

Perspectives of Parents of Children with Down Syndrome on their Child's Language Development and Speech-Language Services

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Introduction

- Delays in language development of children with Down syndrome (DS) are present beginning at an early age and continue through adolescence.
- Few studies have specifically focused on parental views of the services provided to their child with DS.
- This study was designed to examine the parental perspectives of the language abilities of their children with DS and the services their children have received.
- Study Questions:
 - Do the parent-reported stages of language development differ by age?
 - Do type and hours of services received differ by age?
 - How do speech-language goals differ by age?
 - How satisfied are parents with speech-language services?

Method

- 130 parents of children with DS completed online surveys regarding their child's language development and speech-language services.
- Parents throughout the United States accessed the survey through links posted in newsletters and on social network sites of DS organizations.
- The survey consisted of 111 to 231 total questions and required approximately 30-40 minutes to complete.
- Parents characterized their child's language development according to one of five stages:
 - Prelinguistic
 - Early Words and Signs
 - 2-3 Word Utterances
 - 3-4 Word Utterances
 - Conversational
- Parents answered questions regarding the special services their child was receiving at the time of survey completion.

Parent & Child Characteristics

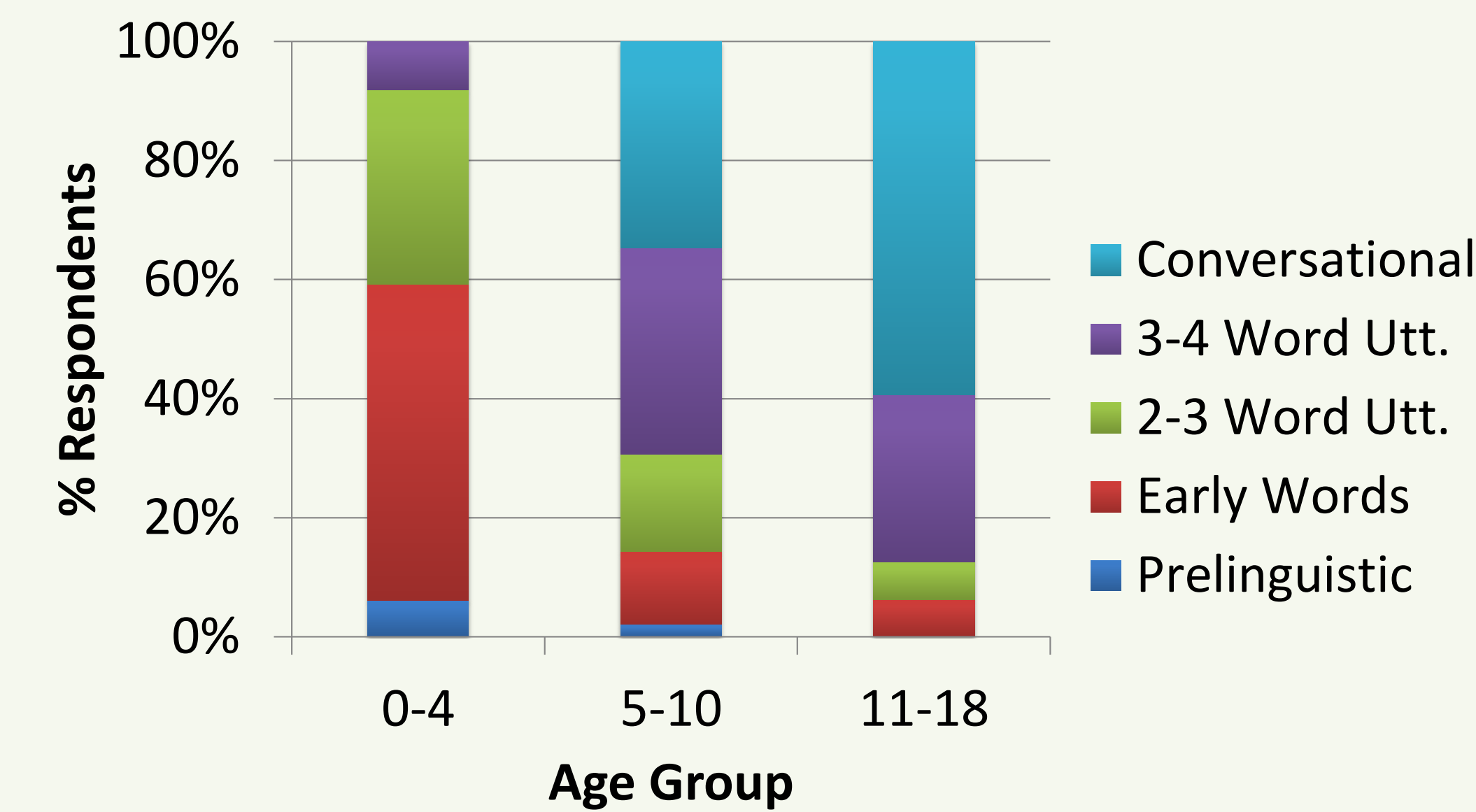
- Table 1 includes a summary of the respondents' characteristics as well as characteristics of their child

