THE UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITES

DATA REPORT:

Educational and Therapeutic Experiences of Children with Cornelia de Lange Syndrome and their Families

March 2010

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INTRODUCTION

This study focuses on families that are affected by Cornelia de Lange Syndrome (CdLS) and is a follow-up to a previous study conducted two years ago. The purpose of this study is to continue to gather information on the experiences of families with children with CdLS in an effort to develop guidelines for parents as well as professionals.

CdLS affects approximately 1:10,000 live births and is a congenital syndrome, meaning it is present from birth. Most of the signs and symptoms may be recognized at birth or shortly thereafter. A child need not demonstrate each and every sign or symptom for the diagnosis to be made.

As with other syndromes, individuals with CdLS strongly resemble one another. Common characteristics include: low birthweight (often under five pounds), slow growth and small stature, and small head size (microcephaly). Typical facial features include thin eyebrows which frequently meet at midline (synophrys), long eyelashes, short upturned nose and thin, downturned lips. Other frequent findings include excessive body hair (hirsutism), small hands and feet, partial joining of the second and third toes, incurved fifth fingers, gastroesophageal reflux, seizures, heart defects, cleft palate, bowel abnormalities, feeding difficulties, and developmental delay. Limb differences, including missing limbs or portions of limbs, usually fingers, hands or forearms are also found in some individuals.

Mental retardation is usually present and ranges from mild to profound. The majority of cases fall in the mild to moderate range. Language ability is often affected, and many children do not communicate verbally at all.

To date, there has been very little published research on this unique population, especially related to the educational and therapeutic needs and experiences of these children. The previous study conducted by this Center surveyed 224 parents of a child with CdLS related to the following topics: (a) Background of Child; (b) Child Health and Medical Care; (c) Child Behavior and Development; (d) Child Learning Style; (e) Child Services; (f) Child Educational Placement; (g) Quality of Life; and (h) Background Information. The results of the previous survey provided valuable information and the basis for the current survey. The current survey focuses more on the educational and therapeutic services and experiences of children with CdLS and their families at different age levels. The data collected will inform professionals in the field and provide parents with an understanding of what others are experiencing. In addition, the information gathered will inform parents and other providers about this unique population about whom little is currently known.

METHODOLOGY

Procedure: The CdLS-USA Foundation is the only resource for parents nationwide that provides support and information for families affected by CdLS (http://www.cdlsusa.org/). Due to the large response rate and valuable information gained from the survey conducted previously, the CdLS foundation contacted us to develop a follow-up survey to provide even more information. Their Counsel and Committee members collaborated with our Center to develop the survey. In addition, the foundation distributed the survey link to their population in the form of email, through their newsletter, and by posting it on their web site.

In mid-November 2009, a recruitment email went out to about 830 families of a child with CdLS. At the same time, a short recruitment blurb was included in the CdLS-USA Foundation's newsletter, which is distributed to approximately 1280 families of a child with CdLS. The email and blurb in the newsletter described the purpose of the study, the types of questions that would be asked, and included a link to complete the survey online and information to request a paper copy. A copy of the newsletter blurb can be found in Appendix A. Information on the survey was also included on the Foundation's website and our Center's website. A reminder email was sent out by the Foundation at the beginning of January and a "last call" reminder was sent out in mid-February with a closing date of March 15, 2010. The survey was closed on Survey Monkey at the end of the day, March 15, 2010. We continued to accept IFSPs and IEPs that were sent through the mail until April 30, 2010.

Data Collection: The survey was available both online through Survey Monkey or as a paper copy by request. Participation in the survey was completely voluntary, and respondents could skip any questions they did not wish to answer.

Questionnaire: The questionnaire was developed in collaboration with the CdLS Foundation's Counsel and Committee members and staff at the University of Connecticut Center on Disabilities (see Appendix B for a copy of the survey). This survey was self-administered online and designed to gather information about the experiences of families with a child with CdlS, specifically their experiences with educational and therapeutic providers.

