



## Use of Enhanced Natural Gestures to Foster Interactions Between Children With Angelman Syndrome and Their Parents

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The acceptability and feasibility of a home-based gestural training program for nine children with Angelman syndrome (AS), deletion positive, and their parents were examined. Children with AS have been found to exhibit a variety of challenges, including severe communication disabilities for which different Augmentative and Alternative Communication (AAC) systems have been of limited use (Alvares & Downing, 1998). Parents in this study were taught to recognize and then enhance their children's use of natural gestures as enhanced natural gestures (ENGs). ENGs are intentional behaviors that are present in a child's motor repertoire or can be easily taught based on a child's extant motor skills. Unlike contact gestures, such as grabbing objects from partners or pulling partners toward preferred activities, ENGs do not require physical contact with entities or interactants

and are readily understood by others in context.

Parents were taught to use four primary teaching techniques: environmental sabotage, mand-model, expectant delay, and molding/shaping, and then to use these techniques over a period of 16 to 18 weeks to foster their child's use of ENGs. A questionnaire Enhanced Natural Gestures-Acceptability Rating Form (ENG-ARF), was administered to sample parents' perceptions about the acceptability and feasibility of the ENG training program. With few exceptions, parents described this method as acceptable, effective, reasonable, and easy to teach others, with minor negative consequences and side effects. Implications for subsequent research are discussed.

**Key Words:** gestures, Angelman syndrome, augmentative and alternative communication, parent instruction, home-based program

This study examined the acceptability and feasibility of a home-based intervention program involving enhanced natural gestures (defined later) as implemented by the parents of nine children with Angelman syndrome. It was approximately 35 years ago that Dr. Harry Angelman, an English physician, described three children who shared a number of characteristics (Angelman, 1965). These included severe mental retardation, seizures, ataxia, an absence of speech, easily provoked laughter, and dysmorphic facial features. The syndrome, initially referred to as 'Happy Puppet Syndrome' was subsequently labeled Angelman syndrome (AS), in honor of its discoverer (Williams & Frias, 1982).

Although AS was first thought to be rare, advances in genetic testing have resulted in investigators revising estimates of its incidence from 1 in 20,000 live births (Chan et al., 1993; Clayton-Smith & Pembrey, 1992) to, more recently, 1 in 10,000 live births (Peterson, Brondum-Nielsen, Hansen, & Wulff, 1995).

The cause of AS was not determined until 1987, when investigators began reporting these individuals exhibited

microdeletions on chromosome 15, band q11-13 (Kaplan et al., 1987; Magenis, Brown, Lacy, Budden, & LaFranchi, 1987). This is believed to be due to the loss or absence of expression of the UBE3A/E6-AP gene (Kishino, Lalonde, & Wagstaff, 1997). It is estimated that more than 70% of individuals with AS are 'deletion positive,' exhibiting deletions of maternal origin in the long arm of the 15th chromosome (Chan et al., 1993; Williams et al., 1995b).

Angelman syndrome can be associated with conditions other than deletions, such as imprinting control region mutations. These occur when there is a disruption or rearrangement of genetic material (Clayton-Smith & Pembrey, 1992). The diagnosis may also be made in the absence of genetic evidence when the individual exhibits the characteristic features of AS. These individuals account for 15% to 20% of the population and are believed to exhibit a genetic disorder that is undetectable with existing technology (Chan et al., 1993; Clayton-Smith, 1997; Williams et al., 1995a, 1995b).

Children who are deletion positive tend to exhibit the more pronounced characteristics of AS. Williams et al.

(1995b) summarized general clinical characteristics that occur in 100% of diagnosed cases, those that occur frequently (more than 80% of diagnosed cases), and associated problems that arise in 20% to 80% of diagnosed cases. This information is presented below.

1. *All diagnosed cases*: Severe to profound mental retardation; no use or minimal use of words; receptive and nonverbal (i.e., Augmentative and Alternative Communication [AAC]) communication skills higher than verbal ones; ataxia of gait; tremulous movement of limbs; a combination of frequent laughing or smiling and apparent happy demeanor; easily excitable; hypermotoric behavior; and short attention span.
2. *Frequently occurring*: Delayed, disproportionate growth in head circumference.
3. *Associated*: Protruding tongue, prognathia; wide mouth; frequent drooling and excessive chewing/mouthing; sleep disturbance; and attraction to or fascination with water.

## Communication Characteristics

All individuals with AS who are deletion positive exhibit severe communication disabilities. Problems are usually noted in early infancy, as these children fail to develop any functional speech (Buntinx et al., 1995; Clayton-Smith, 1993). Williams et al. (1995a) reported that single words may be produced when the child is as young as 10 to 18 months old, yet these words are used indiscriminately. As they mature, delays are noted in children's uses of gestures and other forms of augmentative and alternative communication (Clayton-Smith, 1993; Penner, Johnson, Faircloth, Irish, & Williams, 1993). In the absence of speech, children and their families, along with speech-language pathologists, usually resort to other forms of communication including vocalizations, gestures and modified signs, and aided methods of communication (Alvares & Downing, 1998; Williams et al., 1995b; Zori, 1992).

Children's comprehension of language appears to exceed their expressive language, with many reported to understand simple commands and sentences (Clayton-Smith & Pembrey, 1992; Williams et al. 1995b). Jolleff & Ryan (1993) administered the Receptive-Expressive Emergent Language Scale (REEL; Bzoch & League, 1971) to 11 children between 2 and 15 years old. The children's receptive language scores ranged from 9 to 22 months. Expressive language scores ranged from 9 to 14 months.

## Use of Gestures by Children with AS

Polloway and Smith (1992) defined gestures as unaided, paralinguistic communication acts that convey concrete ideas. Beukelman and Mirenda (1992) defined gestures as fine and gross movements such as facial expression, eye behaviors, and postures. Silverman (1995) commented that in order for a gesture to be used as part of a child's communication repertoire, both communication partners must understand it.

In examining the use of gestures by children with AS, Jolleff and Ryan (1993) found that the vast majority of children's gestures relied on physical contact with the referent or interactant (i.e., contact gestures). For example, they might push away an unwanted object or take their partner's hand and place it on a desired object. The children less frequently used distal gestures such as pointing, which do not rely on physical contact with the referent or interactant.

Children with AS have been found to encounter difficulty imitating gestures, including those that are already part of their communication repertoire (Jolleff & Ryan, 1993; Penner et al., 1993). Still, gestures are common in these children. Clayton-Smith's (1993) evaluation of 82 individuals between the ages of 17 months and 26 years revealed 20% using a limited degree of sign language, and many using gestures. Alvares and Downing (1998) administered questionnaires to 20 families of children with AS who were between 17 months and 13;4 years old. A greater number of children were reported to use gestures than signs (15 and 10, respectively), both of which varied depending on children's imitation skills, cognitive ability, and gross and fine motor skills. Seven of the 10 children who signed did so functionally for spontaneous communication, although motor difficulties made their signs difficult to understand. Two individuals used more than 10 signs, one reportedly using 40 and the other over 200. In comparing children's uses of unaided communication to aided forms of communication such as communication boards and voice output communication aids, Alvares and Downing (1998) concluded, "manual communication, whether gestures or signs, appears to be the preferred expressive modality for most individuals with AS" (p. 21).

## Parent Training

As indicated earlier, this investigation recognizes the significant role parents must play in interventions involving their children. On some occasions, parents may be asked to supplement speech-language services that are provided by an SLP, who is the primary interventionist. However, as in the case of the present investigation, the parent may also be asked to serve as the primary interventionist, with the professional developing the initial directions and methods for change and monitoring both the process and the progress. Training associated with either approach involves (a) creating or enhancing the child's environment to encourage change in the child's language, and/or (b) responding within that environment in a manner that best encourages language use (Reed, 1994). The concept of home intervention may attract increasing interest as speech-language pathologists and others attempt to comply with the spirit and content of the Individuals with Disabilities Education Act (IDEA, 1997), especially regarding educational placement.

