

## Title Page

### Special Education Supports and Services for Rett Syndrome: Parent Perceptions and Satisfaction

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### **Abstract**

There are no published studies describing educational experiences for girls with Rett syndrome. Given the extensive educational needs associated with Rett syndrome, it is important to understand how families perceive their daughter's educational experiences to inform education service provision. The purpose of this study was to survey parents of school-aged children with Rett syndrome to describe the educational services that they receive, and understand parents' perceptions of and satisfaction with the special educational and related services. The majority of parents were satisfied with their daughters' educational services. Communication was the most frequently endorsed priority skill area, and many parents expressed frustration with limited access to augmentative and alternative communication (AAC) devices and staff training in their use. These results suggest there is a need for high-quality speech therapy and an emphasis on AAC support.

*Keywords:* Rett Syndrome, parent satisfaction, special education, related services, augmentative and alternative communication

## **Special Education Supports and Services for Rett Syndrome: Parent Perceptions and Satisfaction**

Rett syndrome is a genetic neurodevelopmental disorder caused, in most cases, by a mutation in the X-linked gene encoding methyl CpG-binding protein (MeCP2; Amir et al., 1999). Prevalence estimates suggest that Rett syndrome affects approximately 1 in 10,000 female births (affected males rarely survive but there are exceptions; Laurvick et al., 2006).

Early development in Rett syndrome appears typical, with most girls reported to make age-appropriate milestones from birth to between 6 and 18 months of age. Following this period, there is a pronounced regression stage, during which individuals lose purposeful hand skills, spoken language, and in many cases gross motor skills such as walking (Neul et al., 2010). Behavioral and health symptoms characteristic of the syndrome begin to emerge including stereotypic hand movements, gait abnormalities, seizures and breathing abnormalities, such that motor control, and communicative behaviors are relative areas of weakness (Lotan & Ben-Zeev, 2006; Neul et al., 2010).

The clinical characteristics of Rett syndrome have been the focus of much of the behavioral research, resulting in a critical need to document quality of life to pinpoint areas of needed improvement and intervention. Currently, there are no published studies describing school and educational experiences for girls with Rett syndrome and their families. Rett syndrome is a rare disorder, and so, many special educators and related school support staff (e.g., school psychologists, occupational and physical therapists, etc.) are unlikely to have had direct experience with students with Rett syndrome (Fyfe, Leonard, Gelmi, Tassell, & Strack, 2001). Communication, mobility, and movement are common areas of concern for supporting individuals with Rett syndrome, and it is therefore expected that students with Rett syndrome

receive regularly scheduled therapies, such as speech therapy, physical therapy, and occupational therapy (Hagberg, Hanefeld, Percy, & Skjeldal, 2002). Because of the high level of support needs, high-quality services would depend on the correct selection of assistive technology for mobility and augmentative alternative communication (AAC) devices (Parette, 1997). There are often daily health issues such as seizures (that are frequently not responsive to ‘front-line’ anticonvulsant medications), breathing abnormalities, and susceptibility to falling due to unsteady gait (Lotan & Ben-Zeev, 2006). With multiple health issues, it is likely that parents have heightened safety concerns for their child while at school. Because individuals with Rett syndrome may be at risk for further loss of skills when they do not receive adequate supports, consideration of extended school year services is also an important service planning component.

Due to motor apraxia, completing traditional academic and cognitive assessments is typically challenging for individuals with Rett syndrome, as most items require verbal or motor responses such as pointing or manipulating items (Byiers & Symons, 2012; Clarkson et al., 2017). There is some evidence that individuals with Rett syndrome may possess greater cognitive abilities than are reflected in standardized assessments (Fontanesi & Haas, 1988), but identifying the sources of item errors (i.e., cognitive skills vs. motor abilities) is currently impossible. As a result, developing educational goals and objectives that are matched to an individual student’s strengths and abilities can be challenging for educators. Some suggest that communicative eye gaze is an area of relative strength for individuals with Rett syndrome, and as a result, advocate that eye gaze tracking technology may help overcome some of the difficulties in both assessment and communication (Clarkson et al., 2017; Djukic, McDermott, Mavrommatis, & Martins, 2012; Townend et al., 2016). It is therefore anticipated that parents of students with Rett syndrome will view communication skills, and specifically the use of eye-gaze

AAC devices, as a priority area for their daughters' educational services.

There have been no reported investigations specifically addressing special education and related services outcomes for Rett syndrome. One logical starting place would be to describe the array of school-based services currently provided to school-aged girls living with Rett syndrome. Parent perception and satisfaction surveys are a widely used assessment method for evaluating young children's educational programs (Bailey, Raspa, & Fox, 2012; Mahoney & Bella, 1998; Murphy, Lee, Turnbull, & Turbiville, 1995). Parent satisfaction indices also provide a reasonable measure of social validity for their child's school services (Park, 2014; Wolf, 1978). Taking these approaches, the purpose of the current study was to survey and document parental perceptions and satisfaction with the special educational and related services provided to their daughters with Rett syndrome.

The study had three primary objectives: a) describe the educational services provided to students with Rett syndrome with regards to the types of early intervention services that they received, their current educational placements, the related and direct services that they are receiving, and the types of adaptive equipment available to them for communication and mobility/positioning; b) describe parent perceptions of their children's school services with regards to parents' priority skills or areas of emphasis for educational services, the IEP process, and safety and medical concerns; and c) evaluate the satisfaction of parents with different aspects of educational services, and whether satisfaction differs based on demographic characteristics.

## **Method**

### **Participant recruitment**

Following IRB approval, respondents were recruited through multiple sources including contact via clinic phone lists, and study descriptions and survey web links posted in regional and

national parent advocacy group online/email newsletters and social media pages. All parents with daughters between the ages of 3 and 18 years with clinical diagnoses of Rett syndrome who were receiving school-based special education services at the time of the survey were invited to participate. Because it is impossible to identify the number of potential participants who were exposed to the information materials, response rates could not be reliably calculated.

## **Participants**

A total of 40 parents completed the consent form on the first page of the survey form. Responses from two parents were excluded because their daughters were outside of the age range to receive school-based educational services, and three parents did not report their daughters' ages. Responses from three families living outside the United States were excluded as it was anticipated that the types of school-based services provided would differ across countries. Three participants began the survey but did not complete a majority of the questions. The responses for the remaining 29 caregivers were included in the study. Ages of the students with Rett syndrome ranged from 3 to 17 years (mean = 9.9). Demographic characteristics are presented in Table 1.