The questions were divided into sections according to the age of the child. All participants completed the first section, which contained questions about the background of the child; and the last section, which included basic demographic questions about the family. All participants were also asked if they would be willing to submit a copy of their child's IFSP/IEP to our research staff, and provided with the information necessary to submit it if they were willing. The middle section was completed according to age groups; (a) Birth through Two, (b) Preschool (3-5), (c) 6-13, (d) 14-21 (in school), and (e) 14-21 (not in school). For all age groups, except 14-21 (not in school), the middle section contained questions about the therapies and services received, IFSP/IEP goals, accommodations and modifications, educational activities and opportunities, medical care coordination, and social activities. For the 14-21 (not in school) group, questions reflected adult life, such as type of work, living situation, and social activities.

Data Management: After the survey was closed, all results from Survey Monkey were downloaded into an Excel spreadsheet and then imported into SPSS for analyses.

Data Analysis: Descriptive statistics (means, frequencies, and percentages) were calculated for the quantitative data. Qualitative answers were coded and themed. The results from the data analysis of the survey are presenting in the following section.

RESULTS

Participants: A total of 158 people participated in the online survey. Thirty-three participants completed only the first six questions, so they were removed from all analyses, leaving 125 participants. The majority of participants indicated being the mother of a child with CdLS. The majority of participants were also married and employed either full- or part-time. Participants represented all regions of the United States; 34 states were represented, with the highest number of respondents from the state of New York. One respondent indicated living in Canada.

Child demographics: Over half of the children were female; and the majority of children were white, with a small representation of Latino/Hispanic, African-American, and Asian children. A few participants indicated their child was of another race/ethnicity including

Filipino, Native American, and Hawaiian. Respondents indicated that the majority of their children were in good to very good health and that, in terms of functioning, they require some assistance. See Table 1 in Appendix C for more information on participant and child characteristics.

Birth to Two: Eighteen respondents (14%) had children birth to age two. Child's health was described as excellent (18%), very good (44%), good (22%), and fair (18%). Fifty percent of participants described their child as needing total assistance, forty percent as needing some assistance, and eleven percent as independent. The majority of children participated in occupational therapy (OT: 78%), physical therapy (PT: 72%), and/or speech language therapy (SLT: 56%). Other therapies/services children received included oral motor (OM: 39%), service coordination (SC: 17%), special instruction (SI: 17%), nursing (11%), and social work (SW: 11%).

For each therapy a child receives, participants were asked to respond to the length, frequency, location, and setting of the therapy/service; as well as the role the parent plays in the sessions and who provides the therapy/service. Table 2 shows the number of responses for each item by the therapy/service. Across all therapies/services, the majority of children received therapy/service sessions that were 31-60 minutes in length (68%) and occurred in the home (78%), with the largest number of children receiving therapy/service two or three times a month (31%). Eighty-six percent of children received therapy/service one-on-one and early intervention provided the majority (87%) of the therapies/services. Parents most often (35%) described their role in the session as "the provider explains what she/he is doing with my child to me."

The next few questions focused on early intervention and the individualized family service plan (IFSP). The majority of respondents indicated that providers met together to discuss the child's goals (78%) and the majority of respondents were invited to these meetings all the time (67%). Eighty-two percent of children had an IFSP. Some of the adaptations being used by children and their caregivers included sign language (56%), other special equipment such as adapted toys or feeding utensils (33%), auditory amplification (22%), special equipment for sitting, standing or walking (22%), and a picture communication system (17%). See Table 3 for participants' responses to items assessing their experience with early intervention.

Participants were also asked about their experiences with care coordination for their child's services. Sixty-seven percent of participants reported needing care coordination among health care providers and services in the past 12 months, yet only 38% felt they had received the care coordination that was needed. Participants reported receiving care coordination never (40%), sometimes (13%), usually (7%), and always (13%). Twenty-seven percent did not know how often they received care coordination. The majority of caregivers were somewhat (36%) or very (29%) satisfied with the care coordination they received. Caregivers were also asked about the communication between various doctors and health care providers about the child's care, as well as the communication between health care providers and the child's educational and therapeutic providers. Table 4 illustrates the variation of responses.