Certainly, the home deserves consideration when determining the least restrictive environment in which teaching and learning occur. The home may constitute an additional context for instruction, supplementing the

classroom and other instructional settings. Home instruction can be one means of fostering continuity with school instruction.

Pritchard Dodge, Andrews, and Andrews (2000) offered several useful suggestions to SLPs who wish to foster parent involvement in their children's speech-language programs. These included (a) asking parents what they would like the outcome of therapy to be, (b) asking parents about how they feel they might help, (c) assisting parents in selecting specific times of day and/or situations in which they might assist their child, (d) demonstrating techniques and strategies for parents, (e) involving parents in therapy, and (f) modeling behaviors you would like to see parents do in place of existing behaviors toward their children.

McWilliam and Strain (1993) cited several principles of intervention, all of which were considered in designing the program described in the present investigation. First, they stated services should be provided in the least restrictive and most natural environment for the child and family. Services should be family centered and responsive to families' priorities. The authors suggested providing services in a transdisciplinary manner, optimizing participation of children and their families. Finally, services should be individualized, developmentally appropriate, and based on empirical results as well as family values.

The present investigation explored the acceptability and feasibility of a home-based teaching program using enhanced natural gestures (ENGs). The investigator designed this approach to teach parents to foster their children's (all AS, deletion positive) uses of gestures in everyday activities. Although natural gestures have been discussed in previous literature (see references cited earlier), the concept of ENGs and their applicability to children with AS are novel to this investigation.

ENGs are intentional behaviors that already exist in a child's motor repertoire or can be easily taught based on a child's existing motor skills. These gestures do not depend on physical contact with entities or interactants to arise. As such, they are a form of unaided augmentative communication.

ENGs, by definition, require some degree of instruction. In some cases the target ENG may be a gesture that is already associated with a particular object or activity. For example, a child might be observed lifting a cup to her mouth with two hands. Her use of this same gesture in the absence of physical contact with the cup would constitute an ENG. In the same way, a child may be observed in music class beating a stick on a drum. Use of that same hand movement, when the drum is in sight but out of proximity, could be a child's ENG for requesting another turn with the drum.

In addition to the shared etiology of their children's difficulties, all parents who participated in this investigation expressed beliefs that their children's current communication systems failed to address basic, daily, functional communication needs. ENGs were offered as one way of addressing this deficiency. The acceptability and feasibility of this approach are the subject of this investigation.

## Methods

### Participants

Children with AS and their parents were recruited in three ways. The investigator offered a preliminary invitation to families following a presentation at the Biennial Conference of the Angelman Syndrome Foundation (ASF). Next, a broader call for volunteers was issued by posting an announcement on the ASF List Serve, majordomo@tbag.osc.edu. This same announcement was mailed to families of children with AS in New York and New England who were within a 300-mile radius of the University of New Hampshire. Names and addresses were obtained from the ASF Directory.

A total of 23 families responded to these calls for participation in the project. The families were then asked to provide a personal letter describing how their child presently communicates, why they wished to participate in the project, and what they hoped to gain in terms of family outcomes. In addition, families provided medical information that confirmed a deletion on the 15th chromosome, and most recent psychological and communication assessments. After a review of the above information, ten children and their families were selected as subjects. One family later withdrew, indicating they could not find the time to implement the protocol. This family requested and was granted two extensions but was unable to follow through. Still, they indicated an interest in resuming instruction at a future time.

Criteria for selection included: cytogenetic information that confirmed a diagnosis of AS; preschool- or early school-aged; minimal, if any, functional speech; intellectual functioning in the severe to profound range of mental retardation; located within 'reasonable' driving distance from the University of New Hampshire, with no two children residing in the same city or town; and parents' beliefs, as conveyed in their application, that their child's current communication system was insufficient in meeting basic, daily, functional communication demands.

The children who participated in this investigation were between 3; 3 and 10; 5 years old ( $M = 7; 1$ ). Five families were from New York, four from Massachusetts, and one from Connecticut. None of the children used words, although two uttered what their parents felt to be two or three approximations of words. Their parents indicated these 'words' were used in various situations with different people and did not have any clear or consistent meaning. Two other children's parents felt their child may have had a few words at an earlier age, then lost them later in life. In summary, none of the children had any functional speech.

Psychological testing revealed all of the children scored in the severe to profound range of mental retardation. Mental age equivalents ranged from 5 months to 1;8, with most of the children operating in the 9 to 15 month range. Instruments used to assess cognitive abilities varied across the children and included the Hawaii Early Learning Profile; Vineland Adaptive Behavior Scales; Birth to Three Scales; 2nd edition of the Mental Scale of the Bayley Scales of Infant Development; and the Carolina Curriculum for Infants and Toddlers with Special Needs.

As indicated in Table 1, the children's communication skills were primarily in the 6 to 12 month range with one child, Tom, performing in the 12 to 18 month range. The children relied on a broad variety of methods to communicate, including gestures and vocalizations. Two children used a modified Picture Exchange Communication System (PECS); two used one or more voice output communication aids, or, VOCAS; and four used modified signs.

All parents stated in their letters of application for the ENG investigation that their children's current communication system was insufficient for basic, daily, functional communication demands. Comments from their letters (Table 2) may be of interest to SLPs, teachers, AAC consumers, and others who are involved with the processes of AAC program development and implementation, as well as those who are confronted frequently with instances of device abandonment.

## Procedures

All training took place in subjects' homes at times the parents cited would be most productive and least disruptive for their families. The investigator made four visits to each home during the 8 to 10 weeks in which the first four phases of the program were administered. The fourth phase concluded with an additional 12 to 14 weeks of parents' implementing the ENG instructional procedures. The Acceptability Rating Form was mailed to families at the conclusion of the project.

### Phase One

Home-based training began with a comprehensive description of the project and its purposes. One or both parents attended, depending on who would be most involved in subsequent training. Also, parents invited one or more ( $M = 1.67$ ) 'observers' (e.g., a speech-language pathologist, special education teacher, personal Aide, and/or general education teacher).

It was explained that the primary purpose of the project was to examine the preliminary efficacy of ENGs in fostering more effective interactions between children with AS and their families at home and elsewhere. It was strongly emphasized that this intervention was intended to supplement rather than replace other forms of AAC their children were using.

Parents were then taught to distinguish between natural gestures and ENGs. "Natural gestures" were described as behaviors their child used spontaneously and without any prompting. Natural gestures could be intentional, such as pushing away food they disliked, or unintentional, such as smiling in response to a pleasurable activity such as rough housing with Dad.

Unlike conventional signs, (for instance, those appearing in American Sign Language) natural gestures involved motor and cognitive behaviors the child was already using, suggesting their child already possessed the skills necessary for production of each gesture. For example, the motion of pulling on the chains of a swing after it is temporarily stopped—showing anticipating for the

swinging to resume—would constitute a natural gesture. Natural gestures are idiosyncratic in that they may vary from one child to another. Finally, natural gestures might or might not be understandable to others.

Next, natural gestures were contrasted with enhanced natural gestures. Unlike natural gestures:

1. ENGs are always assumed to be intentional.
2. ENGs are readily understood by others, in context (defined as two out of three people who are unfamiliar with the child could interpret the behavior correctly).
3. ENGS may involve modifying a natural gesture to make it more comprehensible to others. If a natural gesture is readily understood by others, but not used communicatively by the child, the child might be taught to use the same behavior as an ENG. For example, one child petted his dog when it entered his room. This act was triggered by the dog's presence and was not assumed to have any other communicative significance. This same 'petting' gesture was targeted as an ENG by which the child could request his mother to bring the dog closer to him.
4. ENGS are limited to distal gestures that do not rely on actual physical contact with the referent or interactant. For example, one child was taught to replicate her usual swimming stroke while standing on the deck, asking to be led to the pool. Conversely, natural gestures may include distal as well as contact gestures.

When a child has not been observed using a natural gesture in a particular situation, and such a behavior is warranted, an ENG may be taught. In such cases, it is useful to rely to the greatest extent possible on behaviors that are already in the child's repertoire. For example, a child may enjoy finger painting but have no means of requesting this activity. After observing the child's motions when involved in this activity, the same motions could be learned to request this activity at another time.