## **Procedure and Instrumentation**

A one-time survey was used. All surveys were completed using REDCap<sup>TM</sup>, a secure, web-based survey and database. The survey was an 80-item questionnaire including both multiple choice and open-ended response options. The survey questions are described in more detail below. Prior to distributing the survey, a special education teacher of students with severe disabilities, a mother of a girl with Rett syndrome, a developmental pediatrician with expertise in Rett syndrome, and a researcher with extensive knowledge of Rett syndrome reviewed the survey and provided feedback.

### **Description of educational services**

***Early intervention services.*** Parents were asked to answer whether their child received early intervention services prior to Kindergarten. If yes, parents were asked to report the age at which early intervention services began, and to select all services that were provided during this period from a list (i.e., classroom services, occupational therapy [OT], physical therapy [PT], speech/language therapy [SLT], assistive technology [AT] or augmentative and alternative [AAC] device services, behavioral therapy, family/parent training, psychological services, nursing services, and other). Parents were asked a yes/no question regarding whether they were satisfied with the early intervention services their daughters received, and if not, to describe why they were dissatisfied.

***Current educational placements.*** Parents were asked to report their daughters' current educational placement from a list of the special education continuum of alternative placements (i.e., regular education, regular education plus resource room, self-contained classroom at neighborhood school, public separate day school, private day school, residential facility, homebound/hospital, and other; Taylor, 2004). For participants selecting 'other', the survey included an additional open-ended question asking them to describe the placement.

***Direct and related services.*** Parents were asked to indicate whether their children received school-based physical therapy, occupational therapy, speech/language therapy, developmental adaptive physical education, and extended school year services (ESY). Open-ended questions were included for parents to provide comments about the services they received.

***Communication modes and devices.*** Parents were asked to report the select all of the types of AAC devices/systems and formal and informal communication strategies that their daughters used. Response options for devices included single and multiple message voice output switches, non-computerized picture boards or symbols, computerized AAC devices, other, and

none. Response options for informal communication strategies included AAC device, gestures, signs, nodding or shaking head, blinking, eye gaze, other nonverbal behavior, and none of the above. For both questions, parents had the option to specify alternative answers if they selected the “other” option. Additionally, an open-ended question at the end of the section allowed them to clarify their responses.

***AT for positioning and mobility.*** Parents were asked to describe the types of assistive technology that their daughters used for positioning and mobility from a list (supports for lying, supports for sitting, wheelchairs, motorized wheelchair, standing supports, walkers, gait belt, foot supports, leg splints, bicycles, none), and to describe any other AT devices their children used. An open-ended question allowed them to clarify their answers.

### **Parent perceptions of educational services**

***IEP process.*** To assess parents’ perceptions of the IEP process, parents rated their level of understanding (low, moderate, high) of their daughter’s IEP document and current special education services, and their degree of involvement and input (low, moderate, high) they had in making the IEP document. Parents were also asked to respond ‘yes’ or ‘no’ to whether they had ever disputed a problem with their daughters’ IEPs. If yes, there was an option to describe the reason for the dispute.

***Parent primary priority skills.*** Parents were asked to identify the skill or competency their daughter most needed help with in an open-ended question. This section was adapted from Spann, Kohler, and Soenksen (2003).

***Safety at school.*** In this section, parents were asked to describe whether they had any safety or medical concerns for their daughters while at school. They were also asked whether their daughters had experienced any major safety incidents or injuries while at school in the

previous year, and if so, were asked to describe the incident.

***Satisfaction with educational services.*** Throughout the survey, parents were asked to rate their satisfaction with aspects of their current educational services on a 4-point scale (“satisfied”, “somewhat satisfied”, “somewhat unsatisfied”, “unsatisfied”). Specifically, parents were asked questions about their satisfaction with: their daughter’s current educational placement; amount of time spent with general education peers; the degree to which the current services adequately addressed the parents’ primary areas of educational priority/concern; the most recent IEP meeting; the parents’ level of involvement in creating the current IEP; the IEP document itself; quantity and quality of related/direct services (physical therapy, occupational therapy, speech/language, developmental adapted physical activity, and extended school year); access to communication devices; access to equipment for walking, sitting, and standing (mobility and positioning equipment), and safety precautions.

### **Data Analysis**

Analysis of responses to open-ended questions involved development of themes via an inductive process. To ensure reliability of the theme development and categorization, two coders independently generated themes and classified responses for the comments. Disagreement on themes or comment classification were resolved by consensus.

To evaluate whether satisfaction differed based on demographic characteristics, respondents were divided into groups in several different ways. Three age groups were created: early childhood (ages 3-4 years), elementary (ages 5-10), and middle/high (ages 11-18). Two groups related to educational placement were created: less restrictive (general education or resource room), or more restrictive (separate special education classroom, separate school, residential facility, hospital/homebound). Based on parent comments in response to the priority

skill question, four priority area categories were created: “All areas,” “Communication, AAC, or Speech,” “Gross and Fine Motor Skills,” and “Academics.” As a proxy for the financial resources that might be available within a school district, the median income in 2017 for each family’s zip code was extracted from government databases, and three income groups were created: low resource (less than the state-level and national median income), medium resource (greater than state-level median income but below the national median), and high resource (greater than the state and national medians). None of the zip codes had incomes that were greater than the state-level median, but lower than national levels. Finally, students were categorized based on the communication modes that they used at school: 1) students who had access to some type of formal system (i.e., a flexible form of communication that allows for multiple messages/functions and is likely to be understandable to unfamiliar listeners), and 2) students who did not use any form of flexible aided communication, or unaided (spoken/sign language) system (i.e., no formal communication system).

## Results

### Description of educational services

**Early intervention services.** Nearly all of the respondents ( $n = 28$ ; 97%) reported that their daughters had received some type of early intervention service, with a majority reporting having received occupational therapy ( $n = 26$ ; 90%), physical therapy ( $n = 26$ ; 90%), speech/language therapy ( $n = 25$ ; 86%), and placement in an early childhood classroom ( $n = 20$ ; 69%). Smaller proportions reported receiving assistive-technology/AAC services ( $n = 6$ ; 21%), behavioral therapy ( $n = 6$ ; 19%), family/parent training ( $n = 5$ ; 17%), psychological services ( $n = 3$ ; 10%), nursing services ( $n = 1$ ; 3%), and other ( $n = 2$ ; 7%). Within the “other” early intervention services category, parents listed equine therapy and recreational therapy. Overall,

79% ( $n = 22$ ) of parents whose children had received early intervention services reported that they were satisfied with their daughter's early intervention services. Among those who reported being unsatisfied, two (33%) stated that the reason for being dissatisfied was that there was too much focus on speech or sign language rather than AAC, one (17%) reported that no speech or communication services were provided, one (17%) reported problems scheduling providers, one (17%) commented that "It just scared me more and didn't help with anything," and one (14%) reported that "as soon as people discovered she had Rett syndrome, they gave up on her."