Finally, participants were asked about their child's social experiences. Table 5 shows the percentage of responses to the number of friends who were invited and attended the child's birthday party, as well as the number of birthday parties the child was invited to and attended.

Three through Five: Twenty-five respondents (20%) had children aged three through five. Child's health was described as excellent (16%), very good (40%), good (32%), and fair

(12%). Thirty-two percent of participants described their child as needing total assistance, sixty percent as needing some assistance, and eight percent as independent. The majority of children participated in SLT (96%), OT (84%), and/or PT (72%). Other therapies/services children received included oral motor (32%), special instruction (24%), sensory integration therapy (SIT: 16%), vision and mobility services (VM: 12%), behavior management (BM: 12%), service coordination (SC: 8%), nursing (8%), social work (SW: 4%), art therapy (4%), and hippotherapy (HT: 4%).

For each therapy a child receives, participants were asked to respond to the length, frequency, location, and setting of the therapy/service; as well as the role the parent plays in the sessions and who provides the therapy/service. Table 6 shows the number of responses for each item by the therapy/service. Across all therapies/services, the majority of children received therapy/service sessions that were 30 minutes or less in length (42%) or 31-60 minutes (40%) and most often occurred in a public preschool (50%), with the largest number of children receiving therapy/service two or three times a week (41%). Eighty-eight percent of children received therapy/service one-on-one and the school provided the majority (70%) of the therapies/services. Parents most often (56%) described their role in the session as not being present when their child received services.

The next few questions focused on educational and therapeutic experiences including the individualized education program (IEP). The majority of respondents indicated that providers met together to discuss the child's goals (71%) and the majority of respondents were invited to these meetings all the time (44%) or sometimes (35%). Progress updates from providers occurred quarterly (25%), after each session (25%), once a week (13%), and once a month (8%). Twenty-nine percent of respondents indicated "other." Communication from providers occurs in person

(48%), through a communication notebook (24%), by email (12%), and over the phone (4%). Twelve percent indicated “other;” with the majority indicating that they received communication through multiple methods.

The highest number of respondents had children in public schools (40%); other responses included private school (12%), child care (8%), head start (4%), and other (36%). Participants listed other responses such as the child is educated in the home and child attends a public school specifically for children with special needs. Eighty-eight percent of children had an IEP. Thirty-three percent of respondents indicated their child was given a label for eligibility, while 50% indicated they did not know. Disabilities indicated are as follows: speech/language impairment (64%), developmental delay (60%), hearing impairment (36%), other health impairment (36%), intellectual disability (24%), visual impairment (24%), multiple disabilities (20%), orthopedic impairment (20%), specific learning disability (12%), autism (4%), deaf-blindness (4%), and emotional disturbance (4%). Some of the adaptations being used by these children and their caregivers included sign language (44%), special equipment for sitting, standing or walking (44%), communication notebook (36%), picture communication system (28%), modified curriculum (28%), classroom aide (28%), individual programming (16%), auditory amplification, (12%), behavior intervention plan (12%), other special equipment (12%), visual adaptation (8%), computer assisted communication (4%), computer program (4%), and tape recorder (4%). See Table 7 for participants’ responses to items assessing their experience with educational and therapeutic activities.

Participants were also asked about their experiences with care coordination for their child’s services. Sixty-four percent of participants reported needing care coordination among health care providers and services in the past 12 months, yet only 50% felt they had received the care coordination that was needed. Participants reported receiving care coordination never (59%), sometimes (18%), usually (5%), and always (14%). Caregivers were very satisfied (40%), somewhat satisfied (5%), somewhat dissatisfied (25%), or very dissatisfied (15%) with the care coordination they received. Caregivers were also asked about the communication between various doctors and health care providers about the child's care, as well as the communication between health care providers and the child's educational and therapeutic providers. Table 8 illustrates the variation of responses.

Finally, participants were asked about their child's social experiences. Table 9 shows the percentage of responses to the number of friends who were invited and attended the child's birthday party, as well as the number of birthday parties the child was invited to and attended.

