

DOI: <https://doi.org/10.56663/rop.v1i1.36>

Family support on augmentative and alternative communication (AAC) for raising communication skills of children with Angelman Syndrome - preliminary case study with 6 families

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Abstract

Angelman Syndrome (AS) is a genetic disorder caused by a lack of expression of the UBE3A gene on the 15th chromosome. AS exhibits a broad range of difficulties, including speech and communication impairment and no or minimal use of words. Augmentative and alternative communication (AAC) tools are widely used in AS for raising communication skills. We explored (1) the usage of AAC at home, and (2) family support to raise the communication skills of six children with AS.

Keywords: Angelman Syndrome, augmentative and alternative communication, home training

Introduction

Angelman Syndrome (AS) is a genetic disorder caused by a lack of expression of the UBE3A gene on the 15th chromosome. AS exhibits a broad range of difficulties: developmental delay, functionally severe; speech impairment, none or minimal use of words; receptive and non-verbal communication skills higher than verbal ones; movement or balance disorder, usually ataxia of gait and/or tremulous movement of limbs; behavioral uniqueness: any combination of frequent laughter/smiling; happy demeanor; easily excitable personality, often with hand flapping movements; hypermotoric behavior; short attention span (Williams, 1995). Children with AS typically rely on multiple methods of unaided as well as aided communication (Alvares & Downing 1998). Augmentative and alternative communication is a set of procedures and processes for people who do not use functional speech by which an individual's communication skills can be maximized for functional and effective communication. The goal of AAC is to enable individuals to efficiently and effectively engage in a variety of interactions and participate in activities of their choice. (ASHA 2005; Beukelman & Mirenda, 2014). The common interpretation and handling of the various symptoms of communicational difficulties and lack of speech require extended knowledge and preparedness from those who are communicational partners, supporters, and experts of people with AS. The use of AAC tools and teaching methods in the therapy of AS is supported in the international literature, however, most of these international studies are based on small samples and/or due to some methodological issues provide no solid evidence. The use of these tools and what we know about their efficiency is therefore mostly based on

personal experience and anecdotic knowledge. More recently, it has become also evident within the field of AAC that there is a strive toward an accumulation of better evidence deriving from well-planned randomized controlled trials. (Calculator, 2014)

Even though they have access to electronic devices with speech output that they are able to use effectively, one of their most used communication methods is often natural gestures, (Alvares & Downing, 1998; Calculator, 2014; Didden et al., 2004). Electronic devices accounted for the greatest number and percentage (23.1%) of modes cited by parents of children who accepted their most advanced device. Gestures (21%) were the second most frequently cited method of communication (Calculator, 2014). When communication skills are lacking, it is common to see children resorting to challenging behaviors, such as self-injurious and aggressive behavior, to convey their communicative intentions (Didden et al., 2009). Children with AS also apply vocalizations, and physical manipulations of objects and people effectively (Calculator, 2014; Didden et al., 2004). The Calculator's survey by parental questionnaires also proved that children with AS are multimodal communicators. Practitioners are encouraged to avoid encouraging one method of communication to the exclusion of others for which children may have already exhibited a preference and have demonstrated abilities to use successfully, but parents also pointed out the children's needs for additional training and support (e.g. 'need more time to work on communication skills' and 'modeling would be helpful'), including experiences using and/or observing others using the same or a similar device (Calculator, 2014; 2016).

Method

The aim of this project was to support children with AS (N=6) and their families in the field of communication. The aim of this study is to explore the change in communication skills: at the end of the second month, we planned, that all children could use at least one aided or unaided AAC.

Six, 3;5-11;10 years old (mean=6;88; SD=2,93) nonverbal children with AS and their families participated in the program from different regions of the country. Two-thirds of them are female (n=4) and the thirds are male (n=2) with various intellectual and communicational levels.

During the program, four well-trained AAC professionals assessed the children and supported the families.

For the assessment, the online version of the Communication Matrix (Rowland 1996, 2010), direct observations, and parental interviews were used. Direct observations targeted several key dimensions of communication (e.g. frequency; form, including AAC; functions; partners, initiation, intentionality, spontaneity) in three different contexts: (1) in a special playhouse with peers and professionals (2) at home with parents and siblings (3) in the children's institutions (nursery, kindergarten, school; observer spent 5-6 hours with observing each child). Based on the results of the assessments and the parent's expectations we planned individualized training goals for each child in the field of expressive communication and other goals for establishing essential social-communicational skills for later AAC use (e.g., improve and change activities, choice, receptive communication like orientation to name, answer to a request or instruction, establish social interactions and intentionality). The appropriate long-term goals were discussed with parents.

This paper focuses on the field of expressive communication.

Based on the assessments and the family's needs and expectations we used different aided and unaided communication forms and tools (gestures, objects, pictures, see table 1). In the past

decades, there has been a growing tendency in international and Hungarian literature for ICT tools to be used and included in AAC, the tendency being especially marked in the past decade when mobile technologies gained ground. In one case we used a communication app as a new tool.

partici- pants	age	used communication at the beginning of the program	individualized goals on expressive communication field with AAC
CH1	3:5	nonintentional behaviour (screaming) for refusing	establishing eye-contract, asking by reaching, than pointing during eating and free-time
CH2	5:5	gestures and signs	establishing conventional gestures, using pictures in a mobile app in eating context
CH3	8:5	nonintentional behaviour, vocalisation	asking by pointing
CH4	11:9	behavioural, gaze	asking by communication objects
CH5	5:6	some pictures and signs for asking (nonconsequent)	asking by picture exchange, improving and establishing conventional gestures
CH6	6:3	pointing and some other gestures	asking and refusing by picture exchange

Table 1. The used and targeted expressive communication forms and functions (N=6)

The Professionals met the families three times in two months and observed the child in his/her institution. Professionals operationalized individualized goals: specified training lessons and contexts prepared tools and presented usage. There was continuous cooperation via e-mail, and phone, and data were collected from parents weekly by logging. A second measurement was used at the end of the training period by the Communication Matrix, direct observation, and parental interview.

Results and conclusion

The number of interactions increased significantly with parents. During the training period and according to this sample a notable development was perceptible in children's targeted social and communicative skills and behaviors' quantity and quality in several dimensions.

Each child started using the targeted AAC form at home, and two-thirds in his/her institution too. Efficiency seems to depend on the intensity of training. According to our results, the majority of parents and special teachers have an explicit intent to apply AAC in AS interventions, but the practical training of parents and professionals, and financial-technical conditions fall short of the optimal. Parents need more support to continue planning new goals.

AAC is a promising opportunity to develop social and communicative skills in the group of AS. Adaptation and development of evidence-based methodologies and objective measurements of intervention effectiveness and the protocol of home training seem highly desirable. Our results can potentially serve as a basis for an elaboration of a future research agenda for a better understanding of forms of support families and special teachers need in applying AAC efficiently in everyday life.

Acknowledgments

We would like to thank the cooperation of participant Parents, Children, and the financial support of the Equal Opportunities of Persons with Disabilities Non-profit Ltd. (FSZK). Special thanks to the professionals Klára Czövek, Vera Bíró, and to Gyöngyi Jónás from Hungarian Angelman Foundation.

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