

Table 1: Demographics at time of admission

Characteristics	Total N=29 n (%)
Age Range: Birth to 19 years (total n=29)	
Mean Age	4.7 years
Median Age	1.7 years
Male	15 (51.7)
Living Arrangements	
Home with Parents	23 (79)
Medical Housing	6 (21)
Language in Which the Family Communicated with the Healthcare team	
English	21 (72)
Spanish	6 (21)
Other	2 (7)
Receiving Special Services	
Registered with NY State OPWDDD	9 (31)
Medical Services in the Home Prior to Admission	
Any Medical Service	10 (34)
Nursing	8 (28)
Respiratory Therapy	4 (16)
Home Aide	6 (20)
Community Health Worker	2 (8)
Educational Services at Home Prior to Admission	
Speech/Feeding Therapy	4 (20)
Physical Therapy	7 (28)
Occupational Therapy	6 (27)
Individualized Education Plan in School	6 (27)

*The New York State Office for People With Developmental Disabilities (**OPWDD**) is responsible for coordinating services for New Yorkers with developmental disabilities.

Table 2: Information integral to shared decision making

For each of the 12 key questions, the number of patients in whom the answer was found clearly documented anywhere in the chart. Total n=29 patients.

Information sought	# of patients with clear answer Total n=29
Primary language in which family talks with health care team	28
Underlying respiratory diagnoses	29
Comorbidities	28
*List of all the health care professionals involved in child's care	0
Effect of tracheostomy placement on respiratory prognosis	21
Effect of tracheostomy placement on overall prognosis	19
Whether the family understands the prognosis	24
Whether the family agrees with the prognosis	25
The family's hopes for the child	14
Who the family would like to involve in the decision	8
Health care providers who should be involved in the decision	13
*Any other patient/family concerns that need to be addressed	0

*Question was included in the initial SDM protocol but eliminated from chart review.