Table 1. Participant Characteristics

CHARACTERISTIC	AGE GROUP (years)		
	0-4 (n = 49)	5-10 (n = 49)	11-18 (n = 32)
Respondent			
Father: Mother	7:41	5:42	2:30
Other	1	1	0
No Response	0	1	0
Respondent Age			
24-30	6	3	1
31-40	30	15	3
41-50	12	28	15
Over 50	0	2	13
No response	1	1	0
College Degree			
Yes:No	38:11	35:14	22:10
Region			
Northeast	18	14	5
Southeast	9	12	6
Midwest	15	14	14
West	4	6	5
Southwest	2	2	2
No response	1	1	0
Child Gender			
Female:Male	24:25	15:34	12:20
Child Age (mo)			
Mean	33.06	93.14	171.94
SD	11.57	20.32	27.94
Range	8-58	61-131	133-226
Diagnosis			
Trisomy 21	38	41	26
Translocation	1	2	0
Mosaicism	2	0	0
Not Tested	1	0	0
No Response	8	7	6
English-speaking			
Yes:No	44:2	48:0	32:0
No Response	3	1	0
> 1 Language in Home			
Yes:No	3:46	5:43	2:30
No Response	0	1	0
Hearing Loss			
Yes:No	2:44	10:38	9:22
Not Tested	2	1	1
No Response	1	0	0

