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Supporting Communication of Girls with Rett Syndrome and their Mothers in Storybook Reading

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ABSTRACT *In this study mother–child storybook reading was explored as a context within which to support early symbolic communication of girls with Rett syndrome. Baseline measures of mother–daughter interaction were gathered as mothers read familiar and unfamiliar storybooks with their daughters. Then three experimental interventions were studied in the homes of four girls: (a) resting hand splints, (b) light tech augmentative communication systems such as voice-output devices and symbols, and (c) very basic parent training. Access to devices, symbols, and training increased the frequency of each of the four girls, labeling and symbolic communication during storybook reading. Parent training was particularly useful in increasing the percentage of appropriate switch use by three of the four girls. The study suggests that parents can provide substantial support to early communication development in girls with Rett syndrome, if they are provided with basic information and materials.*

Introduction

The beneficial role of storybook reading in the development of early literacy and communication skills is well documented in the early childhood literature (see e.g., Neuman, 1996; Strickland & Morrow, 1989; Teale & Sulzby, 1986). While there have been fewer studies involving children with identified special needs, there is, nonetheless, evidence to suggest that children with a variety of disabilities also benefit from storybook interactions by increasing spontaneous language use (Bellon,

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Ogletree, & Harn, 2000), verbal and picture communication symbol use (Dexter, 1998), and overall communicative performance (Crowe, Norris, & Hoffman, 2000).

Rett syndrome (RS) presents particular challenges as we attempt to apply what has been learned about the potential of storybook reading to support communication development. For example, mothers of children with other developmental delays appear to respond to their children's level of engagement and responsiveness during storybook reading by making more of an effort to involve their children (Schneider & Hecht, 1995). Unfortunately, girls with RS have a particularly difficult time responding in conventional ways that are easily interpreted or in otherwise demonstrating their engagement. Mothers of children with other developmental delays seem to respond to the frustrations of their children's communication difficulties by (a) reducing the number of storybook readings per week and (b) limiting children's participation to yes/no responses to directives and questions (Light, Binger, & Kelford Smith, 1994; Light & Kelford Smith, 1993; Marvin, 1994). Girls with RS are reported to be pre-intentional in their communication attempts (Woodyatt & Ozanne, 1992, 1993, 1994), and when they do experience success communicating choices with others, they do so inconsistently across tasks and occasions (Sigafoos, Laurie, & Pennell, 1995).

Aims of the Present Study

The present study was part of a larger investigation of storybook reading in the home as a context for early communication and emergent literacy intervention in girls with RS. In an earlier report from this study (Koppenhaver et al., 2001), we examined the effects of resting hand splints, basic assistive technologies, augmentative and alternative communication (AAC) symbols, and parent training on the nature and frequency of children's communication during a sampling of mother–child storybook reading of familiar and unfamiliar books. In the current article, we examine more fully the impact of attempts to provide (a) children with the means to communicate and (b) parents with the support to interpret and attribute meaning to their children's communication attempts. We explore the impact of these interventions on both children's communication modes (i.e., the ways in which they communicate) and acts (i.e., the function of the communication) during storybook reading.

Studies of parents and nondisabled children characterise storybook reading as a socially created and interactive experience (Sulzby & Teale, 1991). Parents rarely just read stories but rather engage in a shared conversation with young children, co-constructing personal meanings from the pictures, story events, and author's language. Researchers have suggested that this parent–child interaction is routinised (e.g., Ninio & Bruner, 1978), thereby creating a predictable context for language learning. Children are supported in developing increasingly sophisticated understandings of what to attend to in storybook reading, what behaviours are expected, how to communicate with parents, and what to communicate about. We believed that by supporting mothers and their daughters with RS in relatively basic ways, we might create similar learning opportunities for the girls.