*Pretest.* Parents and their selected observers completed a pretest (available from the investigator upon email request) to demonstrate their understanding of natural gestures and ENGs. The pretest consisted of ten statements that subjects identified as True or False, and then provided a rationale for their decision. Three examples of test items were, "ENGs are the same for every child. In other words, one child's ENG for drink should be identical to other children's ENGs for drink," (False) "Unlike natural gestures, which can be intentional or unintentional, ENGs are always behaviors that children use intentionally," (True) and "We often need to enhance natural gestures, even those used spontaneously by the child, especially when these natural gestures are difficult for others to understand" (True). Directions for completing the pretest were as follows:

The following assessment is intended to measure your understanding of natural and enhanced natural gestures (ENGs). It is critical that you understand these concepts before moving on to the next phase of this investigation. Please do not approach this as a pass/fail task. If you indicate your understanding of ENGs by earning a score of 80% or higher on this pretest, we will move on to the next phase. If your

**TABLE 1 (p. 1 of 2). Descriptive information about each child's communication skills and current means of communication.**

Children	Communication Skills	Communication Means
Michael	Rossetti Infant Toddler Language Scale revealed abilities in the 3–6 month range; Eye gazes to people and objects; < 12 month level on the communication section of the Vineland Adaptive Behavior Scales. Responds inconsistently to his name; Requires full prompting to follow simple directions.	Reaches for preferred objects; vocalizations convey emotions; Physically withdraws from unpleasant activities.
Greg	Understands simple directions related to daily routines, especially when paired with gestures; Recognizes several photos and Mayer-Johnson Picture Communication Symbols.	Modified Picture Exchange Communication System (PECS) book with photos to request food, objects, and activities; Eye gaze; Gestures; Showing; Giving; Vocalizes to greet and convey emotions; Cheap Talk and Hip Talker were discontinued.
Tom	Performed in the 12–18 month range on the Birth To Three and REEL.	Modified signs for “more,” “gimme,” and “hi.” Makes choices with pictures at mealtime. Sometimes nods or shakes head for yes’ and ‘no’ appropriately; Indicates some choices by touching PCS symbols; Leads adult to a desired object; Facial expressions.
Sean	Beginning to understand one-step directions; Reaches for favorite items; Very responsive to adults; Orients to spoken name; Occasionally performs on verbal cue alone; Inhibits activity in social response to ‘no’; Looks at familiar objects or persons when named; Skills primarily at 9–11 month level with some scatter in the 12–15 month range on the Early Intervention Developmental Profile.	Purposeful reaching; Says ‘mmm’ for more at lunch; Pulls on adult for attention; Limited success using pictures to make choices; use of eye contact; facial expressions; Initiates interactions with peers by approaching, touching, sometimes vocalizing and offering a toy; Looks or moves away to withhold social contact; Pushes away unwanted objects; Vocalizations vary to convey different needs and preferences; Have introduced four signs with minimal success.
Mark	Responds differently to different tones of voice; Sustains attention to preferred people and events; recognizes some pictures; Follows one-step commands inconsistently; Recognizes words that refer to familiar and motivating things, such as references to the Television show “Barney”.	Eye contact; Directed gaze; Acts on objects of interest; Purposeful reaching; Withdraws from unwanted and non-preferred objects and activities; Facial expressions.
Zoe	Responds to name; Can imitate some actions, with prompting; Understands photos but not pictures; Very aware of and interested in others; attends to objects; Inconsistent following one-step directions.	Communication board with photos of familiar people and activities; Shakes head for no; Vocalizations; directed reaching to make choices between objects offered; Withdraws from unpleasant objects and activities; Approximates sign for ‘want’; Touches adult or brings objects to request assistance; Facial expressions; Vocalizes for attention and to convey emotions.
Carly	Very aware of people and her environment; follows some simple requests, especially when paired with gestures; initiates, maintains and terminates conversations nonverbally; makes choices between objects; responds best to objects and photos; little understanding of line drawings.	Vocalizing and whining to get attention; pulling adults by hand to the object of her choice and handing them objects she wants help with; Signs ‘more’; vocalizes for attention; Cheap Talk to request attention; on rare occasions she hands parents a photo to indicate she wishes to go to bed; shakes head ‘no’; eye gazes; one-step Communicator; SuperHawk.

**TABLE 1 (p. 2 of 2). Descriptive information about each child's communication skills and current means of communication.**

Beth	Seeks out adults and peers for attention, affection, and interaction; Vocalizes to gain attention; Reaches toward desired items; Interactions are very brief as she is easily distracted; Initiates and maintains eye contact.	Has been working on PECS but has not yet developed any picture discrimination skills; Greets peers and teachers with smiles, hugs and kisses and occasional vocalizations.
Bailey	Early Intervention Developmental Profile - expressive language skills at 6 months and receptive skills at 8–9 months.	Communicates with a combination of vocalizations, eye gaze, facial expressions and changes in body posture; Reaches for preferred items; Has used an object communication board to select from two choices.

performance suggests you are still unclear of concepts underlying natural gestures and ENGs, we will invest more time teaching you so you are knowledgeable and confident on this subject. We will then move on to the next phase of the investigation.

Participants were permitted to check their notes before responding. An answer was scored as 'correct' only if the respondent's decision and supporting rationale were

correct. All 29 individuals passed the pre-test on their first attempt; scores ranged from 84% to 100% ( $M, 91\%$ ).

Continuing with phase one, parents were then asked to identify five situations at home and/or in the community in which they wished to conduct ENG instruction. Parents instead opted to identify two to five situations, some of which included bath time, outdoor play, free play indoors, mealtime, snack, swimming, church, and walking their dog in the neighborhood. Situations (a) occurred frequently

**TABLE 2. Written comments by parents of the nine children that indicate their lack of satisfaction with their children's present means of communication.**

Child	Parents' Written Comments
Michael	"Mike's current communication system is insufficient to meet his daily functional needs. At the present time, Mike's communication skills are very limited. In life, you take many things for granted, for example your eyesight, your hearing, your ability to walk and your ability to talk. Obviously we as a family have learned not to take any of these things for granted."
Greg	"He isn't always going to have a photograph available (referring to her son's PECS notebook). He needs other options. How can anyone not get involved in a project (referring to this investigation) that will open so many closed doors."
Tom	"While we have a variety of different methods of communicating with Tom, clearly it is not sufficient. We believe the lack of communication is falsely characterized as behavior problems in school. We really need to expand our communication channels to help Tom communicate."
Sean	"With much of communication with Sean it's difficult for us to know what he is trying to 'say.' Since we don't know what he really needs or wants, when he gets upset we usually work through a list of about ten things. Through this process of trial and error, we usually eventually discover the cause of his discomfort and successfully calm him down. A communication system based on the second party guessing, however skillfully, what the first party is trying to say must lead to frustration on the part of the speaker. Because we are only guessing, Sean's current communication systems are inadequate for meeting his present communication needs."
Mark	"Currently we have no 'real' communication with Mark. It is so hard to watch my 'angel' and only be able to make an educated guess of what's going on inside his head."
Zoe:	"Our biggest concern is that Zoe will not be able to communicate with people outside the circle (family)...as she gets older she will need communication skills that everyone can understand. We all want Zoe to have the ability to communicate with the world."
Carly:	"We have always recognized that despite our daughter's full exposure to the entire gamut of communication systems, these other methods to enhance communication are never really going to be very practical or functional in a natural or social environment. We keep asking ourselves, how practical is it to visit the grocery store with a picture board and have Carly select her favorite cereal or fruit. Likewise, carrying around a Cheap Talk or Ablenet device at the restaurant or on the playground is equally impractical." Carly has been exposed to a variety of signs, however she cannot use most due to her lack of fine motor coordination."
Beth	"I'd be very interested and grateful to get your opinion on communication methods for her. Her therapists have been teaching her the PECS system and she is showing some improvement (starting to discriminate a blank card from one with a picture)."
Bailey	"She shows us what she wants with her eyes, but it would be so wonderful if she could really tell other people her wants and needs. It is very frustrating to think that she is a child like any other, and that she has thoughts and feelings that she can never express to us."

and/or consistently in the family's lives; (b) afforded opportunities for children to interact directly with one or more family members; (c) were usually enjoyable for the children; and (d) would be more enjoyable if children had more effective means of communicating with their parents.