**Current educational placements.** The most common placement for students in this study was self-contained classrooms ( $n = 14$ , 48%). All ( $n = 5$ ) of the early childhood students were in more restrictive placements, with four (80%) being in self-contained classrooms, and one (20%) in a homebound or hospital setting. Six (67%) of the elementary-aged students were in the less restrictive placements (i.e., regular education or regular education plus resource room). Among the elementary-aged students in more restrictive placements, two (22%) were served in self-contained classrooms, and one (11%) was in a separate day school. Only three (20%) of the middle/high school-aged students were served in general education settings, with ten (67%) served in separate classrooms, one (7%) in a separate day school, and one (7%) in a residential facility. Demographic characteristics by placement type are presented in Table 2.

**Direct and related services.** A large majority of respondents reported that their daughters received related services including physical therapy ( $n = 27$ ; 93%), occupational therapy ( $n = 28$ ; 97%), speech-language therapy ( $n = 28$ ; 97%), and developmental adapted physical education ( $n = 25$ ; 86%). Just over half of the parents ( $n = 15$ ; 52%) reported that their daughters received ESY services. Among those who did not, three parents specified that their daughters qualified for ESY services but that they had opted out of receiving it, due to issues

with transportation, poor quality of services, or because they preferred to send their child to summer camp. Several other parents expressed frustration that their daughters did not qualify for ESY services. Notably, there was a relationship between the median income of the student's neighborhood and the likelihood that they received ESY services. Specifically, seven of eight (88%) students in high income neighborhoods received ESY services, compared to four of nine (44%) in medium income neighborhoods, and only 2 of 9 (22%) in low income areas.

**Communication modes and devices.** One parent (3%) did not complete the survey section regarding their child's communication strategies and AAC use, resulting in a total sample of 28 parents for this section. Several different informal modes of communication were reported by caregivers. Eye gaze was the most common mode that respondents reported ( $n = 19$ , 68%), followed by gestures ( $n = 17$ , 61%). Three parents (11%) reported that their children did not use any type of informal communication strategies.

In total, 17 parents (61%) reported that their child used at least one flexible/multiple function form of aided or unaided communication, and 11 (39%) reported that their child did not use any flexible aided or unaided communication modes. Among those with formal communication systems, two parents (7%) reported that their daughters used words or word approximations as their primary communication mode, and just over half ( $n = 16$ ; 57%) reported that their children used at least one form of aided communication. Seven students (25%) used a combination of computerized communication devices and other aided strategies (i.e., symbol boards, picture exchange systems, or voice-output switches). Six students (21%) used computerized devices only. Two (7%) used a combination of low-tech symbol boards and voice-output switches. One (4%) used only a low-tech symbol board. All parents who reported the use of at least one formal communication strategy reported that their children used multiple formal or

informal modes of communication.

There were no systematic differences in the use of AAC devices or strategies across age groups (see Table 1). Students in less restrictive placements appeared to be more likely to use multiple communication modes (7/9; 78%) compared to students in more restrictive environments (10/20; 50%).

**AT for positioning and mobility.** A majority of parents reported that their daughters used wheelchairs for mobility ( $n = 20$ ; 69%). Foot supports ( $n = 15$ ; 52%), and supports for sitting ( $n = 13$ ; 45%) were also commonly reported.

### **Parent perceptions of educational services**

**Parents' areas of concern or priority.** Five of the parents responded with multiple priorities. To facilitate analysis, only the first skill area listed was included in the analysis. The most common priority area for parents was social/communication skills ( $n = 17$ ; 59%). Gross and fine motor skills were the most important skills for 17% ( $n = 5$ ) of respondents. Four (14%) indicated that academic skills were a priority concern. Three parents (10%) listed “everything,” “most things,” or “all.” When examined across grade levels, parents of students in early childhood were most likely to report motor skills as their primary concern ( $n = 4$ ; 80%), whereas the majority of parents of elementary aged students had social or communication skills as their primary concerns. Parents of children in less restrictive educational placements were more likely to report social/communication goals as the focus compared to those in more restrictive settings (see Table 1 for more details).

**IEP process.** The majority of parents reported either a high ( $n = 15$ ; 52%) or moderate ( $n = 12$ ; 41%) degree of understanding, with very few reporting a low level of understanding ( $n = 2$ ; 7%). When asked their degree of input in creating the IEP document, 55% ( $n = 16$ ) of

respondents reported having a ‘high degree’ of input; 38% ( $n = 11$ ) of respondents endorsed a ‘moderate amount’ of input and 7% ( $n = 2$ ) of respondents indicated a ‘low degree’ of input. Parents of students in more restrictive environments were overall more likely to report being highly involved in IEP development compared to parents of students in less restrictive environments ( $n = 13$ , 65% vs.  $n = 3$ , 33%). On the other hand, both parents who reported a low level of involvement had children in more restrictive settings. This pattern may be explained, in part, by the fact that parents of middle/high school-aged students were most likely to report a high level of understanding (middle/high:  $n = 10$ , 67%; elementary:  $n = 4$ , 44%; early childhood:  $n = 1$ , 20%), and a high level of involvement (middle/high:  $n = 10$ , 67%; elementary:  $n = 3$ , 33%; early childhood:  $n = 3$ , 30%), and students of this age group were most likely to be placed in restrictive environments.