Results

Stages of Language Development

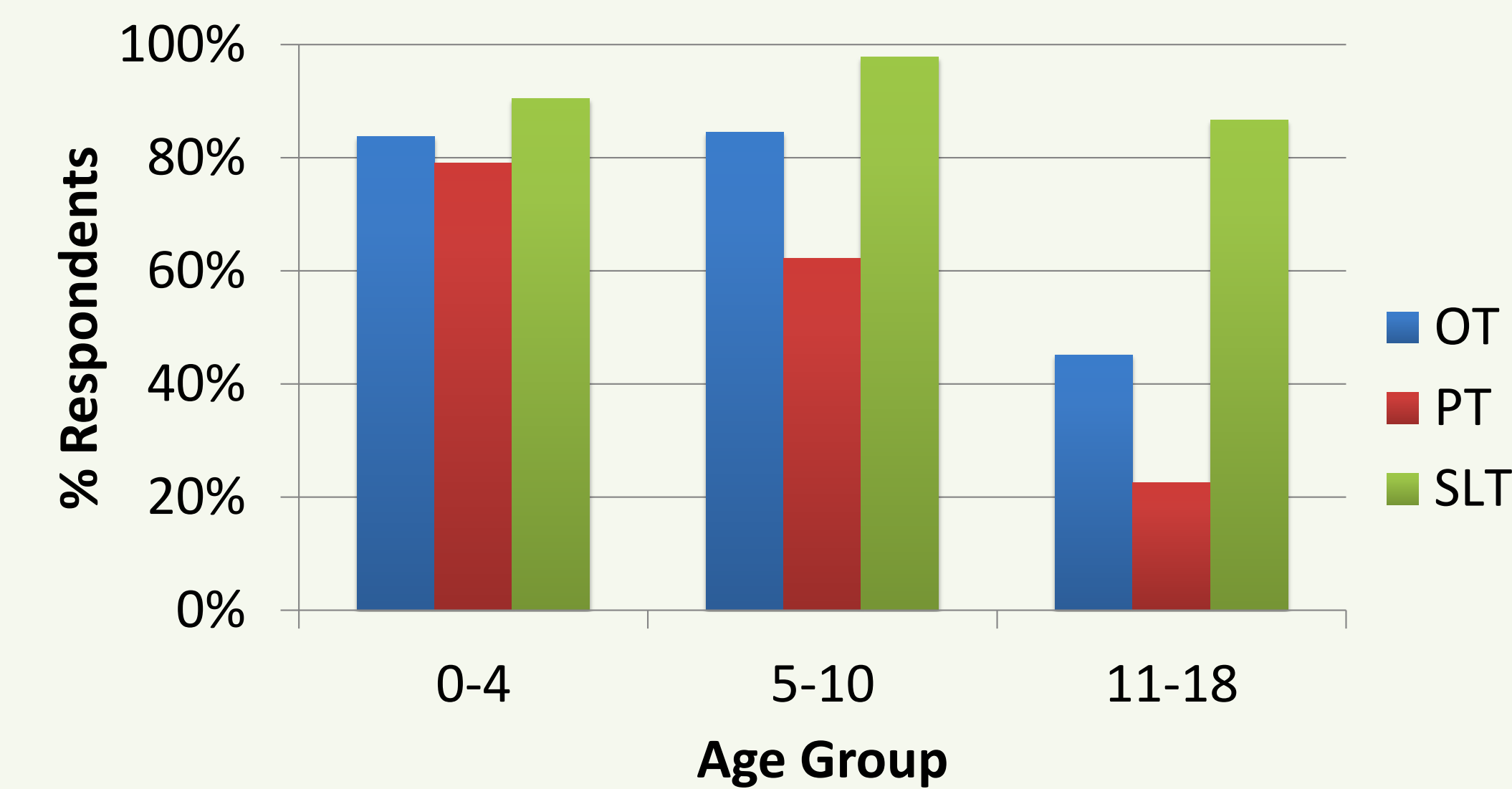


- $p < .01$; $\Phi = .71$: Significant differences between 0-4 Age Group and older groups with more children reported to be in the early word stage