Method

Participants

Girls. Four girls with a primary medical diagnosis of RS participated in the study. The girls ranged in age from 3.6 to 7 years at the onset of the study and all exhibited severe communication impairment as evidenced by limited to no intelligible speech. All of the girls (i.e., Amy, Baylee, China, and Petesie) communicated through a variety of nonconventional gestures and vocalisations. All looked at people or objects to indicate attention, wants, or needs. Amy and Baylee were able to ambulate independently, while Petesie and China required physical assistance such as hand-holding. All four girls engaged in various forms of repetitive hand-wringing, and two girls also engaged in hand–mouthing behaviours. Two of the girls, Amy and Baylee, wore elbow splints for significant portions of each day. Baylee and China would grab desired objects within reach. All four girls reportedly had normal hearing and vision and all met the mental retardation criteria of the American Association on Mental Retardation (1992) since they exhibited pervasive needs in all major life domains (e.g., self-care, social skills, communication, home living). Age equivalent scores on the Bayley Scales of Infant Development (BSID-II) (Bayley, 1993) ranged from 5 to 19 months and on the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) from 9 to 17 months. Finally, all four girls were perceived by school personnel as functioning in the range of severe to profound intellectual disability.

Mothers. All study participants were Caucasian and reported that they read two or more times a week with their daughters prior to involvement in the present study. They used neither AAC symbols nor devices regularly, but one had used a BigMack [1] single-message communication device and picture communication symbols at times in the past.

Experimental Design

A multiple baseline design across behaviours was employed with four parent-child dyads (Barlow & Hersen, 1984) in order to evaluate how resting hand splints, basic AAC and assistive technologies, and parent training impacted the participants' communication modes and acts. The study consisted of a baseline and three intervention phases as described below.

Procedures

Families attended five, individual, monthly assessment and informational sessions at Lenox Baker Children's Hospital in Durham, NC, USA across the 4 months of the study. During these sessions, the first author met privately with the parents who accompanied each child to explain plans for each study phase, introduce equipment, and explain procedures. Simultaneously, the second author worked with a team of speech-language clinicians to conduct play-based communication and emergent

literacy assessments and activities with each girl individually. Each session lasted approximately 2 hours.

Phase I (Baseline). The principal goal of phase I was to record the typical ways in which mothers read and interacted with their daughters during storybook reading. During the initial visit, the overall goals of the study were explained to the parents. VHS-C video cameras, tripods, videotapes, and pre-addressed and stamped envelopes were provided to each family. Parents were instructed in the operation of the cameras and guided in how best to videotape storybook reading (i.e., to videotape at approximately a 45-degree angle and in front of the mother and daughter, so that eyes were not hidden behind books, and to capture the entire length of the girls, so that nonverbal behaviour could be observed).

The parents were also given an opportunity to select books from a display of more than 30 children's storybooks. Parents were asked to select two books that they believed would be interesting for their daughter, one that they judged to be familiar to their daughter and one they judged to be unfamiliar. Families were instructed to read the unfamiliar book only twice a week and to videotape on each occasion. They were instructed that they could read the familiar book as often as they, and their daughter, wished to read it, but only to videotape the reading and interaction on the two days that they recorded the unfamiliar storybook reading. Since in all four families, parents agreed that the mother read more often with the daughter, the research team decided to to videotape only mother–daughter readings and interactions. This not only allowed comparison across dyads but was also consistent with the research literature.

Simultaneous to this initial parent session, the research team also attempted to familiarise themselves with each girl's modes of communication. The team videotaped each session as they attempted to gather data about the girls' interests, language comprehension, communication, use of switches and other simple technologies, and emergent literacy understandings.

Phase II (Hand splinting). The goal of this phase was to investigate the effects of a resting hand splint on the participants' non-dominant hand. These hand splints were custom-made by a registered occupational therapist (OTR) during each family's visit. Parents were asked to provide their best judgement regarding their daughter's dominant hand, and this information was confirmed by the OTR through careful observation of play-based interactions with the girls. Puppets, bubbles, baby dolls, and musical instruments were used to entice the girls to reach out.

Once hand dominance was established and the splints made, each girl wore the splint for 20 min in the clinic so that pressure points and other indicators of incorrect fit could be assessed. During this time, the research team members continued to interact with the girls in play and storybook reading. Parents were directed to have their daughter wear the splint during storybook reading and encouraged to explore its usefulness in other environments. The two girls who already wore elbow splints continued to wear them with the hand splint.

