES**

654 parent/provider respondents

(n=2)

(n=3)

3 professionals (.46%)

**PARTICIPANTS** 

- 651 including parents (99.54)
- Individuals with AS that were included ranged from birth to adulthood (age 66), with a total sample of 954.

- Acceptability and usefulness- perceived acceptability and long-term use Effectiveness/success- perceived effectiveness, effectiveness when used consistently, changes in previously used gestures, and ease of teaching others
- Willingness willingness to utilize and change daily schedules, as well as reasonableness of the intervention
- Priorities- summarizes parent perceptions and priorities of AAC use
- Disadvantages- perceived disadvantages, disruptiveness, negative side effects, amount of use, and reason for rejection

### **COLLECTION METHODS**

- Likert scale questionnaires
- Web surveys
- Communication Inventories.
- Parent and professional reports

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#### Discussion and Implications

- Individuals with AS are reported to benefit from AAC supports, evidenced by both the quantitative and qualitative studies.
- The specific AAC interventions and supports that best meet the needs of individuals with AS is still unclear; however, guidance from parent perspectives can be beneficial.
- Acceptance of a device for individuals' with AS was based on increased success in interactions and independence; while parent willingness and perceived usefulness of device was based on the individual with AS' success with a device.
- The use of systems that were non-symbolic for individuals with AS received higher ratings in the themes of usefulness and importance, followed by electronic devices (i.e. aided AAC), and finally enhanced natural gestures (i.e. unaided AAC).
- Across all included studies, all individuals with AS made gains when using AAC—including both aided and unaided AAC; however, outcomes for younger individuals tended to be larger and reported to be more important by caregivers/family members.
- Individuals with AS should be provided with effective, evidence-based AAC supports that are functionally equivalent to their current idiosyncratic means of communicating.
- When providing AAC systems for individuals with AS, access should be quick and reliable; providing meaningful and beneficial outcomes for meeting wants and needs, as well as social closeness.

#### References



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