Phase one concluded by orienting parents and observers to the data collection system they would use (see phase two) to assess their child's current use of natural gestures. Role-play was used to provide respondents with practice recording data. Examples of natural gestures were demonstrated after first describing the context in which they occurred. Respondents then entered a brief description of the gesture they observed, the situation in which it occurred, and what they believed to be the meaning of the gesture. A maximum of 15 minutes (range of 7 to 15 minutes) was required for any parent or observer to identify these features accurately. 'Accurate' was defined as scoring all features correctly in nine out of ten trials.

### **Phase Two**

Parents were asked to practice recording their child's natural gestures in each of the two to five situations they selected. Directions were as follows:

You are now ready to record your child's use of natural gestures in each of the five situations you selected. In doing so, we ask that you note the date of your observation, the natural gestures your child produces, the corresponding situations in which each of these natural gestures occur and the corresponding meaning you think your child is conveying. Record gestures that inform you of your child's feelings, wants, needs, interests, dislikes, difficulties, and so forth. DON'T FORGET the criteria we reviewed in deciding whether or not to count a behavior as a natural gesture.

### **Reliability**

Once they felt comfortable with these procedures, but not until they used them daily for a minimum of two weeks, parents contacted their outside observers to schedule a series of inter-rater reliability checks of their ability to identify the presence and meaning of their child's natural gestures. A minimum of three checks in two different situations was conducted. Each visit was approximately thirty minutes long. Reliability checks continued until an average point-by-point agreement of 80% or greater was attained over three consecutive visits.

During each visit, the outside observer used a stopwatch to identify two-minute intervals in which the parent and child interacted, while noting children's gestures and associated meanings. The observer and parent compared their findings for up to one minute following each two-minute interval. The observer then noted the greater number of natural gestures observed by the parent or them for that interval. For example, if the parent recorded three gestures in the same two-minute interval in which the observer recorded one, three gestures were counted for this interval.

Next, the observer computed the number of agreements (+) between the observer and the parent in each two minute interval. A '+' was recorded each time the parent and observer agreed on both the presence and meaning of a gesture. For example, let's say the observer and parent noted the same three gestures and agreed on the meaning of the first two gestures and not the third. This would be recorded as two agreements and one disagreement (+ + -). If the parent and observer agreed there were no natural gestures in a two-minute interval, this was recorded as a single agreement (+). However, let's say the parent didn't record any natural gestures but the observer recorded two. This would be counted as two disagreements in that interval (- -).

The observer computed the total number of agreements and disagreements across all intervals, divided that sum by the total number of agreements, and then multiplied by 100 to arrive at a percentage of agreement. Thus, if there were 18 agreements and 6 disagreements over the course of 8 two-minute intervals, then point-by-point inter-rater agreement that day would be 18/24, or, 75%. Participants quickly met the criterion for inter-rater agreement, requiring a mean of 4.56 sessions (range of three to seven) to do so.

Families continued to examine their children's uses of natural gestures for an additional two to four weeks following the last reliability check. These data served as a basis for selecting ENGs for each child in phase three.

### **Phase Three**

The investigator returned to the home of each family to review data from phase two. All nine families' (and respective observers') data collection forms confirmed their understanding of natural gestures was consistent with the working definition of natural gestures employed in this investigation.

Each family was asked to identify up to two gestures, in each of up to five of their previously selected situations, that they would like to teach their child. Concerns about needing to modify a natural gesture to make it more understandable to others, or replace it with a different gesture that would be more understandable, were discussed. The resulting gestures constituted each child's prospective inventory of ENGs. Examples of ENGs selected by families included: (a) reaching toward an object out of proximity ("I want"); (b) pushing motion with hand ("I don't want that; Take it away"); (c) stroking motion ("I want to play with the dog"); (d) brings both hands, cupped, to mouth ("I want a drink"); (5) twisting motion of hand, as though turning a door knob ("I want to go outside"); (6) rocks body back and forth (wants Mom to resume pushing her on swing). Parents varied with respect to the number of ENGs (three to eight) they wished to teach their child.

Parents and observers were then taught to use four different techniques (i.e., environmental sabotage, expectant delay, mand-model, and molding-shaping) to help their children learn ENGs. It was explained that previous investigators found these techniques particularly effective in teaching skills to children with severe disabilities in various natural settings. The techniques required parents

and observers to be aware of their child's natural gestures and other behaviors and to seize opportunities for instruction when they arose naturally. Parents were advised that they might find one or more of these techniques worked especially well with their child while others were of comparatively little use, especially while trying to maintain a semblance of "normality" in their homes. Each technique was defined and discussed and multiple examples were presented.

"Environmental sabotage" involves manipulating the environment in such a way that a child's access to a desired object or activity is prohibited and an opportunity for communication is created (Constable, 1983; Lucas, 1980; Owens, 1999). The partner can take actions (e.g., standing in the child's way) or remove elements (e.g., the child's chair before she reaches the table for snack). Parents were encouraged to avoid frustrating their children when implementing this and the other three procedures. The following example was presented to all nine families.

"Your daughter may sit down for dinner expecting her cup of milk to be at her place setting. On a particular day it is not there since you have sabotaged this situation. In doing so, you have created a reason and opportunity for her to ask for her milk."

"Expectant delays" have been used successfully to cue individuals to communicate in reaction to environmental stimuli other than verbal prompts, and to create opportunities and reasons for individuals to use communication skills that are already in their communication repertoire (Halle, 1988; Halle, Baer, & Spradlin, 1981). First, the environment is arranged in such a way that children are expected to require some type of assistance. Next, partners position themselves in proximity to the child and orient their bodies toward the child. Partners remain silent for a pre-established period of time and then gaze at the child with an expectant facial expression. If the child exhibits the required communicative behavior, the action is praised and complied with by the partners. Otherwise, partners are expected to model the appropriate behavior.

The participating families and observers were told that expectant delays work best in situations that involve routines, are very predictable, and are highly expected by the child. Typically, an anticipated event is put off for a brief duration. For example, a child may love to have his head rubbed and shampooed in the tub. One day he can watch as his Dad pours the shampoo into his hands, just like he always does. However, on this particular day rather than commencing to shampoo his son's hair, Dad instead looks at his son expectantly. His son brings his own hands to his head and rubs his hair. Dad responds immediately by fulfilling the natural gesture request and applying the shampoo.

"Mand-Model" was introduced by Rogers-Warren and Warren (1980) as a way of fostering children's generalization of communication skills from pullout instruction to more natural settings. This technique has also been used successfully as a direct language-teaching approach (Alpert & Rogers-Warren, 1983; Warren, McQuarter, & Rogers-Warren, 1984). The procedure begins with partners

arranging the physical environment in a manner that encourages their child to communicate. Partners wait until the child shows interest in the event. They then "mand" (i.e., demand, command, or request) the individual to communicate in some way. If the child responds to the mand with the desired communicative behavior, he/she is praised and offered a contingent response. Otherwise the desired behavior is modeled for the child.

Participants were warned their children might resort to whining and other ambiguous ways of communicating upon attempting to teach them ENGs. They were encouraged to respond with a clear indication of an expectation for a more specific behavior such as an ENG from their child. The parent was encouraged to mand by saying something like, "You need to show me Sherry. Show me the gesture!" Parents were then encouraged to wait approximately five seconds for their child to produce the desired ENG. They were to comply quickly if the child responded as planned. Otherwise, their next step was to model the desired gesture. Once again, they were to wait about five seconds, see if their child imitated their gesture and, if not, model the gesture a second time as they complied with their child's request, thus consequating on a positive note.