The research team also conducted preliminary investigations of the participants' use of the basic technologies that were to be introduced in the third phase. Accessibility issues (e.g., appropriate positions for switches and books) were explored. As in all phases, parents chose an unfamiliar and a familiar storybook for reading at home. In phases II to IV, the books had a repeated line throughout the book. The titles of the books were documented and appropriate communication symbols later were created for use in the next phase of the study.

Phase III (Assistive devices). The purpose of this phase was to study the impact of a variety of assistive technologies on the storybook reading and communicative interactions. A similar range of technologies and environmental adaptations were introduced to each family, including laminated books and BigMack switches, but the positioning of those technologies, specific features of some of the technologies, and environmental adaptations differed by child. Parents were introduced to the operation of the technologies, but not provided guidance in their application during communication events. In keeping with a minimalist intervention structure, we were attempting to simulate the experience of many parents who find particular technologies at conferences or in catalogues and explore their utility independently.

Each family was given (a) a set of Picture Communication Symbols [2] (PCS) to accompany each of the familiar and unfamiliar books they selected, (b) a single-message BigMack, (c) a multi-message Four In-Line Cheap Talk, [3] and (d) a variety of stands made from PVC pipe and used for mounting these devices and symbols. The set of PCS symbols represented the repeated line and key vocabulary of a book they had read in phase II. For example, symbols from the book *Brown Bear, Brown Bear, What Do You See?* (Martin, 1992) represented the main characters and the repeated line, "What do you see." All of the symbols were laminated to increase durability, and velcro was attached to the back of each. Corresponding velcro was placed on each page to enable use of the symbols for interaction during reading. The families also received a single 3-by-3-location communication board with core vocabulary symbols. Mothers could use these displays to model pointing to PCS symbols as a form of communication.

The BigMack, a single-message communication device, provided a means for children to speak a repeated line from the story. A communication symbol could be attached to the BigMack and the corresponding message recorded. The Four In-Line Cheap Talk allowed four PCS symbols to be attached and four corresponding messages to be recorded. Children activated this device by touching the appropriate symbols attached to the switch surfaces.

In addition to the communication symbols and devices, parents received a variety of stands made from PVC pipe. An eye-gaze frame was designed to be placed in front of the child, which parents used to display symbols during the readings. All of the families also received a stand on which the BigMack was mounted at a 45-degree angle. For Baylee, the mount held the BigMack at a 90-degree angle about 2.5 feet (76.20 cm) off the floor to facilitate activating the switch with a head movement when she sat cross-legged on the floor.

Phase IV (Parent training). The goal of this phase was to evaluate the effects of parent training on the nature of the interactions and communication during storybook reading. During the parent session, training was provided individually to each parent on the use of the technologies provided in phase III. Careful review of videotapes submitted by parents during the previous phase guided us in developing the directions. When families came to the clinic for their fourth monthly visit, both strategies were explained to parents and also modeled with children. Each mother then practiced the strategies as the research team provided additional feedback and guidance. Total training time for modeling, practicing, and asking questions was less than 2 hours for each family. The intervention strategies included:

1. *Attribute meaning to your child's attempts to communicate even if the meaning is uncertain.* In many cases, the girls were vocalising and gesturing during the storybook interactions, but their meaning was unclear. Parents were taught to acknowledge the attempts and give them meaning. For example, one girl shrieked and looked at her mother when she turned the page to the picture of the cicada in the book *The Very Quiet Cricket* (Carle, 1990). The mother was taught to reply with expressions like, "Oh, you like that beautiful picture of the cicada, don't you? I wonder if we could find a cicada in the field near our house."

2. *Prompt the use of communication devices or symbols through natural questions and comments rather than commands.* Mothers often guided their daughters to use the devices and symbols by telling them to "hit your switch" or "look at the———." We instructed parents to think of the AAC devices and symbols as their child's voice and prompted them to ask questions that their child could answer with available symbols and voice output messages. Instead of telling a child to hit her switch when she missed a communication turn, mothers were encouraged to ask questions like, "Do you think Spot is under the bed?" Then the child could use the BigMack to respond with the repeated word, "No." Parents were also taught to demonstrate use of the symbols and devices throughout the storybook readings and interactions.