Just over half ( $n = 15$ ; 52%) of parents reported disputing a problem with their daughter’s IEP at least once in the past. Of the 15 parents of middle and high school-aged students, 10 (67%) reported at least one previous dispute. Parents of students in less restrictive environments were slightly more likely to report having had previous disputes (less restrictive: 6/9; 67%; more restrictive: 10/20; 50%). Comparing across neighborhood income levels, parents in high income areas had the highest rates of previous disputes (6/8; 75%), followed by parents in low income areas (5/9; 56%), and parents in medium income areas reporting the lowest levels (3/9, 33%). Among the 15 parents who reporting previous disputes, six parents reported multiple problems, for a total of 22 separate disputes. The most common theme was a lack of requested or programmed services, which was cited by eleven parents (38% of the total sample). Of these, six (60%) were related to difficulties getting access to AAC devices or services. Problems with inadequate staffing and/or staff training were mentioned by four parents (14%). Four parents

(14%) reported problems related to the IEP document itself, such as goals and objective that were vague or inappropriate for the student's skill level. Two parents (7%) reported that the schools had provided services or procedures that were inappropriate for the student's skills or needs, such as use of a wheelchair for a student who could walk, and use of a communication device that was inaccessible to the student due to motor apraxia. The reasons for the final two (7%) disputes were not specified (i.e., "too many to list"). Looking across all of the responses to open-ended questions, the most common general issues that parents reported were a lack of knowledge specific to working with individuals with Rett syndrome, which was mentioned by four parents (14%), and a concern that schools underestimated their daughters' potential due to apraxia ( $n = 4$ , 14%).

**Safety and Health Concerns.** Overall, 21 parents (72%) reported at least one safety or medical concern for their child at school. Five parents listed two concerns, and five parents listed three, for a total of 35 separate concerns. A total of 13 parents (45%) reported concerns regarding medical conditions, particularly seizures, and breathing problems, and 13 parents (45%) reported concerns regarding injuries due to falls or transferring were most common. Five parents (17%) reported concerns regarding feeding, with two of these related to concerns regarding feeding tubes, one regarding sufficient water intake, one related to eating and drinking safely, and one regarding adherence to a special medical diet. Concerns related to social relations, including lack of communication skills, and bullying, were reported by three parents (10%). The last comment regarded a concern that painful conditions might be missed ( $n = 1$ ; 3%).

Nine parents (31%) reported their daughter had experienced a major safety incident or injury while at school in the previous year. Anecdotally, major safety incidents included falling when walking ( $n = 3$ ), falling due to failure to secure the student into her wheelchair or use the

brake ( $n = 2$ ), seizures ( $n = 1$ ), being accidentally hit during play ( $n = 1$ ), school personnel missing signs of major illness ( $n = 1$ ), and being left unattended ( $n = 1$ ). Many of the parents ( $n = 12$ , 41%) reported updating their school on new medications and health concerns on a weekly basis.

### **Parent satisfaction with school services**

Parents' responses to the satisfaction questions are presented in Table 2. The majority of parents responded that they were satisfied or somewhat satisfied across all aspects of school services. The areas in which parents were most likely to report being unsatisfied were: time spent with general education peers, quantity of occupational therapy, quantity and quality of speech/language therapy, and quantity and quality of extended school year services.

When evaluated by age group (see Figure 1), parents of middle/high school aged students were most likely to be unsatisfied with the quantity of related services provided. Parents of early-childhood aged students were most likely to be satisfied with their child's educational placements.

Figure 2 shows levels of satisfaction broken down by placement type (less vs. more restrictive). Parents of students in more restrictive environments were less likely to be satisfied with the amount of time spent with peers, the quantity of related services provided, and with the AAC technology provided for their children.

Figure 3 shows the levels of satisfaction broken down by income area by home zip code, as a proxy for financial resources available. Parents of students in low income areas are most likely to be dissatisfied with the quantity of physical therapy, occupational therapy, and speech/language therapy, and with the quality of occupational therapy. Parents of students in high income neighborhoods are least likely to be satisfied with educational placement, time spent with peers, the way the school team address parent educational priorities, quality of extended

school year services and communication technology.

Finally, Figure 4 presents levels of satisfaction broken down by the students' communication modes. Parents of students who had access to formal communication systems were more likely to be satisfied with the communication technology available to their children at school, but less likely to be satisfied with the quality of speech/language therapy. These parents were also slightly less likely to be satisfied with the amount of time their children spent with general education peers, and the degree to which the school addressed their priority skill, but more likely to be very satisfied with the last IEP meeting, and their level of involvement in the IEP process, compared to parents of students without access to formal communication systems.

## **Discussion**

The purpose of the study was to provide a preliminary descriptive analysis of the school-based special education and related support services for school-aged girls living with Rett syndrome. Our results suggest that, overall, parents of students with Rett syndrome are satisfied with most of the services that they receive at school. Nevertheless, the results also suggest that there are specific dimensions of school-based services that could be improved.

In the domain of early intervention services, most parents reported that their daughters had received early intervention services and satisfaction with these services was fairly high overall. Most respondents reported receiving both occupational and physical therapy, which is consistent with the developmental course of the disorder in early childhood, with loss of hand skills or mobility being among the initial symptoms. Many respondents also reported receiving speech therapy, which is consistent with the loss of communication that typically occurs during this period. This suggests that individuals with Rett syndrome are being identified relatively early, maximizing potential positive effects of intervention. Despite this, few parents reported

receiving access to or training in AAC devices for their daughters during the early intervention period. This finding may be due to the fact that, historically, parents and educators have been hesitant to introduce AAC strategies to young children because they believe that either the child is too young and lacks prerequisite skills for the acquisition of AAC strategies, or because they are concerned that introduction of such strategies will delay or interfere with the child's acquisition of spoken language (Cress & Marvin, 2003). Existing evidence suggests, however, that early introduction of AAC may facilitate the development of spoken language (Millar, Light, & Schlosser, 2006). In the case of Rett syndrome, however, most individuals will never acquire spoken or sign language as a result of severe apraxia (Urbanowicz, Downs, Girdler, Ciccone, & Leonard, 2015), making early introduction of AAC strategies even more important in this population. Because many children with Rett syndrome do not receive a formal diagnosis until after age 3 (Fehr et al., 2011), however, it is possible that many of the individuals in the current sample were receiving early intervention services without a formal diagnosis of Rett syndrome.

Access to AAC devices and strategies was a common theme among respondents' comments regarding their children's current educational services as well. Social and communication skills were the primary area of concern for the majority of parents in the study. Further, while parents were more likely to be dissatisfied with the number of hours of related services that their children received than with the quality of those services, speech/language therapy was an exception to this pattern. Interestingly, parents of children who had access to formal communication devices and strategies were most likely to be dissatisfied with the quality of speech therapy than parents of children without access to formal systems. One possible explanation for this is that teachers and other educational staff may not have sufficient experience and training in the use of high-tech communication devices. For example, one parent

commented that “The devices themselves are not terribly effective – they required skilled team members who are trained in their use and trained in teaching [the students] to use them with greater independence.” Another parent noted that “keeping communication devices up to date is a full-time effort.” These results are consistent with the results of a Dutch survey of parents of children with Rett syndrome who used high tech eye gaze AAC devices, which reported that parents expressed frustration with the support available for use of the devices, although satisfaction with the devices themselves was relatively high (Townend et al., 2016). Nevertheless, in the current sample, the most common reason that parents reported for disputing the IEP was the school not providing access to a high-tech AAC device. The results overall point to the need for increased training of school staff on both the AAC options that are available for individuals with Rett syndrome, as well as how to program high-tech devices, and to teach students to use them.