"Molding-shaping" has been recommended as an effective method of teaching signs to individuals with mental retardation (Mayberry, 1976). Parents were told this technique can be especially effective when teaching children to use signs in which the hand shape suggests the referent or action it represents. For example, many individuals drink by placing one hand around a cup and bringing the cup to their mouth. This same hand shape and motion can be used to mean "drink" in the absence of the cup.

Parents were instructed that certain gestures could be taught effectively by placing an object in their child's hand, then removing it while sustaining the hand shape as though the object remained in the child's possession. The hand shape associated with manipulation of the object was then selected as the child's ENG.

On many occasions, children's existing methods of manipulating objects might be neither conventional nor potentially understandable to others as gestures. For example, children might handle objects indiscriminately by banging them on the table or bringing them to their mouth. Parents were encouraged to "shape" these gestures to promote more instrumental and recognizable actions on objects that could later be molded and shaped into ENGs.

The investigator provided participants scenarios such as the following to illustrate this technique:

"John is found to drink from his Nike water bottle by placing both hands around the bottle and bringing it to his mouth. This is his natural gesture. We have identified an excellent way for John to request his water bottle and now must teach John to use it as an ENG. We will do so using molding/shaping. Mom places the water bottle in John's hands, *molding* his hands around it, and then quickly pulls it out of his grasp. As John reaches for the bottle, his mom *shapes* his hands into the gesture as though he was holding the bottle in his hands. She quickly reinforces John's use of this ENG. As John drinks, his

Mom models the gesture several more times. Later, she again removes the bottle and waits for John to request it using the appropriate ENG. If he doesn't, Mom *shapes* John's hands into the appropriate gesture then quickly places the water bottle back in his *molded* grasp.

"Your child may be attempting to hit the remote control to turn on a television. You might identify this motion, tapping with one finger into the palm of the hand that contains the remote control, as a natural gesture to be enhanced as an ENG. Later, you might observe your child fussing. You know he always does so at a particular time of day when *Barney* is on the air. You can seize this teachable moment to encourage him to request the TV by tapping his finger into his palm in the absence of the remote control."

In addition to the four teaching methods, participants were taught to distinguish between five progressively more intrusive levels of prompting that might be used in conjunction with any of the techniques. They were encouraged to offer as little prompting as necessary when conducting ENG instruction.

Regardless of which of the four techniques you use, it is important that you provide as little prompting as necessary to encourage your child to produce an ENG. If a situation calls for your child to use an ENG, and he/she does so spontaneously, no prompting is necessary (level 1). Otherwise, introduce a verbal prompt (level 2), such as "*Show me your gesture.*" If that doesn't work, resort to a prompt at level three, four, or five. At level 3, you would provide a model. If he/she still fails to use the ENG, you might further encourage him/her by touching the body part necessary to produce that ENG (level 4). If this fails, provide full hand over hand assistance (level 5). Remember, start with the least intrusive prompt (level 2) before moving to higher levels of prompting. You decide the level of prompting your child needs in any particular situation. Still, remember to look for spontaneous ENGs and/or those requiring minimal prompting.

All participants were given as much time as they needed to review written descriptions of each technique, as presented above, and then discuss this material with each other and the investigator. One father was unable to read so his wife read this material to him. Multiple scenarios were described and participants were asked to identify the teaching method and level of prompt being illustrated.

Once there was consensus among all in attendance that all parents and observers understood these procedures, this was confirmed by having each individual complete a pretest that assessed this knowledge. While completing the pretest, participants were able to refer to handouts from the investigator and their notes. They were told that regardless of their performance on the pretest, they would receive direct, in-home training on all teaching techniques.

Part one of the pretest required participants to identify the primary teaching techniques, highlighted with *italics*, in

ten different scenarios. Following are six examples:

When Tara goes to the closet for her lunchbox, she is surprised to find it missing. Her mother has purposefully provided Tara the opportunity to use an ENG to ask for her lunch box. *Her mother hid the lunchbox in a corner of the closet earlier that morning.*

(Environmental sabotage)

Serena waits her turn as her Mom passes out books to three other children in a circle. *When she reaches Serena, however, the Mom just gazes at Serena and smiles. The Mom's expression suggests she is anticipating some type of response from Serena.* Serena quickly produces her gesture for book (two hands, palm together, springing open) and is given a book by her Mom. (Expectant delay)

After eating breakfast, Andrew is led away from the kitchen. He suddenly stops in his tracks and starts whining. His Dad senses that Andrew wants to wash his hands, since Andrew loves water and enjoys washing up after eating. *His Dad reacts, "Andrew, Tell me what you want." Andrew continues whining. His Dad follows by showing Andrew his enhanced natural gesture for "hand washing" which consists of rubbing his hands together as if washing them.* Andrew imitates and is immediately taken to wash his hands and play with the water. (Mand-model)

Every morning, Liz goes to her bookshelf and brings back a Sesame Street book she enjoys having read to her by her older brother Sean. *One morning, Sean moves the book to a high shelf that is out of Liz's reach.* After a brief period of unsuccessfully trying to climb the shelves to get to her book, Liz goes to her brother and produces the gesture for "book." Sean brings Liz back to the shelf, reaches up and grabs the book Liz wants, and then reads it to her. (Environmental sabotage)

Josh's ENG for the elevator at school is to make a twisting motion of his hand (he uses a key to operate the elevator). One day, while walking in the hall, Josh throws himself to the ground refusing to get up. It's obvious he is upset that he will not be using the elevator, which is incorrect on his part. *His Aide says in a firm voice, "You need to tell me what's wrong Josh. Tell me what you want." By now, Josh is writhing on the floor. Next, the Aide demonstrates the gesture for "key."* Josh immediately calms down and imitates the gesture. The Aide lets him hold the key as they make their way to the elevator. (Mand-model)

Ms. Smith passes plates of food to Sheila's two siblings after each request a helping of food. *She then turns to John, and places the plate over his out-reached hands. She withdraws the plate, keeping John's hands in the same position they were in when he was holding the plate.* Ms. Smith remarks enthusiastically, "Look John, you're telling me you want

*your plate, too." She places the plate in his hands, keeping John's hands in the same position.* Later in the meal, Ms. Smith repeats this routine to encourage John to use this ENG to ask for a second helping of food. (Mold-shape)

The second part of the pretest required participants to describe how they could use each of the techniques to teach a child an ENG for "bicycle." Participants were required to score 80% or higher on the pre-test to move on to phase four of the program. Incorrect responses were reviewed with examinees and further instruction was provided by the investigator as necessary. All of the participants passed the pretest without difficulty; scores ranged from 88% to 98% ( $M = 92\%$ ).

Phase 3 concluded by teaching the parents and observers how to record parents' uses of the different teaching methods and prompting levels in subsequent instruction with their children (see Figure 1). All participants were provided opportunities to practice using the form with the investigator until they were at least 90% accurate across ten consecutive trials in making these judgments. This involved presenting a series of scenarios in which they had to enter data on their respective forms. Examples continued until each participant met the criterion. A maximum of 16 scenarios was presented for one participant to meet the criterion.

#### **Phase Four**

Over the next 2 to 4 weeks, parents invited their respective observers to their homes on three occasions to share feedback on each parent's use of the four teaching methods. Parents and observers filled out the monitoring form (see Figure 1) concurrently, as the parent and child interacted in a minimum of three situations. They then discussed their findings. Parents decided when they were familiar enough with the teaching protocols to "go off on their own" without further direct assistance from their observers. In all cases, this occurred immediately following the third visit by the observer.

Three families stated that formal data collection made them more confident in their abilities to recognize and implement the various teaching methods and prompts. However, all nine families (including the preceding three) and their respective observers indicated that it was difficult to use this form and interact naturally with their children concurrently. Despite its perceived benefits, five parents opted to discontinue using this form for the duration of the project. They felt they could interact more naturally with their children if liberated from this task of data collection.

Since the informed consent procedure provided all participants the right to withdraw from all or any part of this investigation at any time, the parents' wishes were honored and this component of data collection was terminated for all of the families. This left the qualitative measure, the Acceptability Rating Form, as the primary means of examining the feasibility of ENG instruction.