3. *Provide sufficient wait time and a hierarchy of support after asking a question.* When the girls did not respond quickly and independently, mothers tended to immediately provide hand-over-hand support. Mothers were taught instead to wait 10 to 30 s, depending on the child, before repeating the question. If the child failed to respond appropriately to this second opportunity, mothers were taught to provide informative feedback. For example, when one child incorrectly selected *waa-waa* as the sound a bus horn makes, her mother was taught to respond, "Horns go beep-beep; babies go waa-waa," and to model the correct response using the child's symbols and device. If the child did not respond after the question was repeated a second time, mothers could provide the child with hand-over-hand assistance.

4. *Consistently ask questions and make comments that maximise use of available symbols and voice output messages as appropriate communication turns.* Mothers were asked to survey the stories before reading and select the vocabulary for voice output that occurred with high frequency.

Measures and Data Analyses

The data reported here result from analysis of all videotapes of familiar and unfamiliar storybook readings from each of the four phases. Children's participation in the storybook interactions was coded by communication mode and communication act. Communication mode included in the current study include pointing with eyes, fingers, or objects to pictures or symbols; facial expressions; and activation of voice-output message devices. Communication mode was coded only if the child had acted independently, not if the parent provided guidance or hand-over-hand assistance. The only communication act coded for in the present study was labeling/commenting, which included labeling pictures by any mode and making comments. A child might comment by responding via a BigMack switch to a parent question or comment (e.g., "Hmm, I wonder what the little sheep is going to say to the next animal.") with the repeated line from a story (i.e., "Are you my mommy?").

Interobserver agreement was calculated as follows: number of agreements divided by number of agreements plus disagreements and omissions. The third author coded all of the videotapes, and the first author randomly coded 20% of the storybook reading sessions, sampling from each phase (range = 16 to 24%) and each child (range = 19 to 21%). An overall percentage agreement was calculated for each phase and for each child using the above formula. Reliability coefficients were .91 or better. Disagreements and omissions were resolved in discussion between the three authors.

Per minute frequencies of communication acts, including labeling and commenting, and use of communication modes were calculated for each child. This established a common metric for comparing parent-child dyads since numbers of books read and amount of time spent reading varied widely.

Results

A total of 195 storybook interactions totalling almost 20 hours (19:45:08) were analysed. Table I reports the range per dyad in number of storybook reading episodes and total amount of time spent in storybook reading by phase. Parents were asked to select familiar and unfamiliar storybooks during each phase of the study to allow for an analysis of differences under the two conditions. However, our analysis across reading conditions revealed no differences between familiar and unfamiliar books on the variables of interest to the present study. Consequently, the two conditions have been combined in the current report.

Children

Labeling and commenting. In phases I and II, the girls were limited to using their own gestures, vocalisations, and pointing to pictures in the storybooks for labeling and commenting. With the introduction of AAC symbols and assistive technologies in phase III, the children were provided with a broader means of communicating

TABLE I. Range of storybook reading episodes and amount of time spent reading per phase by dyad

Phase	Range of storybook reading episodes	Range in time spent reading
I	10 to 19	40:55 to 1:55:08
II	6 to 23	39:45 to 2:49:43
III	4 to 8	25:58 to 54:11
IV	12 to 19	49:46 to 2:56:24
Total	32 to 69	2:49:50 to 7:52:18

labels or comments, including the BigMack switch, the PCS symbols, and the multimessage Cheap Talk. This resulted in increased frequency of labels and comments for all four subjects during phases III and IV when compared to phases I and II. For three of the four girls, parent training (i.e., phase IV intervention) resulted in the highest rates of labeling and commenting. For Amy, access to the AAC symbols and assistive technologies proved sufficient, and labeling and commenting decreased in phase IV, though remaining well above baseline. In none of the girls did splinting have a significant impact on labeling and commenting (see Figure 1).