of development or using 2-3 word utterances.

Services

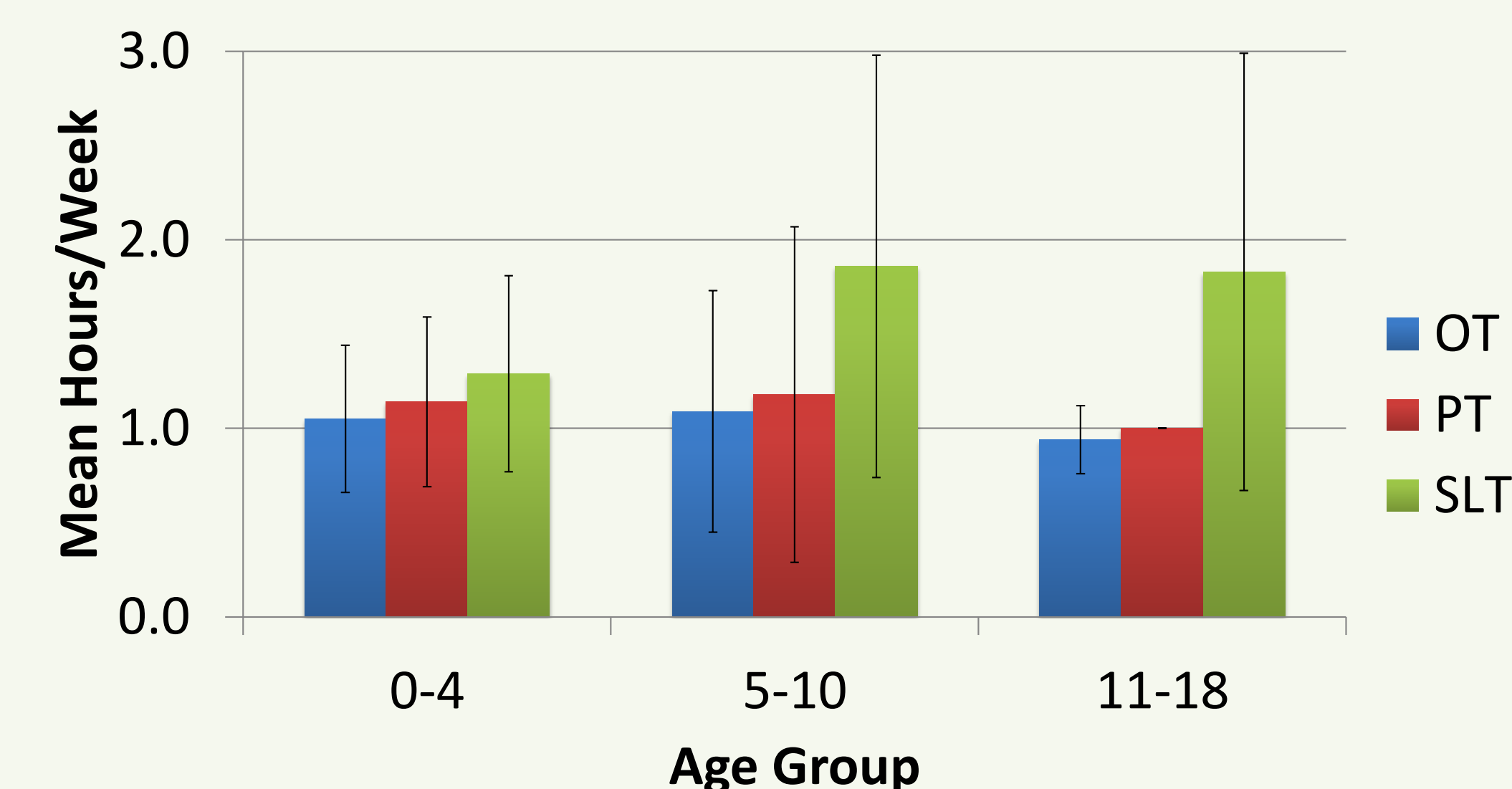
- 93% of parents reported that their child currently had an Individualized Family Service Plan or a Individualized Education Plan.