When examining the reported rates of direct and related services for students with Rett syndrome, a large majority of respondents reporting having received speech therapy, occupational therapy, physical therapy, and adapted physical education. In a previous study of students with various disabilities, 40% of which had multiple disabilities, indicated that on average 41% of students received speech language therapy, 9% received occupational therapy, 8% received physical therapy, and 4% received adapted physical education (Leiter & Wyngaarden Krauss, 2004). This suggests that special educators are successfully identifying and including these areas of needed support for students with Rett syndrome. Because communication and motor skills were the two primary areas of concern for parents, this high rate of related service provision may suggest IEP teams are addressing parental concerns in this sample, a crucial tenant of the Individuals with Disabilities Education Act. This is further

illustrated by the majority of parents reporting at least a moderate amount of input in the IEP process.

In contrast, many of the parents in the sample reported that their children did not receive extended school year services, and children in low-income areas were least likely to receive these services. Specific criteria for the provision of ESY services are not specified under IDEA (services are determined by the IEP team on an individual basis), but the evaluation for ESY services should be needs-based and include an assessment of student needs using multiple types and sources of assessment data. A review of ESY service case law and research by Etscheidt (2002) discussed that eligibility is highly variable at the school level, and that some schools use inadequate and flawed assessment and/or decision criteria. This could explain why only half of the sample received the option of ESY services. Previous guidelines have included if, among other factors, a student's skills are likely to regress during the break from school more and that relearning those skills is likely to take excessive support, more than what would be needed for a student without disabilities (reviewed in Etscheidt, 2002). The regression in RTT syndrome typically occurs in the preschool and elementary years, and thus it seems ESY services would be appropriate for those individuals. Federal law does, on the other hand, specify that a school's lack of resources cannot be a reason to withhold ESY services (IDEA), and that these services must be provided if the IEP team feels they are necessary for that student's appropriate education. It appears, however, that there is a breakdown between these services and area income level in this sample.

Another area of potential improvement in the educational services for students with Rett syndrome is increased inclusion in general education settings. Most of the parents surveyed reported that their daughters were served in restrictive environments, such as separate special

education classrooms and separate schools. Students with Rett syndrome frequently receive special education services under the eligibility criteria of multiple disabilities due to the numerous health problems they frequently face. Compared to national rates of educational placement for students with multiple disabilities, students with Rett syndrome within our sample and those with multiple disabilities in the national sample are spending similar amounts of time within a self-contained classroom (53% vs 46%, respectively; Snyder, de Brey, & Dillow, 2016). In this sample, however, parents of children served in less restrictive settings were more satisfied, on average, with most aspects of their educational services compared to parents whose children were served in more restrictive settings. This suggests that inclusive settings can be successful educational environments for students with Rett syndrome from the perspective of parents. Additional training of school personnel, including general and special education teachers, may be necessary to facilitate inclusive education for students with Rett syndrome, however, as several parents noted frustration that school personnel did not seem to have the knowledge necessary to adequately serve their daughters, and several noted that they felt their children's abilities were underestimated.

With nearly a third of the respondents reporting a major safety incident within the school year, it is important for educators to be aware of the possible safety threats to students with Rett syndrome. The most common types of safety incidents were seizures, falls, feeding problems, breathing problems, bullying, and wandering away from school staff/grounds. Considering many of the parents reported that they were satisfied with the safety precautions taken at school, this seems to be an area in which school personnel are meeting expectations. This level of satisfaction may be attributed to parent's success in educating and updating the school on their health and safety concerns.

## **Limitations**

There were several limitations of the study that should be noted. A convenience sample was formed based on a one-time survey to parents with a daughter with Rett syndrome. A convenience sample was used because Rett syndrome is a low incidence disability with approximately 1 in 10,000 females being born with the syndrome, therefore making it difficult to find a large enough sample to randomly select participants. We used social media and mailing lists to contact willing participants to take the online survey. Consequently, any type of generalizations made from the study should be done so with caution as it is possible that our sample is not representative of the entire population of school-age girls with Rett syndrome in the United States. Another limitation of surveying a rare disorder is the size of the sample. Although our survey was available nationally, 28 eligible respondents completed the full survey. The small sample makes it difficult to parse the results too finely (e.g., with respect to any regional differences, etc.). The sample size, however, is consistent with other rare disorder survey research, including Rett syndrome (see, for example, (Epstein et al., 2016). By increasing the sample size, future studies should analyze how different regions or states provide educational services to school-age girls with Rett syndrome and whether parents are more satisfied in particular states or regions across the country.

## **Implications for Practice**

The results from the study have multiple implications for school personnel who work with school-age girls with Rett syndrome. First, it has been stated that school personnel and related service providers need continuing education on how to provide the necessary AAC training for girls with Rett syndrome. To improve the quality of speech-language services, AAC training should educate school personnel how to recognize the need for AAC, assess

communication needs and select proper AAC devices, and evaluate the effectiveness of the AAC interventions on improving communication (Costigan & Light, 2010). Another concern that the survey brought up was the large percentage of parents who reported disputing a problem with their daughter's IEP, especially parents with a child in middle/high school. To avoid such disputes, school personnel should update parents frequently on progress toward IEP goals and the teacher of record should continually check-in with members of the IEP team to ensure that related services are being provided. While the majority of parents were satisfied with the safety precautions taken by their school to keep their daughters safe, a third of the sample stated their daughters experienced a major safety incident. To prevent safety incidents in the school, schools may create programming similar to that of medically fragile students. This may include interviewing parents on the medical needs of the child and gathering medical documents, creating IEP goals and objectives to promote health-related needs and identifying staff who will carry out the services, making decisions on the type of nursing services needed (one-on-one or on-call care), and developing an emergency protocol (Prendergast, 1995). Schools should also consider having nurses and school personnel read the Rett Syndrome Handbook that covers common problems, such as seizures and motor problems, as well as day-to-day care, nutrition, and feeding (Hunter, 2007).