Communication modes. All four girls demonstrated significant increases in accessing voice–output message devices in either or both phases III and IV (see Figure 2). In three of four girls (i.e., Petesie, Baylee, and China), frequency of accessing voice–

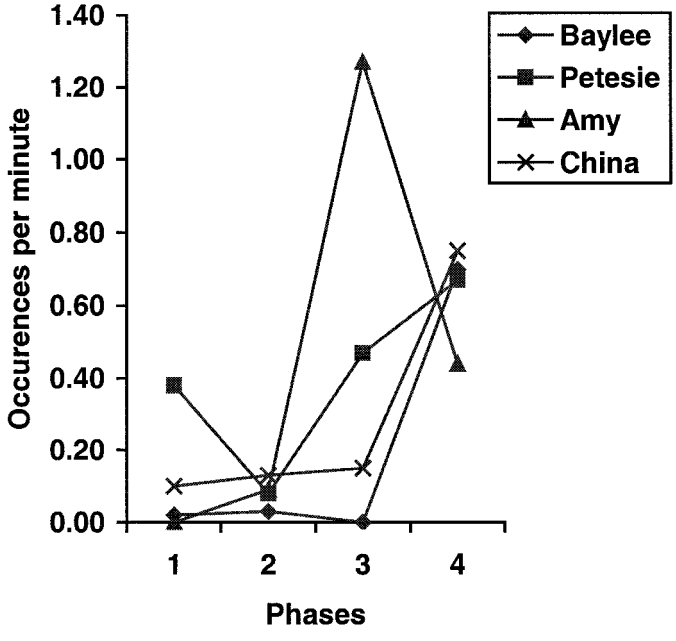

FIG. 1. Per minute frequencies of girls' labels and comments by phase.

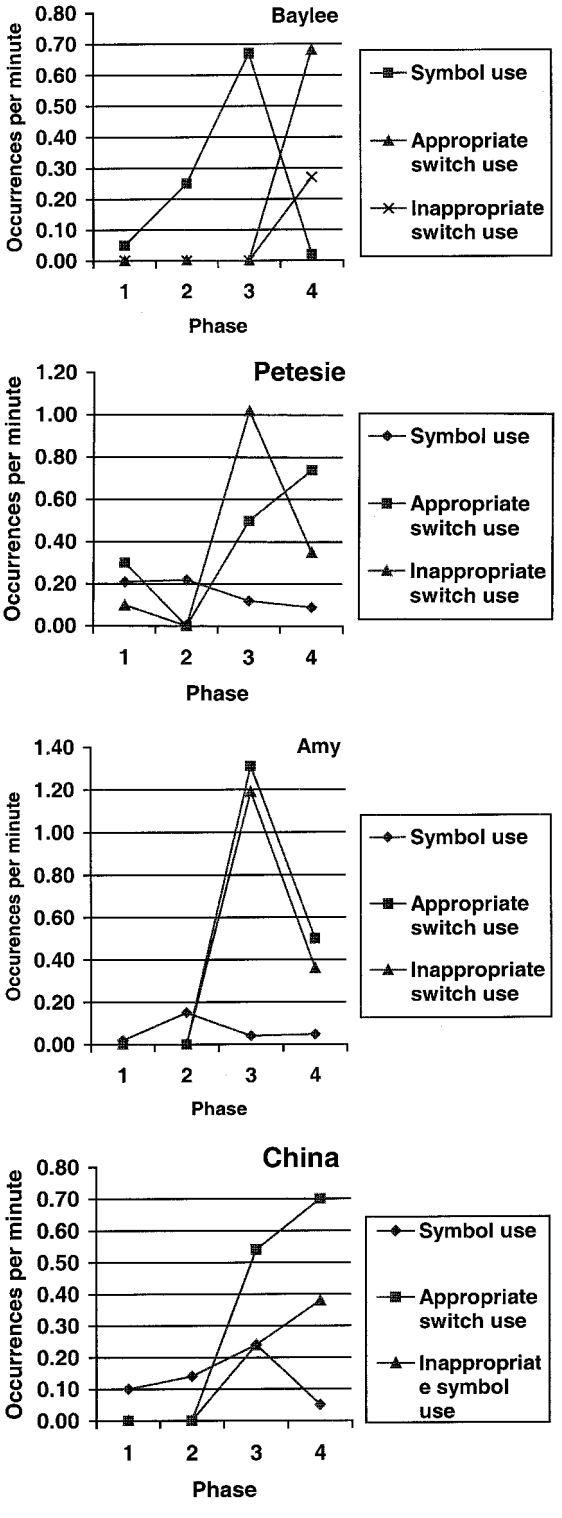

FIG. 2. Per minute frequencies of girls' modes of symbolic communication access by study phase.

output message devices increased in phase IV after parents had received training in ways of structuring communication so that the girls could respond with available symbols and/or devices. Amy's appropriate switch use decreased from phase III to phase IV, though it is well above baseline rates.