Type of Service



- OT: $p < .01$; $\Phi = .39$; PT: $p < .01$; $\Phi = .45$. Significantly fewer children in the 11-18 age group received OT and PT services than the younger age groups.

Service Hours

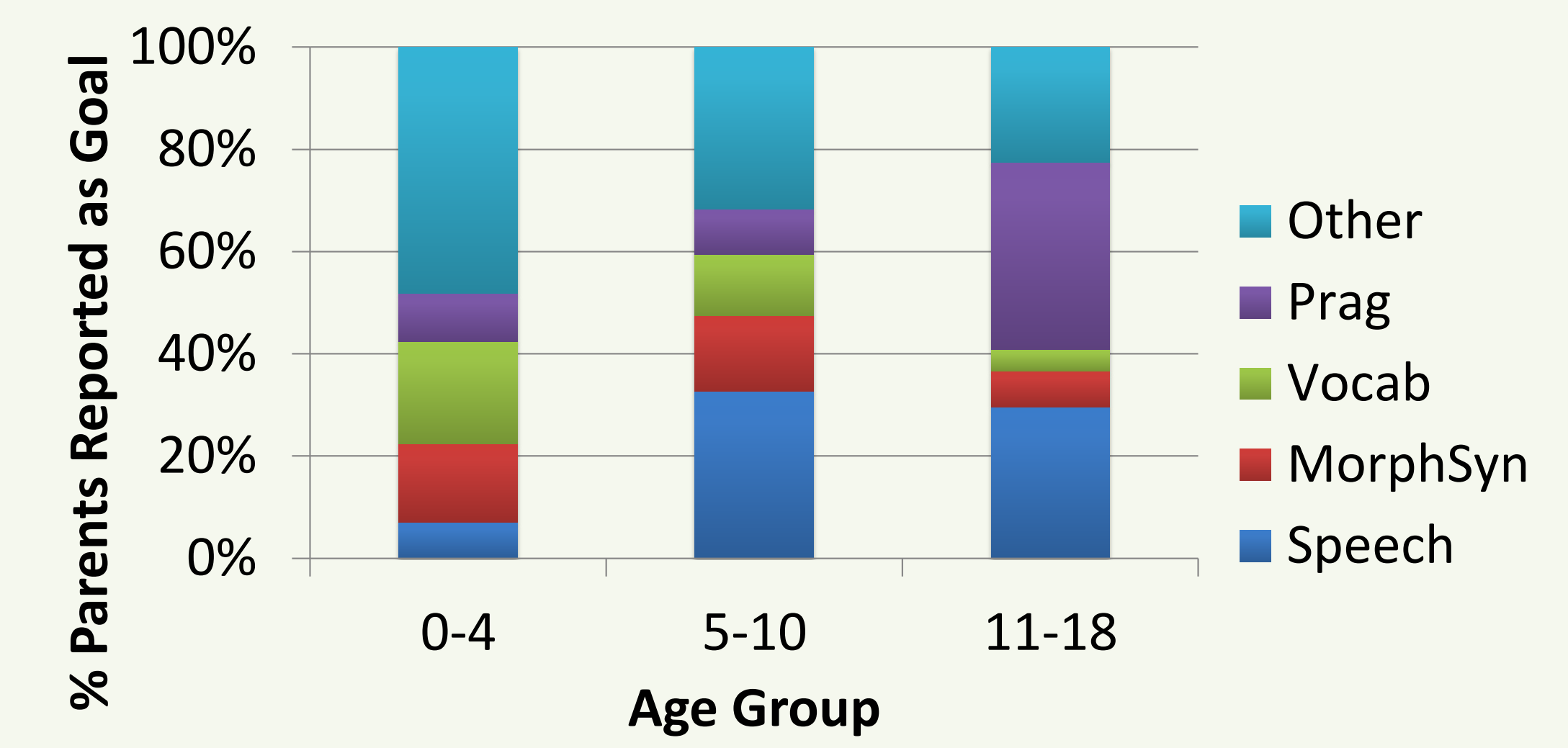


- SLT: $p = .03$. Fewer hours of speech-language services per week for 0-4 Age Group compared to 5-10 ($d = 0.65$) and 11-18 ($d = 0.60$) Age Groups.