## **Conclusion**

Our specific aim was to survey parents of school-aged girls with Rett syndrome about the nature of special education and related school-based supports their daughter had received. The overall goal is to provide 'targets' for school-based services that reflect the needs, priorities, and values of caregivers and their daughters with Rett syndrome. Based on the results, it is clear that there is a need for high-quality speech/language therapy and an emphasis on AAC support.

Future studies could extend the depth of our analysis by examining the individualized education plans (IEPs) of school-age girls with Rett syndrome to better understand the type of goals and objectives being addressed by their special education teaching staff and related service providers. Doing so may lead to a more informed approach to prioritizing special education services and specific targets for school-based special education and rehabilitation goals for school-aged girls with Rett syndrome.

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**Figure captions**

*Figure 1.* Parental satisfaction with special education services by grade level

Note: Extended school year services were not provided for any of the early childhood students.

Abbreviations: IEP = individualized education plan; PT = physical therapy; OT = occupational therapy; SLT = speech/language therapy; DAPE = developmental adaptive physical education; ESY = extended school year

*Figure 2.* Parental satisfaction with special education services by educational placement

Note: Abbreviations: IEP = individualized education plan; PT = physical therapy; OT = occupational therapy; SLT = speech/language therapy; DAPE = developmental adaptive physical education; ESY = extended school year

*Figure 3.* Parental satisfaction with special education services by neighborhood income level

Note: Neighborhood income information was not available for 3 respondents. Abbreviations: IEP = individualized education plan; PT = physical therapy; OT = occupational therapy; SLT = speech/language therapy; DAPE = developmental adaptive physical education; ESY = extended school year

*Figure 4.* Parental satisfaction with special education services by communication modes

Note: Abbreviations: IEP = individualized education plan; PT = physical therapy; OT = occupational therapy; SLT = speech/language therapy; DAPE = developmental adaptive physical education; ESY = extended school year

*Table 1.* Characteristics of the students with Rett syndrome by grade level.

Participant characteristics	Grade Level		
	Early Childhood n (%)	Elementary n (%)	Middle/High n (%)
<b>Placement</b>			
Less restrictive	0 (0)	6 (67)	3 (20)
More restrictive	5 (100)	3 (33)	12 (80)
<b>Communication mode</b>			
Formal communication system	3 (60)	6 (67)	8 (53)
No aided communication	2 (40)	3 (33)	6 (40)
Not reported	0 (0)	0 (0)	1 (7)
<b>Parent priority area</b>			
Social/communication	1 (20)	8 (89)	8 (53)
Fine/gross motor	4 (80)	0 (0)	1 (7)
Academics/all	0 (0)	1 (11)	3 (20)
All/everything	0 (0)	0 (0)	3 (20)
<b>Income group</b>			
Less than US median	2 (40)	3 (33)	4 (27)
100-150% US median	3 (60)	1 (11)	5 (33)
>150% US median	0 (0)	4 (44)	4 (27)
Not reported	0 (0)	1 (11)	2 (13)
<b>Region</b>			
Midwest	1 (20)	4 (44)	6 (40)
Northeast	1 (20)	1 (11)	3 (20)
South	2 (40)	2 (22)	3 (20)
West	1 (20)	2 (22)	3 (20)
<b>Total</b>	<b>5 (17)</b>	<b>9 (31)</b>	<b>15 (52)</b>

Table 2. Characteristics of the students with Rett syndrome by educational placement

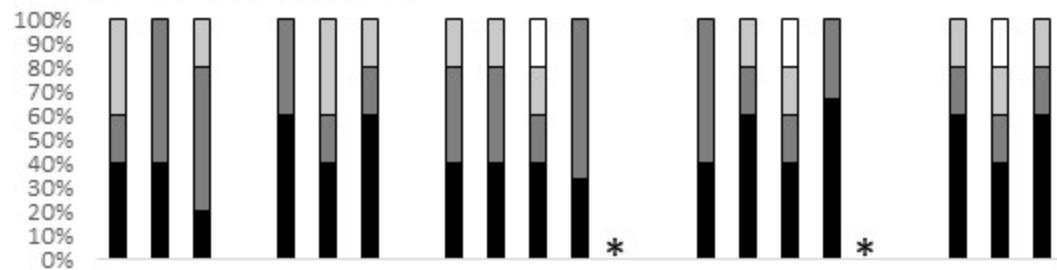
Participant characteristics	Educational placement	
	More restrictive n (%)	Less restrictive n (%)
<b>Grade level</b>		
Early childhood	5 (25)	0 (0)
Elementary	3 (15)	6 (67)
Middle/High	12 (60)	3 (33)
<b>Communication mode</b>		
Formal communication system	10 (50)	7 (78)
No formal communication	9 (45)	2 (22)
Not reported	1 (5)	0 (0)
<b>Parent priority area</b>		
Social/communication	9 (45)	8 (89)
Fine/gross motor	4 (20)	1 (11)
Academics	4 (20)	0 (0)
All/everything	3 (15)	0 (0)
<b>Income group</b>		
Less than US median	5 (25)	4 (44)
100-150% US median	8 (40)	1 (11)
>150% US median	5 (25)	3 (33)
Not reported	2 (10)	1 (11)
<b>Region</b>		
Midwest	5 (25)	6 (67)
Northeast	5 (25)	0 (0)
South	5 (25)	2 (22)
West	5 (25)	1 (11)
<b>Total</b>	<b>20 (69)</b>	<b>9 (31)</b>

Table 3. Overall parent satisfaction for all educational services surveyed.