While the girls increased their use of voice output switches for symbolic communication, they demonstrated decreases in other forms of symbolic communication (i.e., eyepointing or pointing to picture communication symbols and pointing to pictures in the books). Amy and Petesie demonstrated relatively low rates of pointing to symbols or pictures (i.e., frequency $< .20$ occurrences per minute across phases), but even that low frequency declined in phases III and IV. Baylee demonstrated a significant increase in pointing to symbols and pictures in phase II. Both she and China demonstrated their highest rates of pointing to symbols and pictures in phase III. This communication mode was nearly extinguished in both girls in phase IV and replaced by comparable or higher rates of appropriate switch use.

Patterns of appropriate (i.e., accessing voice output when it was the child's communication turn) and inappropriate (i.e., accessing voice output when it was the parent's communication turn) switch use varied across the four girls (see Figure 2). Amy, China, and Petesie demonstrated high levels of appropriate switch use in phase III. For China and Petesie, these levels rose even higher in phase IV with parent training. Baylee never used a switch appropriately until phase IV, when her frequency reached that of Petesie and China (i.e., approximately .70 occurrences per minute). Baylee, Petesie, and China demonstrated increasing frequencies in appropriate switch use relative to inappropriate use across books and phases. Amy's appropriate switch use remained steadily, but marginally, above her rate of inappropriate switch use. Petesie's success with appropriate switch use in phase I resulted entirely from a single, highly interactive storybook session, while phase III and IV data hold across multiple storybook sessions.

We examined also changes in appropriate switch use as a percentage of total use of switches (see Table II). Appropriate switch use at rates of 50% or higher in phases III and IV were commonplace (i.e., Amy, 15 of 20 readings; Baylee, 10 of 11; China, 22 of 26; and Petesie, 15 of 16). Amy, Baylee, and Petesie demonstrated most appropriate switch use in phase IV. China's percentage of appropriate switch use was approximately equal in phases III and IV, but phase IV represented more than three times as many occurrences as phase III. Petesie's 75% appropriate use in phase I represented 24 total occurrences in a single book; her 68% appropriate use in phase IV represented 192 total occurrences across 16 books.

Discussion

Results of the present study suggest that girls with RS and their mothers can engage in interactions during storybook reading that benefit early symbolic communication and labeling. Splinting the non-dominant hand did not lead to substantial increases in either communication acts or modes, except for Baylee's pointing to pictures in phase II. However, access to communication symbols, assistive technologies, and

TABLE II. Percentage of appropriate switch use by girl and phase

	Phases			
Participants	I	II	III	IV
Amy	0%	0%	52%	58%
Baylee	0%	0%	0%	72%
China	0%	0%	69%	65%
Petesie	75%	0%	33%	68%

parent training consistently enhanced children's frequency of labeling/commenting and appropriate symbolic communication.

Communication Acts

All four girls engaged in higher frequencies of labeling and commenting in phases III and/or IV than they did in phases I or II, and three of the four achieved their highest rates of labeling when parents had received basic communication training. This is a particularly important finding given that the girls seldom labeled or commented at all in baseline or when provided greater physical access to pointing through splints. The challenges of communicating in an interpretable way for these girls were apparently overwhelming. The result was relatively passive child participation. Without interpretable child contribution, parents who wished to involve their children in storybook interaction had to carry a heavy interaction load: reading the book, commenting on and asking questions about story pictures or actions, interpreting children's vocalisations or facial expressions or other nonconventional hand or body movements, elaborating on these (non)responses and continuing with the reading. They also had to carry on this interaction in the presence of medical and educational data suggesting that their daughters had severe to profound mental retardation.

