

## School Age Case Study for Ethics Presentation at KSHA 9/15/11

**Relevant History:** Cale is an 8 year old boy with multiple medical issues including Cerebral Palsy (CP) resulting in severe impairments. These include the following: a history of spastic CP, dependent for ambulation, limited use of his hands/arms, limited oral intake of a modified diet, dependent for feeding, limited verbal communication skills. Cale is in a self-contained classroom and has a manual wheelchair for mobility.

The following are issues that have been raised by school staff and Cale's parents:

1. **Communication:** Comprehension: mild impairment. Cale is able to understand information at the conversational level and is able to use yes/no gestures (head up for yes and head down for no) to indicate understanding. The child appears able to comprehend basic directions and conversation in the classroom. Expression: profound impairment. Cale is able to vocalize (oooh) when he is excited or becomes frustrated. Cale also has limited vocalizations that only his family understands to indicate discomfort, fatigue or boredom. Cale has limited facial affect which reduces communication effectiveness. He is limited with skills for socialization with peers due to his significant communication deficits.

Cognition: Cognition is considered appropriate for learning new information and Cale demonstrates good sustained attention skills.

Cale has been receiving speech therapy with focus on improving current communications skills (compensatory strategies for increased intelligibility at the single word level). Functional improvement is considered very limited. An assessment for augmentative and alternate communication skills was completed. Cale was considered an excellent candidate for a communication device to provide more effective communication skills for home and school. School staff have met with the parents and provided the results of the assessment. Staff outlined the specific recommendations for the communication device identified. They also outlined the training needs that will be necessary for Cale to use the device effectively. They stated that the focus of speech therapy will change to include providing training to Cale for effective use of the communication device. The parents were not in agreement with these recommendations. They stated that they wanted to have Cale continue with traditional speech therapy to focus on increasing verbal output. The parents strongly indicated that they did not want to pursue any type of alternate communication techniques including a communication device at this time. Multiple meetings with the parents have resulted in no change in the parents' response to pursuing augmentative communication strategies. In the meantime, Cale is becoming more isolated from his peers and appears more frustrated including acting out behaviors in the last two weeks.

2. **Dysphagia:** Cale has received a Videoswallow evaluation in the last month at a local hospital. The results were mild-moderate oral stage dysphagia. Pharyngeal stage of the swallow was considered mildly impaired. The results of the evaluation indicated that Cale could safely tolerate a modified diet with consistent use of compensatory strategies. The recommendation was for oral intake of a pureed diet and thin liquids with 100% supervision and following swallow guidelines (small bites/sips; double effortful swallows, slow rate of eating, alternating

bites/drinks). It takes approximately 50-60 minutes for Cale to consume his lunch meal. He requires complete feeding assistance. The parents have requested that these recommendations be followed at his lunch meal. They have also requested that Cale be assisted with any oral intake during celebrations in the classroom (birthdays, holidays). School staff has indicated that they are not able to provide the level of assistance required (60 minutes, total feeding assistance) on a consistent, daily basis for each lunch meal. They have indicated that they will try to assist with swallowing/feeding assistance at celebrations but it will depend on their staffing situation for each occasion. They indicated that the family or other caregivers will need to provide assistance at lunch meals. Both parents work at locations that are not close to the school. The parents are not able to commit to providing the assistance for each lunch meal at school. Cale does have permanent alternate nutrition (PEG tube) but the family desire that Cale be provided with oral nutrition consistently. They provide assistance with his other 2 meals at home.

The parents have indicated that in no uncertain terms if their wishes are not followed (no pursuit of alternate communication strategies, staff assistance with all oral intake for lunch meals daily and any celebrations in the classroom), "we will go to the school board to have our wishes carried out." This has been a pattern in the past when they were not in agreement with recommendations from the school staff.

An Ethics Consult was requested.

1. What are the ethical issues?
2. What other information is needed to understand this case?
3. What other options might be explored to respond to caregivers' requests for assistance with their son's care?
4. What is the SLP's role in these discussions?