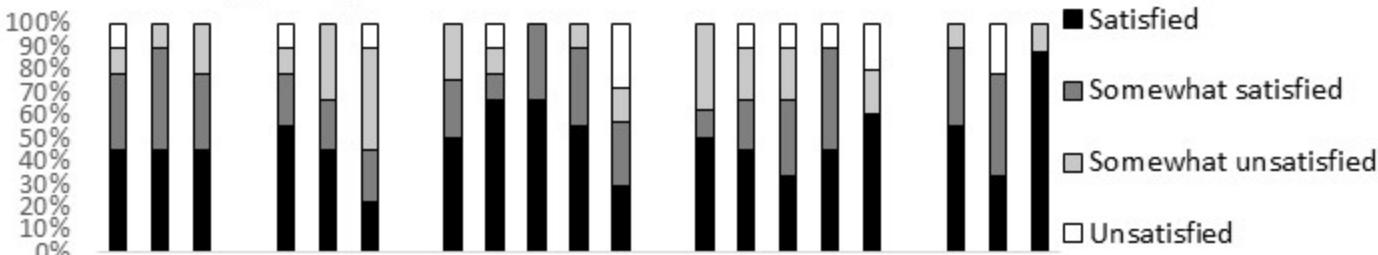
Educational service area	Parent satisfaction				
	Satisfied n (%)	Somewhat satisfied n (%)	Somewhat unsatisfied n (%)	Unsatisfied n (%)	NA/missing n (%)
<b>Special Education Services</b>					
Last IEP meeting	13 (45)	10 (35)	5 (17)	1 (3)	0 (0)
Level of parent involvement	13 (45)	14 (48)	2 (7)	0 (0)	0 (0)
IEP document	10 (35)	12 (41)	7 (24)	0 (0)	0 (0)
Educational placement	16 (55)	8 (28)	3 (10)	2 (7)	0 (0)
Time with peers	11 (38)	7 (24)	4 (14)	7 (24)	0 (0)
Addressing parent priorities	6 (21)	13 (45)	7 (24)	3 (10)	0 (0)
<b>Quantity of related services</b>					
Physical therapy	7 (24)	8 (28)	5 (17)	7 (24)	2 (7)
Occupational therapy	11 (38)	7 (24)	2 (7)	8 (28)	1 (3)
Speech therapy	9 (31)	8 (28)	3 (10)	8 (28)	1 (3)
DAPE	11 (38)	9 (31)	3 (10)	2 (7)	4 (14)
Extended school year	5 (17)	2 (7)	5 (17)	3 (10)	14 (48)
<b>Quality of related services</b>					
Physical therapy	11 (38)	8 (28)	6 (21)	2 (70)	2 (7)
Occupational therapy	13 (45)	6 (21)	3 (10)	6 (21)	1 (3)
Speech/language therapy	6 (21)	9 (31)	5 (17)	7 (24)	2 (7)
DAPE	12 (41)	9 (31)	3 (10)	1 (3)	4 (14)
Extended school year	7 (24)	1 (3)	4 (14)	3 (10)	14 (48)
<b>Other areas</b>					
Safety	15 (52)	9 (31)	2 (7)	2 (7)	1 (3)
Adaptive mobility equipment	19 (66)	5 (17)	2 (7)	0 (0)	3 (10)
Adaptive communication equipment	10 (35)	9 (31)	3 (10)	5 (17)	2 (7)

Note. IEP = individualized education plan; DAPE = developmental adaptive physical education.

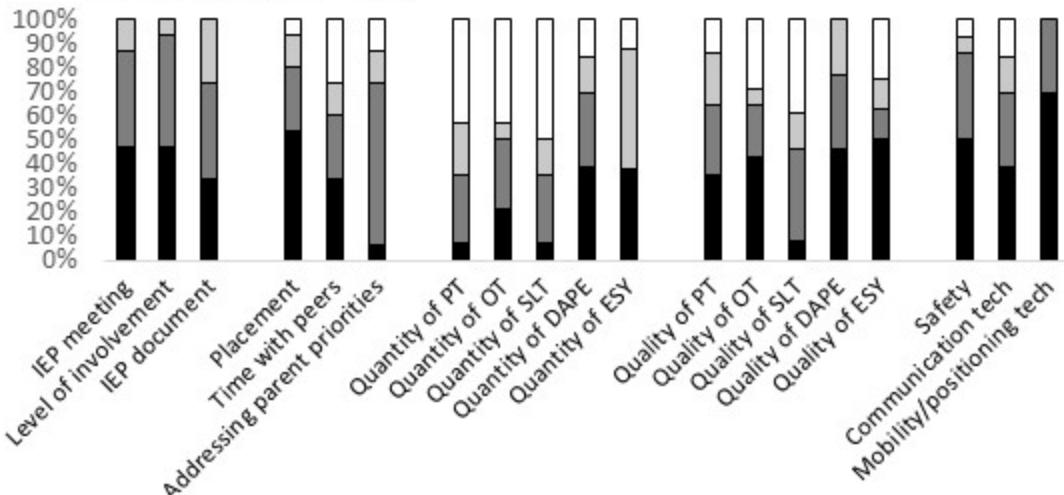
### Early Childhood (N = 5)



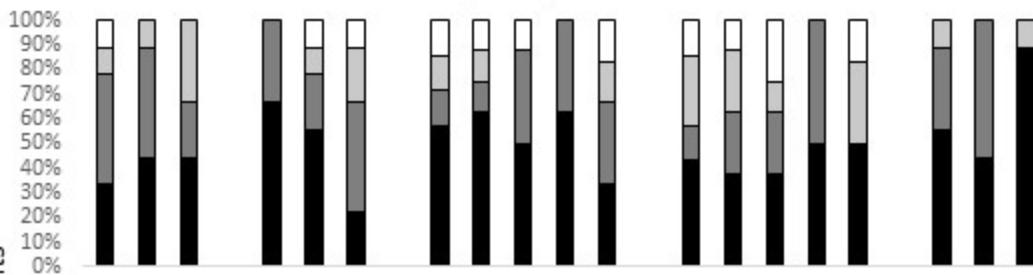
### Elementary (N = 9)