Over the next 12 to 14 weeks of Phase 4 (having already practiced the various teaching techniques the previous two to four weeks), parents continued teaching their children to

use ENGs. The investigator and observers remained "on call" by phone or e-mail in the event that parents required further assistance. None of the families requested further assistance. Three families emailed the investigator; one did so on two occasions. Correspondences from families shared observations and feedback but did not request additional instruction from the investigator.

#### **Phase Five**

Parents evaluated the acceptability and feasibility of the ENG program by completing the Enhanced Natural Gestures–Acceptability Rating Form (ENG-ARF). This questionnaire was adapted from a previous instrument, the Treatment Acceptability Rating Form–Revised (TARF-R) (Reimers, Wacker, Cooper, and DeRaad, 1992). Items on the TARF-R reflected data-based, recommended practices for assessing consumers' acceptance of instructional procedures.

Kazdin (1980a) pointed out interventions that are evaluated by professionals as equally effective may be viewed differently by consumers. Reimers, Wacker, Derby, and Cooper (1995) suggested that interventions should be selected based on their viability and acceptance by consumers, thus increasing the likelihood of their being implemented. Along these same lines, consumer satisfaction has been defined as the rated acceptability of a proposed treatment (Reimers & Wacker, 1988).

Factors that influence ratings of acceptability include perceptions of disruptiveness, time, effectiveness, and willingness (Kazdin, 1980b; Reimers & Wacker, 1988). These factors formed the basis for items included on the TARF-R as well as the ENG-ARF (see Figure 2).

Parents responded to 14 questions on a seven point Likert-type scale with a value of four representing a neutral opinion and values of one and seven representing either the maximum positive or negative perceptions, depending on the wording of the individual items. For example a rating of seven on item #13, "How difficult would it be for you to teach others to use this method of communication?" (Very difficult) would represent a negative outcome. Conversely the same rating (seven) would represent a maximally positive response to the statement in item #12, "How often are you and your child presently using enhanced natural gestures at home?" Five of the items (5, 7, 8, 9, and 13) were rescored prior to further computation because they were worded in such ways that high scores denoted negative perceptions. This resulted in items on either end of the pole consistently denoting negative (score of one) or positive (score of seven) responses.

Parents were told that ENG-ARF questionnaires were numerically coded, with no other identifiable information. These measures were taken to encourage parents to respond candidly. Directions for completing the ENG-ARF follow:

The questionnaire that follows is designed to measure how acceptable you found Enhanced Natural Gesture (ENG) instruction to be. Your responses will be very helpful in evaluating the effectiveness of this approach and possibly introducing changes in the instructional methods. Please be as candid as possible

**FIGURE 1.** Form used by parents and observers in Phase IV to record parents' uses of the various teaching methods and levels of prompting.

Date of Instruction	Situation (of the 5 predetermined)	ENG you targeted for instruction	Technique(s), you used to teach ENG: Environmental sabotage; expectant delay; mand/model, molding/shaping.	Prompting Level: 1. Spontaneous. 2. Verbal prompts. 3. Modeling. 4. Touch body. 5. Hand over hand assistance.

in responding to each question. Feel free to write in additional comments following each question.

## RESULTS/DISCUSSION

This investigation examined the acceptability and feasibility of ENGs in enhancing interactions between young children with AS at home with their families. Since outcomes were measured primarily on the basis of parents' responses to the ENG-ARF questionnaire, results should be presented and interpreted cautiously.

It is important to note that each child's mother and/or

father completed the ENG-ARF at the conclusion of the investigation. In retrospect, it may have been beneficial to examine intra-rater reliability by readministering the questionnaire or to compare inter-rater reliability by comparing ratings between parents and/or parents and observers, since this was the primary instrument used to examine acceptability and feasibility of the intervention. However, a single administration of the ENG-ARF was deemed sufficient given the duration of the intervention phase, parents' ability to complete the form in their own time, the request that ratings be accompanied by qualitative comments, and the assurance of confidentiality.

Quantitative data documenting changes over time in the

**FIGURE 2.** Items comprising the Enhanced Natural Gestures-Acceptability Rating Form (ENG-ARF) used by parents to evaluate the feasibility and effectiveness of ENGs.

1. How acceptable do you find Enhanced Natural Gestures instruction? (Not at all/Very acceptable)
2. How effective is this treatment likely to be for your child? (Not at all effective/Very effective)
3. How willing are you to carry out this treatment? (Not at all willing/Very willing)
4. How reasonable do you find this training to be? (Not at all reasonable/Very reasonable)
5. To what extent do you think there might be disadvantages in following this treatment? (None are likely/Many are likely)
6. Thinking in the long term, how likely is this treatment to make permanent improvements in your child's communication success at home? (Unlikely/Very Likely)
7. How much time is needed each day for you to carry out this treatment? (Little time/Much time)
8. How disruptive is it to your family (in general) to carry out this treatment? (Not disruptive/Very disruptive)
9. To what extent are undesirable side-effects likely to result from this treatment? (No side-effects are likely/Many side-effects are likely)
10. How effective do you think Enhanced Natural Gesture instruction would be if used consistently at home? (Not at all effective/Very effective)
11. How willing are you to change your family routine to carry out this treatment? (Not willing/Very willing)
12. How often are you and your child presently using enhanced natural gestures at home? (Not very often/Very often)
13. How difficult would it be for you to teach others to use this method of communication? (Not very difficult/Very difficult)
14. During the **baseline phase** you were asked to identify natural gestures your child was already using. What did you find out about your child's use of natural gestures during this initial phase of the investigation, before you were asked to provide instruction? (Used fewer gestures than I expected/Used many more gestures than I expected)
15. The overriding objective of this investigation was to enhance interactions between children with AS and their families at home. Please discuss the extent to which this objective was or was not met for your family. Attach additional pages if necessary.

*Note.* Qualifiers for each pole of the Likert-type scale appear in parentheses following items 1–14(# / #). Parents were encouraged to assign a rating along with an accompanying comment for each of these items. Item #15 was answered in narrative fashion.

type, number, rate of learning, and frequency with which the respective children used natural gestures would have provided further, more substantive information about the efficacy of this approach. Such data collection was initiated but discontinued at the request of several parents who indicated they found this to be cumbersome.

Parents felt interactions with their children could proceed more naturally if they could refrain from pausing intermittently to record information. In addition, all nine parents independently stated they would be far less likely to follow through with the procedures used in this investigation, especially at the end of the study, if they were expected to continue collecting data.

Assuming these subjects' observations were consistent with those of subsequent parents who might use this approach, the investigator reasoned that to continue data collection against parents' preferences would pose a threat to external validity while doing little to assure internal validity. Such an action would also violate content in the informed consent agreement, which affirmed parents' rights to withdraw from all or any part of the investigation at any time they so desired.

In light of parents' requests to be spared from the task of data collection, information pertaining to the efficacy of ENG instruction must be considered preliminary at best. E-mails from the respective families indicated that two children continued to require moderate to full assistance in order to use their three and seven ENGs, respectively. Five children were progressing toward independent use of three to seven ENGs, but still required prompts at levels 1–5, depending on the situation. The other two children were occasionally using ENGs (two and five, respectively) spontaneously (level 1) but, depending on the situation, relied on prompts at levels 1–5 on different occasions. Other ENGs (4 and 3, respectively) continued to require hand-over-hand assistance (level 5), with an occasional level 4 prompt. These data are based totally on parent reports in the absence of any formal data collection. They suggest children's progress in acquiring ENGs was slow and protracted.

In light of the relatively slow rate of language acquisition and communication development in children with AS, it was determined a priori that a primary way of assessing the immediate and long-term efficacy of ENG instruction would be to elicit parents' opinions. All of these parents had committed more than one year to this investigation, from the initial call for subjects to their completion of the ENG-ARF. This included a minimum of (a) two weeks practice in identifying their child's use of natural gestures; (b) two weeks to establish reliability; (c) two weeks to continue recording natural gestures and begin identifying possible ENGs; (d) two to four weeks to practice the various intervention techniques, with support from their observers; and (e) 12 to 14 weeks carrying out the intervention program. This amounted to a minimum of 20 weeks in which they were actively involved in the investigation. All nine families expressed their confidence that they had enough experience with ENGs to offer an assessment of its acceptability and effectiveness.

