

BOX 1: Case report – Past Medical History of a 5-Year-Old Girl With Speech Impairment
IDENTIFY POTENTIAL NEED – Beatrice (Bee) was born 6 weeks preterm with hyperbilirubinemia (jaundice), requiring a month-long stay in the neonatal intensive care unit. She was discharged with no medications or equipment and a normal newborn hearing screening. She achieved her gross motor milestones within typical age expectations, but her language milestones were significantly delayed. At age 2 years, she whined or grunted while pointing to items of interest, but she did not have any words.
Her physician referred Bee to a state-run early intervention (EI) program, but her parents opted to wait and see how Bee would do for a few more months. When Bee was 32 months of age, her parents had her evaluated by EI therapists because of her lack of progress. Since she was almost 3, she had aged out of EI services and therapies.
GATHERING INFORMATION (assessing communication and physical capabilities) – Based on the EI evaluations, Bee's nonverbal IQ was low average (80). A parent-report instrument indicated that out of 396 possible words, Bee understood 100 words but only said 3 words. An occupational therapist and physical therapist working together found that Bee was not delayed in either fine motor or gross motor skills. She began to work with a private speech-language pathologist (SLP) who introduced her to a picture communication system and encouraged her to speak more words. By 40 months of age, Bee said 15 words but was not using phrases. She remained hard to understand and she consequently became more frustrated and irritable during expressive communication. At 42 months of age, Bee was given a diagnosis of autism spectrum disorder (ASD) by a developmental/behavioral pediatrician.
FEATURE MATCH (What may work best for the child) – Initially, Bee continued with the picture communication system, but her parents were concerned that her worsening temper tantrums might be caused by problems with her not being able to communicate well. Her parents brought this behavior concern to the attention of her pediatrician. Upon re-evaluation, since Bee had no fine motor delays and was used to pointing at pictures and letters on a smartphone, an adapted touchscreen tablet was selected for her. In order to determine Bee's abilities, the SLP selected a system with a dynamic, changeable display, which would allow for more pictures and words being added as her vocabulary increased, adapting with her as she developed.
TRIAL/DIAGNOSTIC TRAINING – The SLP working with Bee and her parents was very experienced with AAC and was fortunate enough to have different tablet-based speech generating systems that she used on a trial basis with Bee. The SLP requested and obtained a loaner copy of a comprehensive but expensive AAC program to try with Bee. After determining the best AAC program to use, the SLP then locked out all the other features of the touchscreen tablet so that Bee could only use the speech-generating program by touching certain pictures. Her parents felt very comfortable with the use of the tablet after training from the SLP.
RECOMMEND/FUNDING – Since the SLP was able to find an AAC system that worked well for Bee and her parents, they prepared a report and recommendations. The SLP assessed funding mechanisms for the recommended AAC system. Bee's physician and SLP sent a letter to the school board describing why AAC is important for children like Bee. Unfortunately, this did not result in the school purchasing a device for her, as Bee's public school early childhood program was poorly resourced and unable to fund her AAC device. Bee's physician and SLP sent a letter of medical necessity and a DME request to the family's insurance company (see Table 3.) Despite 2 appeals over a period of 10 months, the insurance company refused to pay for the tablet-based AAC system, insisting that their policy would only pay for a much more complicated single-use AAC device. The family had a very high-deductible insurance plan and were concerned that they would not be able to pay the deductible. Both the parents and the SLP also felt that Bee would not be able to effectively use such a complex single-use device. Eventually, the family found funding from a philanthropic organization suggested by the company providing the AAC system, and her AAC system was delivered within 2 weeks.
TRAINING/MONITORING – After the AAC system was delivered, the SLP began additional in-person training with Bee, school personnel, and family. Caregivers were taught to how to do minor repairs and updates when needed as well as how to encourage Bee to use it. Bee was quite excited to use the AAC device at school since the other children and her teacher liked to watch her use it. At home, the AAC was rarely used as the parents felt that they could usually understand her when she said 1- or 2-word phrases. Bee's SLP and physician encouraged the parents to work with Bee using the AAC at home to begin putting several words together to make sentences. This “homework” reinforced what was already being done at school and with the private SLP. After a year of using the AAC device, Bee began saying 3-word phrases and sentences using her own voice. She still had trouble being understood most of the time with longer connected speech, although she had hundreds of single words she could say. Using her AAC device, Bee effectively communicated in 6- to 7-word sentences even with unfamiliar communication partners.

may influence its successful uptake. The ultimate goal for using any AAC device is to achieve the highest possible functional communication.

ROLE OF THE PHYSICIAN CARING FOR CHILDREN WITH COMMUNICATION DISORDERS

Identification, Referral, and Care Coordination

Guidance through *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* (4th Edition) can equip the PCP to recognize pediatric communication disorders and make appropriate referrals.⁷³ Children at any age who are nonverbal or have unreliable intelligible speech are potential candidates for AAC. At present, there are many cost- and time-efficient ways to

perform screening and surveillance of communication problems, including some clinical guidance from the AAP.⁷⁴ Knowing appropriate community resources and professionals for assistive technology is crucial. Children needing AAC systems require services for evaluation, procurement, training, and monitoring of devices and therapy programs. These services are ideally coordinated with existing therapies and educational programs while also being family centered. This integrative process can be confusing and overwhelming for the family, and it is within the role of the pediatric medical home to assist with and make referrals to all available resources.⁷⁵ Table 2 lists the 4 major components involved with coordinating care for children with communication disorders. Beyond providing medical home services for individual children, PCPs are also