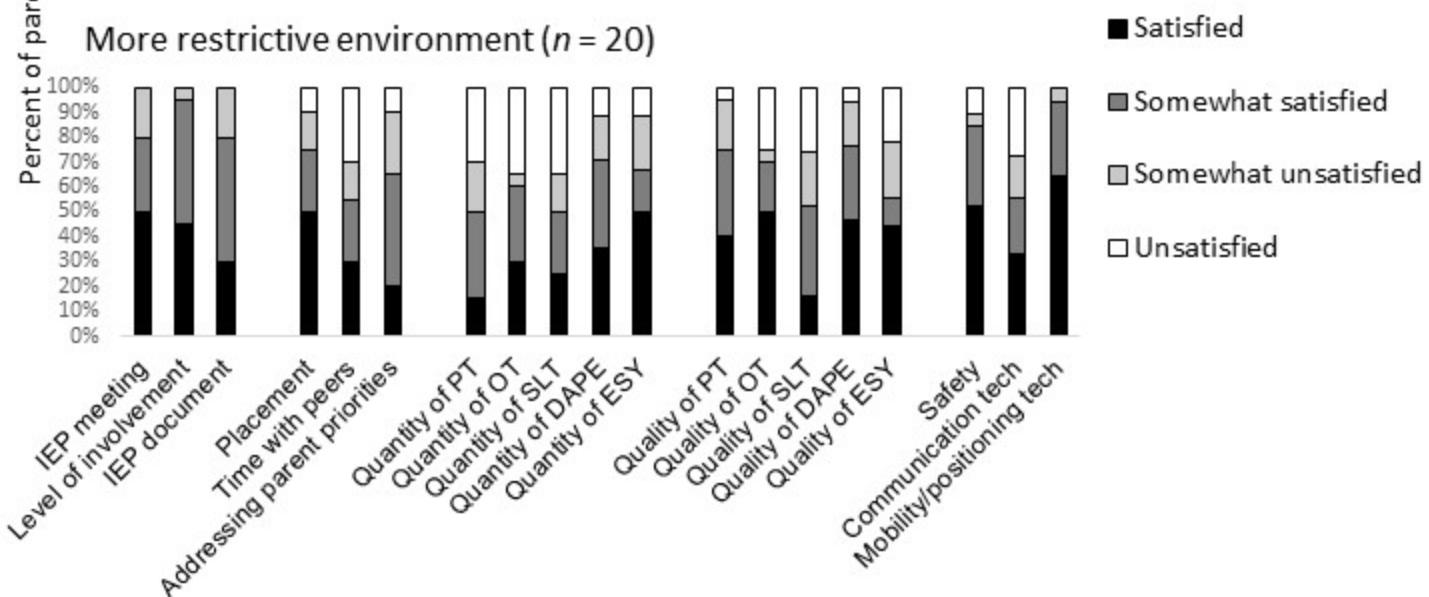
### Middle/High (N = 15)



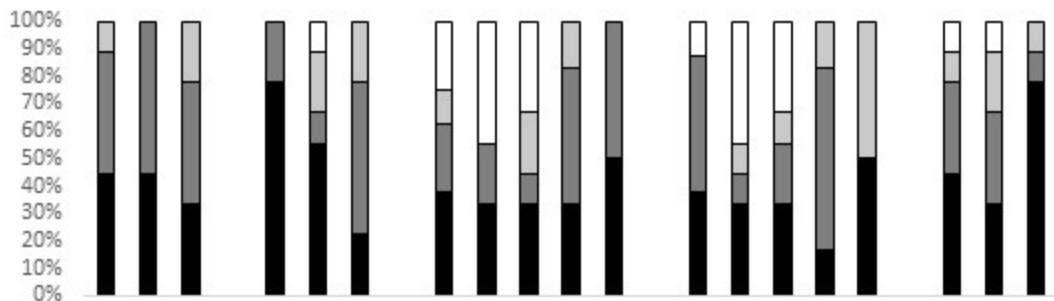
### Less restrictive environment ( $n = 9$ )



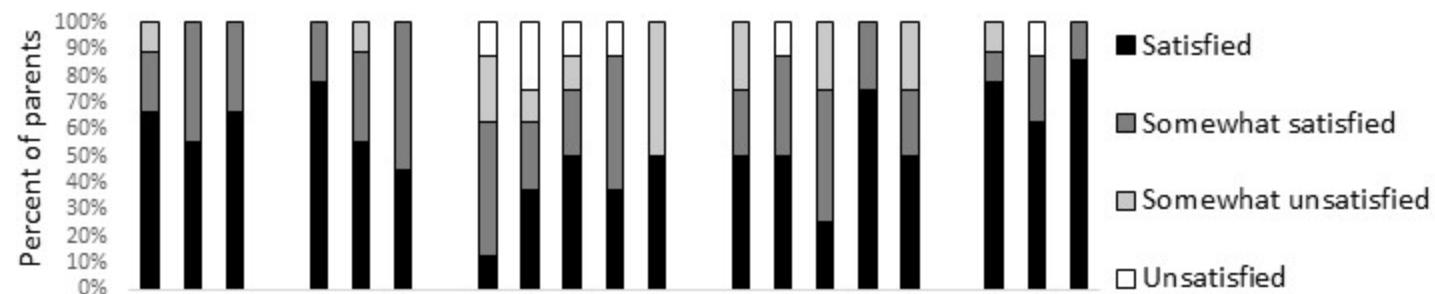
### More restrictive environment ( $n = 20$ )



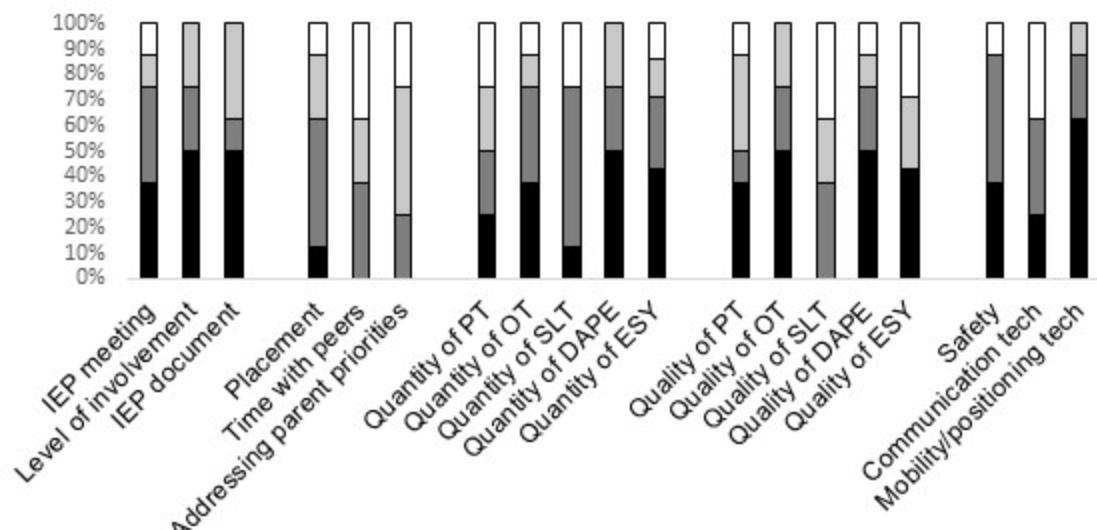
### Low income area (*n* = 9)



### Medium income area (*n* = 9)



### High income area (*n* = 8)



### Formal communication systems ( $n = 17$ )