As noted earlier, all of these parents had expressed, in

writing, disappointment with their children's methods of communication prior to this investigation. Responses to the ENG-ARF provided information about the acceptability of this instructional program and the likelihood that parents would persist with it.

Family's responses to the questionnaire are summarized in Table 3. Scores are ordinal and uniform in that higher scores denote higher levels of acceptability by parents. Parents assigned a score of four to aspects of the program about which they were neither positive nor negative, but neutral. Scores of one, two or three corresponded to negative impressions (one being the most negative) while scores of five, six and seven represented increasingly positive impressions and levels of acceptability by parents.

These data provide strong evidence that parents approved of the Enhanced Natural Gestures instructional program. Item #1, "How acceptable do you find ENG instruction?" received a mean score of 6.33, which (along with item #9) represented the highest score across all items. Parents' written comments were consistent with this positive rating: "great written material for instruction;" "always knew professor/staff would be available for any questions;" "I found it to be a very realistic approach to communication;" "makes sense, it requires time but not as much as other programs."

The above comments alluding to the program making sense and being understandable were reiterated in responses to item #13, "How difficult would it be for you to teach others to use this method of communication?" which received a mean score of 5.78. Parents remarked, "I hope it's okay, I've talked with other parents already. They're picking up gestures in their kids;" "Difficult only in the sense that parents have to remember to use gestures and encourage their child to use gestures rather than interpreting for them;" "self-explained but would need training."

The third highest score, 6.11, was assigned to item #11 which sampled parents' willingness to change family routines to carry out this treatment. One family commented, "I thought I was very willing but 'life' just gets in the way. I needed more of a set schedule to abide by." A similar feeling was expressed by another family, "The mind was willing, but chaos often intruded on our efforts;" "[It was] hard to devote much time during the week with work hours, therapy sessions, and activities of other siblings."

These comments suggested that families were willing to alter their routines to carry out this treatment, but not without a level of inconvenience.

Willingness was also sampled in item # 3, "How willing are you to carry out this treatment?" Like item #11, this item received a relatively high score ( $M = 5.67$ ).

Some of the negative comments in response to item #11 alluded to the time required to implement this program. One would thus anticipate relatively low scores for item #7, "How much time is needed each day for you to carry out this treatment?" As expected, this item received the second lowest score ( $M = 3.67$ ). Parents' comments were generally consistent with this rating: "In the beginning stages it's time consuming because of the tracking and logging of gestures;" "If you're like most parents, you are in a constant rush from home to school to after school activities;"

**TABLE 3. Responses by the nine families to questions 1–14 from the Enhanced Natural Gestures-Acceptability Rating Form (ENG-ARF).**

Question	Michael	Greg	Tom	Sean	Mark	Zoe	Carly	Beth	Bailey	Mean
1. Acceptability	7	6	6	5	6	7	7	6	7	6.33
2. Effectiveness	5	6	2	4	4	7	4	6	6	4.89
3. Willingness	6	5	2	6	6	7	7	5	7	5.67
4. Reasonableness	6	5	5	4	5	6	7	6	6	5.56
5. Disadvantages	4	5	5	5	7	7	7	3	7	5.56
6. Long-term	5	7	2	5	4	7	5	6	7	5.33
7. Time	3	1	6	1	1	6	7	3	5	3.67
8. Disruptiveness	6	4	4	3	2	7	4	3	7	4.44
9. (–) Side effects	4	7	7	7	7	7	7	5	6	6.33
10. Effectiveness if used consistently	5	7	4	6	5	7	5	5	7	5.67
11. Willingness to change routine	7	6	5	5	6	7	7	5	7	6.11
12. Amount of use	5	5	2	1	1	6	5	3	4	3.55
13. Ease in teaching others	6	6	3	6	5	7	7	5	7	5.78
14. (+/-) Existing gestures	6	1	5	5	5	7	4	6	7	5.11

“Probably my single biggest complaint.” Still, two families assigned scores of 5 and 6 respectively. One observed, “Of course some time is needed, but I tried to streamline my efforts. I put a master list up on a cabinet in the kitchen that I could refer to. It listed all the ENGs we were working on and the prompting levels. I kept my data sheets right on the counter so it was easy to write stuff down as it occurred.”

Despite time demands, parents responded positively to items 2 (“How effective is this treatment likely to be for your child?”) and 6 (“Thinking in the long term, how likely is this treatment to make permanent improvements in your child’s communication success at home?”). Mean scores for these items were 4.89 and 5.33, respectively. One family’s comments, in responding to item #2, were representative of most of the families, “Each individual will be different. Effectiveness is based on caregivers, families, schools, paraprofessionals, etc. Everyone must have the same enthusiasm and conviction.” Comments associated with item #6 included the following, “For a child that has *no* real means of communication, it has to be an improvement. If you combine this with other methods, it’s that much more complete;” “Less frustration. Less negative behaviors. Positive self-image amongst peers.”

The negative comments associated with items 2 and 6 alluded to children’s slow rates of progress and continued difficulties initiating communication: “Just slow going, child won’t initiate requests;” “Slow going, motivation is a factor;” “While we think our child understands the gestures, we can’t seem to get him to initiate the gesture.” Recall problems initiating communication were noted in the earlier review of literature pertaining to communication characteristics that are prevalent in children with AS.

Item # 10, “How effective do you think ENG instruction would be if used consistently at home?” received a mean score of 5.67. Time (or more specifically, time management) was a factor in the following comments, “If I could have the support (constantly) I see it could be very effective;” “Consistent repetition seems to be the key as well as planned out situations in advance;” “I just think you need

months for these children to use the ENGs consistently;” “You need to stay with it and make it part of your routine.”

At first glance, these favorable responses to item #10 might appear to contradict those associated with item #12, “How often are you and your child presently using enhanced natural gestures at home?” The latter item received a mean rating of 3.55, which falls in the direction of, “Not very often.” However, this score was *not* indicative of parents’ actual use of the procedure. To the contrary, families were encouraging ENGs along with other methods of communication by their children: “We use gestures when we’re together, but lots of time we’re not interacting with each other so there’s no use for gestures or anything else;” “We usually don’t use gestures more than 15 minutes or so each day. It’s more on weekends;” “The gestures are helpful but we still use his other ways of talking with us.” All three of these families scored this item 3 or less. However, their comments indicate they use natural gestures often when interacting with their child, even though they may not be interacting with their respective children for much of the day. One might expect this situation to be the norm in many households in America upon examining the total number of minutes in a day relative to those in which parents are communicating directly with one another or with their children!

Other comments related to item #12 alluded to children’s overall slow rates of progress and parents’ propensity to spend more time with gestures their children used successfully: “We use the three that were very successful a lot, but I haven’t worked on any new ones;” “Only using a few for now.” It thus appears that the question, while intended to address the number of ENGs being used, was interpreted by some parents as asking how often they and their children were using gestures at home. For example, a family that assigned a score of 6 to this item commented, “We keep introducing new gestures.” Once again, this tells us little about the frequency with which this family is using ENGs. In summary, item #12 proved to be highly ambiguous, and we cannot be certain

how it was interpreted and then evaluated by the families.

Parents' ratings and comments about the program were predominantly positive in their overall acceptance, understanding, judgements of effectiveness, willingness to be involved, and justification of time required implementing the various procedures. Considering this, one would expect positive responses to item #4, "How reasonable do you find this training to be?" Data supported this expectation; the item received a mean score of 5.56. Parents' comments revealed some reasons for this positive rating: "If you want to improve communication with your child, you must spend some time and the training takes time but is well worth it;" "Training was thorough and understandable with the case examples of how to implement various gestures;" "It takes effort but what doesn't?"