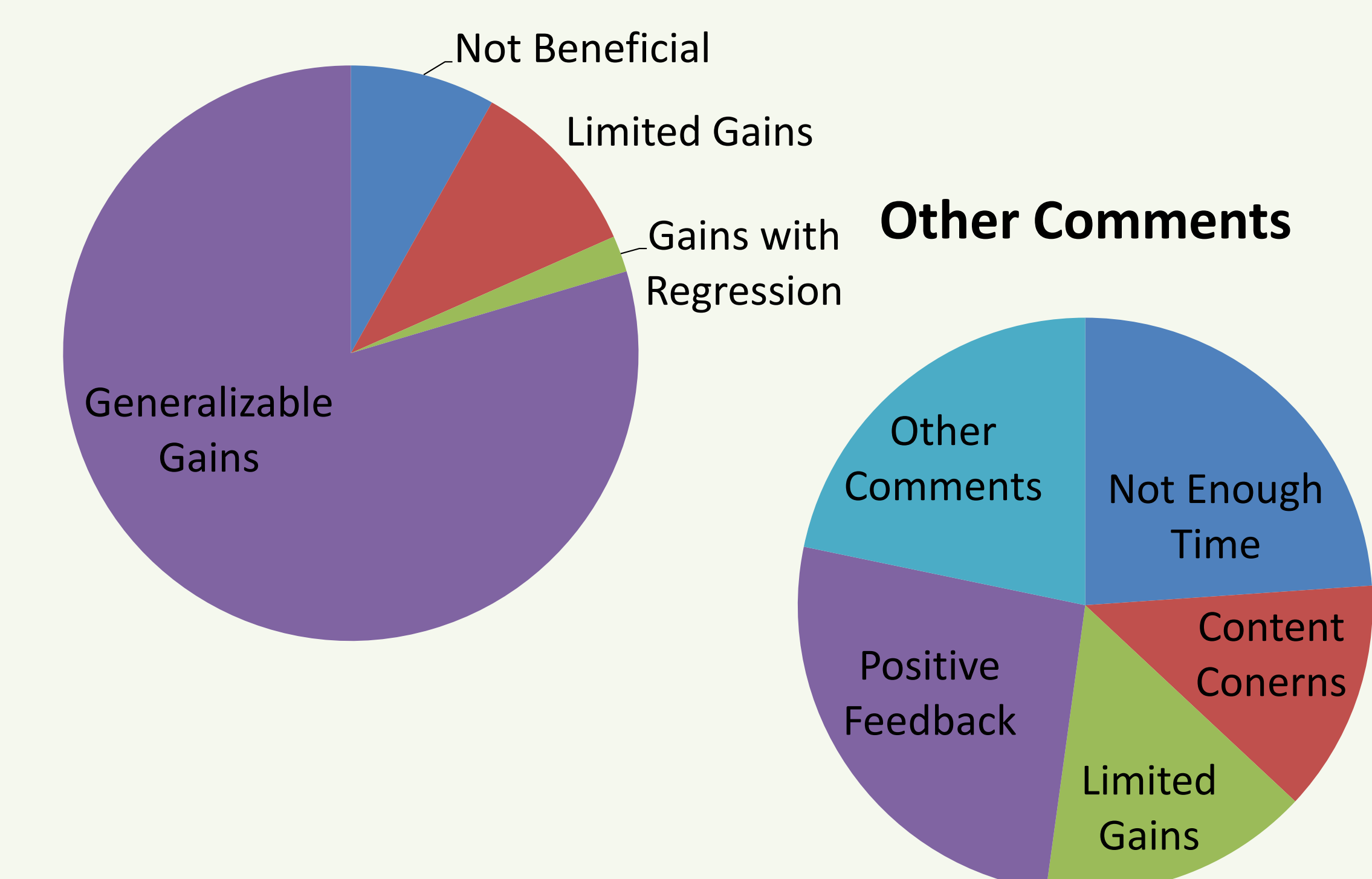
Results continued

Speech-Language Services

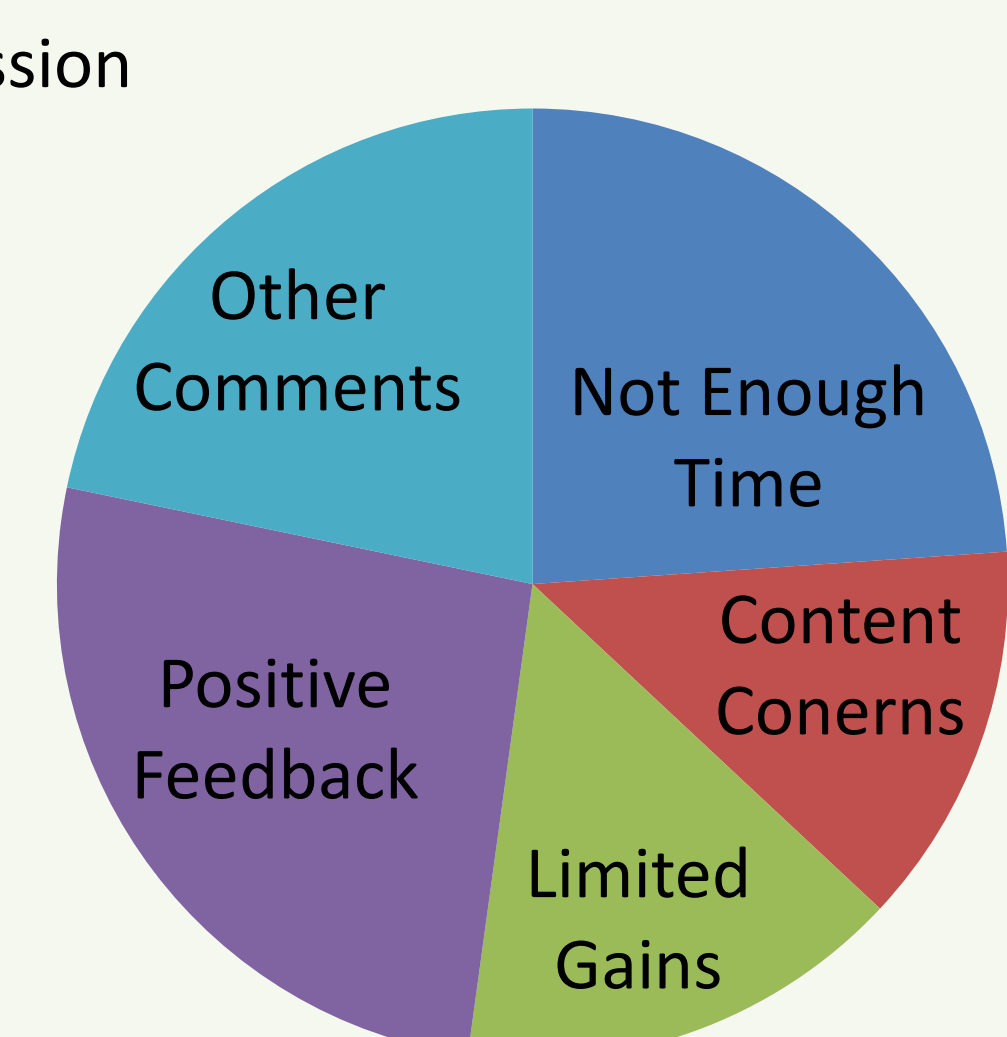
Areas Addressed



Speech-Language Benefits



Other Comments



Conclusions

- Although most adolescents with DS use conversational language, many have more limited language abilities.
- Children with DS consistently receive speech-language services, although young children receive significantly fewer hours per week than older children.
- Parents are generally satisfied with speech-language goals and services, but expressed concerns regarding treatment intensity, content, and gains.
- Future research is needed to directly measure speech-language outcomes.

Acknowledgments

- Special thanks to all of the organizations and parents who generously participated in this study.