Providing access to picture communication symbols linked to a familiar, but previously passive experience, dramatically increased China and Baylee's frequency of labeling from approximately one every 7 to 30 min of storybook reading to 7 labels or comments every 10 min. Petesie's rate of labeling almost doubled from baseline, and Amy's rate in phase IV was five times higher than in phases I or II. Petesie, Baylee, and China continued to increase their frequency in phase IV when parents had greater understanding of how to support the girls' use of symbols and assistive technologies for the purpose of labeling or commenting. In concrete terms, 10 min of storybook reading in baseline would have resulted in nil to one labels or comments from three girls and as many as four from Petesie. That same 10 min of storybook reading in phase IV would have resulted in four to eight labels or comments by each of the girls.

Amy's frequency increased to 12 labels or comments for every 10 min of story-

book reading in phase III and fell to approximately five every 10 min in phase IV, a rate remaining more than five times as frequent as in baseline of phase II. There are a variety of factors that may explain this difference. First, because this study was conducted in the natural environment of each family's home, there was little experimental control. In examining videotapes, for example, we noticed that Amy wore an elbow splint on both arms in phase IV but only on her non-dominant arm in phase III. Second, we observed that in phases I and II, Amy and her mother typically sat next to each other on a sofa when reading. With the introduction of technologies and symbols in phase III, they moved to the floor. There Amy sat on her mother's lap or between her legs, with the BigMack switch balanced on mother's knee, on the floor between Amy's legs, and in a variety of other nearby locations. Easy access but varied switch location appeared to lead to what the research team judged as a number of switch activations that may have been accidental as Amy rocked or engaged in hand clapping and wringing with arms outstretched because of the elbow splints. In phase IV, the switch was mounted on a PVC frame at a 45-degree angle. Amy most often was seated independently on the floor with her mother next to her or at a small desk during this phase, and she had to lift her hand to activate the switch to make a label/comment. Third, Amy's mother had previous training and experience in special education. It is possible that access to these communication symbols and devices was all Amy's mother needed and that, in attempting to provide guidance, the researchers impaired a successful process.

The only comparable data examining frequency of labeling in children with multiple disabilities is Light, Binger, and Kelford Smith's (1994) study of nonspeaking children with cerebral palsy interacting with parents during storybook reading. These researchers reported frequencies of .94 to 1.34 labels per minute across participants. In the current study of girls with RS, we found peak rates following intervention of .67 to 1.27 labels per minute across participants. These differences may be due to a variety of factors including the greater prevalance and severity of motor apraxia in girls with RS and differences in parent or child awareness and understanding of AAC. Light, Binger, and Kelford Smith is a descriptive study. At the descriptive level of the current study—baseline—we find rates of 0.00 to .38 labels per minute in girls with RS. Given the relative emphasis on minimal intervention in the current study (i.e., off-the-shelf technologies, easily made PVC frames, little parent training), we believe that awareness campaigns are essential for parents of girls with RS and professionals who serve them. None of these four children were receiving AAC intervention services at home or school prior to the study.

Communication Modes

All four girls appropriately accessed a voice output switch with picture communication symbols with greater frequency in phases III and IV than in phases I or II. In three cases, the highest levels of appropriate switch use for symbolic communication were achieved in phase IV. Amy, again, demonstrated significantly greater appropriate switch use in phase III than in any other phase, but her frequency of appropriate switch use for symbolic communication in phase IV remained well above baseline

and phase II when she rarely communicated symbolically and had no access to a switch.

It is troubling that three of four girls pointed to pictures in books as a form of symbolic communication more frequently in baseline than in phase IV. It is more troubling that Baylee's and China's substantial gains in pointing to PCS symbols in phase III all but disappeared in phase IV. It is possible that children, and/or parents as communication partners, found communication via the voice output switches more powerful or easily interpreted. It may also be the case that the success that each dyad experienced in using the switch for communication, led to an initial embracing of this new mode of communication to the exclusion of others. It would seem important to share with parents the value of a diverse array of communication modes. Fluent, adult, augmented communicators may use voice output to deliver a lecture, gestures to clarify a request or need, a spelling board in a noisy café, and speech to talk with familiar listeners. These girls and their parents were experiencing their first successes in symbolic communication and will need support in moving to increasingly diverse and powerful modes of communication. Finally, it is also the case that most of the storybooks contained a repeated line that parents were instructed to record on the voice output switch. Children had many, many more opportunities to use this message in communication turns as the repetition occurred throughout the text. Other vocabulary was important but may have been relevant to only a single page or a few pages of the storybook reading and interaction.