Several items on the questionnaire related to possible negative outcomes associated with the program. Parents' responses to these items suggested this was not a major concern. For example, the mean score for item #9, "To what extent are undesirable side effects likely to result from this treatment?" was 6.33. The two negative comments were: "I can't see any side effects other than initial frustration of not getting what they want right away," and; "Other family members get less attention." Items related to disadvantages of the program ( $M = 5.56$  for item #5), and disruptiveness to the family ( $M = 4.44$  for item #8) indicated these were not general concerns. Still, one family offered comments indicating disruptiveness was a personal concern of theirs, "It's not disruptive but it can interrupt the flow of the family day. It's hard to work with our angel when his sibling is screaming and wanting something to eat."

Item #14 on the questionnaire inquired about the number of natural gestures that parents observed their children use, relative to what they expected. Phase one of this investigation required parents to identify the presence and corresponding meaning of natural gestures their children were already using prior to their implementing ENG instruction. Two of the nine families reported their children used fewer gestures than they expected. One parent commented, "He used our hands mostly to indicate needs."

The remaining seven children used more gestures than their parents expected. Associated comments by parents suggested that teaching parents to identify and interpret natural gestures increased estimations of their children's communication prowess. Comments included: "Once taught about observing gestures, we didn't realize how many gestures our child actually uses;" "This phase made you so much more aware of what your child was doing;" "I thought she wasn't trying to communicate, but I was very surprised at how many gestures she tried;" "I felt badly to see how many gestures she had that me and my wife never noticed. No wonder she would get mad. We weren't 'listening' to her."

All nine parents indicated by their ratings and/or comments that they intended to continue using ENGs following the conclusion of this investigation. Four families cited frequent use of the techniques, assigning scores of 5 or higher to this item on the questionnaire (#12). Rating by a fifth family was neutral and the remaining four families indicated they were not using the methods very often.

However, in reviewing these latter families' comments it was evident that they were continuing to use ENGs with their children. Their responses were driven largely by the frequency with which ENGs were used over the course of the day. For them, this included situations in which they and their child were apart or not interacting with one another. Also, some parents misinterpreted "amount of use" to refer to the number of different gestures their children were using, rather than the frequency of use of any one or combination of gestures overall. These findings also indicate that item # 12 should be either eliminated or reworded in future administrations of the ENG-ARF.

In addition to ENGs, parents continued to encourage and reinforce their children's other methods of communication (as reported on the parent questionnaires). Parents discovered their children were using significantly more natural gestures than they anticipated prior to this investigation (Item #14 on the ENG-ARF). Parents identified many contact gestures they previously ignored or responded to inconsistently. Upon deciphering the underlying meaning of these gestures, parents reported that this also made interactions with their child easier. Examples of contact gestures included: (a) pushing an object away ("I don't want that"); (b) handing their Mom an individually wrapped slice of cheese ("I need help"); (c) pulling their Dad toward a cupboard and then alternating their gaze between Dad and the cabinet ("I want a snack"); (d) placing their mother's hand on the refrigerator handle ("I want something to eat"); (e) pushing a plate of food away or throwing a spoon on the floor ("I'm all done"); (f) Pulling another child toward them ("I'd like a kiss and a hug").

Unlike items 1–14, item 15 was open-ended. It stated, "The overriding objective of this investigation was to enhance interactions between children with AS and their families at home. Please discuss the extent to which this objective was or was not met for your family."

Several families included negative comments in response to this item. For example, Mark's family wrote, "We personally didn't have any real success due to the school personnel NOT being involved at all. Things were just not consistent enough...and that's too bad, as it seems a very reasonable communication system. Maybe at another time I'll try again." Carly's parents indicated, "I think this is a wonderful method and everyone should try this to see if it will work." They went on to say, "We ran into a problem with motivation. Our child wouldn't care if he didn't get the toy or book if his first request wasn't observed as an ENG...but we're not giving up." Beth's parents stated, "Due to my husband's changing work schedule on a weekly basis and my full time work schedule which included filling in taking care of our two children, I found little time to implement the methods." Finally, Tom's family noted, "We had difficulty in getting our child to initiate the ENGs... Our child loves to eat and is so intense at mealtime it was physically difficult to get him to use the mold/shape technique. Conversely, we used an ENG for computer, which was very natural and required less physical hand over hand, and we had some success. So the type of ENG and the type of technique could impact success of using this methodology."

There were many examples of positive comments. Beth's family commented, "I found the gesture study to be well thought out and detailed as to the desired outcomes." Comments from Michael's parents included, "This study was definitely useful and encouraging." Sean's family remarked, "Yes, our child now communicates his wishes and desires more clearly. Eventually we used the protocol to teach fairly standard gestures/signs." Bailey's family remarked, "The thing that was great about all this is that I now was spending time really watching her. I saw things that I never saw her do before."

Finally, Greg's parents provided several insightful remarks. They wrote, "Guidance and fostering our relationships are so important.... It's just one part of this 5,000-piece puzzle. I look at my son differently. I allow him to express himself more rather than make the decision for him. How we mold that expression needs to be well thought out because once a behavior/communication is learned, they tend not to forget.... I think most families are exhausted with day to day stuff. You also have the opposite parent that is so enthusiastic they use every breath they take, and the child loses out on the whole experience of life."

In summary, parents' ratings and comments in response to items 1–14 on the ENG-ARF Questionnaire provided strong evidence that they found the Enhanced Natural Gestures training program acceptable (#1), effective (#2, #6, #10), reasonable (#4), and easy to teach others (#13). In addition, parents indicated they were willing to carry out this treatment (#3) even if it meant changing family routines (#11), and they felt it was likely to make permanent improvements in their children's communication success at home (#6).

Parents did not associate negative consequences with the training program, in terms of disadvantages (#5), disruptiveness (#8), or undesirable side effects (#9). Still, they felt a moderate amount of time was necessary to implement the program (#7).

## Next Steps

Several families suggested that combining home instruction with school instruction could further enhance the effectiveness of this program. They emphasized their children's needs for consistency and support. This would require minimal changes in the protocol and is certainly worth pursuing.

Although this investigation was limited to nine families, the children's skills and abilities were consistent with those cited in the literature for children with AS who are deletion positive and may be generalizable to that population. Future research might address the usefulness of ENG training with other populations including older children and adults with AS, movement disorders, mental retardation, and autism spectrum disorders.

It may be useful to administer the ENG-ARF following the initial four phases of a follow-up investigation, rather than waiting until the conclusion of the intervention. This would allow investigators to observe the cumulative effect each phase has on parents' perceptions about the efficacy of ENGs.

Studies might also extend beyond this examination of acceptability and feasibility to assess the actual effectiveness of ENGs alone and in comparison with other gestural behaviors such as manual signs and natural gestures—which would require quantitative analyses.

Parents' reluctance to collect data might be managed by leaving the task of data collection to observers. Another alternative would be to videotape parent-child interactions at home to analyze at a later time. Problems could be posed, however, by subjects' reactions to being videotaped, which could threaten the validity of the investigation.

Although parents were taught to use environmental sabotage, expectant delay, mand-model, and molding/shaping procedures, their actual use of each of these techniques was not monitored once formal data collection ceased. E-mail exchanges following this investigation indicated parents seemed to prefer the molding/shaping and mand-model techniques. They found environmental sabotage required too much time and planning and, thus, used this procedure infrequently. Expectant delays were used often, depending on their child's temperament, many times in conjunction with mand-modeling.

As indicated earlier, parents were especially satisfied with the effect ENG training had on their own abilities to recognize communicative behaviors of their children, such as contact gestures. They cited this as an important component in enhancing interactions with their child. Subsequent research might examine children's acquisition of contact gestures and ENGs, comparatively and/or sequentially. As noted earlier, children with AS have been reported to have difficulties initiating communication. It is possible that contact gestures circumvent this problem more so than ENGs.

In the time spent working with these children and their families, the investigator was continuously reminded of the importance of involving parents in every aspect of their children's instruction. The investigator often found his skills and insights pale in comparison to the common sense borne from experience that was demonstrated by these parents. Parents must be partners in the instruction of their children. They should be encouraged to recognize their expertise with respect to their children's communication and related needs, for if parents fail to see significance in the actions of professionals, the latter's actions will be for naught.

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