In examining appropriate and inappropriate switch use, we can see different patterns and growing levels of competence across the participants. Amy demonstrated parallel and approximately equal frequencies of appropriate and inappropriate switch use across phases. China, Baylee, and Petesie demonstrated increasing frequency of appropriate switch use from phase III to IV that carried across individual storybook interactions almost without exception.

Implications

Parenting, educating, and communicating with children who have multiple disabilities is challenging. The current study suggests that those challenges need not be frustrating. The interventions explored in this study are widely available and user-friendly. Other parents, educators, classroom aides, volunteers, and classmates who are interested in communicating with, or supporting the communication of, girls who have RS could implement these strategies at relatively little cost in materials, personnel, training, or preparation.

We believe that the current study suggests some important guidelines in successfully supporting early communication of girls with RS. First, AAC symbols and voice output technologies must be made more widely available in the homes, schools, and communities where children with RS live, learn, and communicate. Only one family in this study knew about a BigMack before the study, and none of the girls' education programs involved significant integration of AAC intervention, yet all of them benefited substantially in a very short period of time during this study. Particular emphasis in preservice, inservice, and degree programs must be

made in educating medical personnel, speech-language pathologists, special educators, and early interventionists who serve families and children with RS. One useful starting place is the resources of the International Society for Augmentative and Alternative Communication (http://www.isaac-online.org), an organisation whose membership comes from more than 50 countries.

Second, successful educational interventions require educational models. Medical models are useful for diagnosing and treating medical conditions. Learning to communicate is an educational issue. Our research team explored the literature on storybook reading interactions involving nondisabled children. We considered AAC interventions with children who have cerebral palsy and autism. We problem-solved around the fundamental issue of supporting dyadic communication when one partner cannot talk or use her body in conventional ways for communication. We did not arrive at an RS-specific intervention. We supported parents and children in communicating by drawing on principles that have worked for a wide variety of children: (a) selecting a predictable and familiar context, (b) incorporating picture symbols in lieu of anarthric speech, (c) identifying conditions required for successful pointing by various means to those symbols, and (d) developing partner skills to encourage augmentative communication and interpret nonconventional communication attempts.

Third, while professionals continue to seek the best solutions to children's communication and learning difficulties, it is important to begin implementing some solution, any solution, today. This study did not employ the latest, greatest technology. It did not involve elaborate materials or extensive training of participants. The 10 to 15 min that these parents read with their daughters and used AAC symbols twice a week are available in every classroom and home. Despite the minimal investment, each of the four girls demonstrated significant communication gains. Clinicians, educators, and parents can all implement the strategies described in this study. If they can implement them daily across environments, they might expect greater effects on children's communication and learning than were achieved in the present study's low-intensity intervention.

Finally, professionals and parents must assume competence in all children. Professionals had consistently conveyed messages to the parents in this study that focused on the severity and range of their daughters' disabilities in communication, cognition, mobility, health, and other areas. Despite these messages, these parents believed in their daughters' capabilities. They sought meaning in nonconventional communications, accepted it, and encouraged it. They did their best with what they knew about off-the-shelf technologies and picture symbols. They listened intently to clinicians and worked hard to implement strategies. Their daughters' increased labeling, symbolic communication, and growing appropriate switch use are a testament to the parents' beliefs and efforts.

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Notes

[1] AbleNet, Inc., 1081 10th Ave. SE, Minneapolis, MN 55414–1312, USA. Tel. +1 800 322 0956.

[2] Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA. Tel. +1 800 588 4548.

[3] Enabling Devices/Toys for Special Children, 385 Warburton Ave., Hastings-on-Hudson, NY 10706, USA. Tel. + 1 800 832 8697.

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