Six through thirteen: Forty-two respondents (34%) had children aged six through thirteen. Child's health was described as excellent (10%), very good (41%), good (41%), and fair (10%). Twenty-four percent of participants described their child as needing total assistance, sixty-four percent as needing some assistance, and twelve percent as independent. The majority of children participated in SLT (86%), OT (74%), and/or PT (48%). Other therapies/services children received included special instruction (31%), behavior management (19%), oral motor (12%), sensory integration therapy (12%), nursing (10%), social work (10%), service coordination (7%), vision and mobility services (5%), hippotherapy (5%), art therapy (2%), and pet therapy (2%).

For each therapy a child receives, participants were asked to respond to the length, frequency, location, and setting of the therapy/service; as well as the role the parent plays in the sessions and who provides the therapy/service. Table 10 shows the number of responses for each item by the therapy/service. Across all therapies/services, the majority of children received therapy/service sessions that were 30 minutes or less in length (45%) or 31-60 minutes (40%) and most often occurred in school – in the classroom (56%) or out of the classroom (41%), with the largest number of children receiving a therapy/service two or three times a week (49%). Seventy-four percent of children received therapy/service one-on-one and the school provided the majority (70%) of these. Parents most often (28%) described their role in the therapy/service as receiving quarterly updates from the provider.

The next few questions focused on educational and therapeutic experiences including the individualized education program (IEP). The majority of respondents indicated that providers met together to discuss the child's goals (78%) and the majority of respondents were invited to these meetings all the time (40%) or sometimes (37%). Progress updates from providers occurred quarterly (42%), after each session (24%), once a week (10%), and once a month (10%). Communication from providers occurs in person (34%), through a communication notebook (34%), by email (15%), and over the phone (5%). Twelve percent indicated "other;" with the majority of participants indicating that they received communication through multiple methods.

Respondents had children in public schools (73%), private schools (7%), and other (20%). Participants listed other responses such as the child is educated in the home, child attends a magnet school, and child attends a public school specifically for children with special needs. The highest percentage of respondents indicated their child spent none of their time in a regular classroom (33%); other responses included the child spent half (25%), most (20%), a little bit (18%), or all (5%) of their time in a regular classroom. Ninety percent of children had an IEP. Fifty-three percent of respondents indicated their child was given a label for eligibility, while 31% indicated they did not know. Disabilities indicated are as follows: developmental delay (69%), speech/language impairment (55%), intellectual disability (52%), multiple disabilities

(31%), hearing impairment (29%), orthopedic impairment (21%), autism (14%), other health impairment (12%), visual impairment (12%), specific learning disability (7%), emotional disturbance (7%), and deaf-blindness (2%). Some of the adaptations being used by these children and their caregivers included communication notebook (57%), modified curriculum (50%), classroom aide (45%), picture communication system (41%), sign language (38%), individual programming (31%), behavior intervention plan (26%), resource room (24%), special equipment for sitting, standing or walking (24%), computer program (21%), adaptive PE (21%), other special equipment (14%), visual adaptation (10%), auditory amplification (10%), and computer assisted communication (4%). Thirty-eight percent of students participate in state assessments. Modifications used for participation in states' assessments were alternative response methods (21%), extended time (19%), alternative assessment (17%), other timing/scheduling practices (17%), personal assistant (14%), modified presentation (10%), additional materials (10%), and alternative setting (10%). See Table 11 for participants' responses to items assessing their experience with educational and therapeutic activities.

Participants were also asked about their experiences with care coordination for their child's services. Thirty-two percent of participants reported needing care coordination among health care providers and services in the past 12 months, yet only 39% felt they had received the care coordination that was needed. Participants reported receiving care coordination never (60%), sometimes (26%), usually (6%), and always (3%). Caregivers were very satisfied (7%), somewhat satisfied (32%), somewhat dissatisfied (11%), or very dissatisfied (32%) with the care coordination they received. Caregivers were also asked about the communication between various doctors and health care providers about the child's care, as well as the communication between health care providers and the child's educational and therapeutic providers. Table 12 illustrates the variation of responses.

Finally, participants were asked about their child's social experiences. Table 13 shows the percentage of responses to the number of friends who were invited and attended the child's birthday party, as well as the number of birthday parties the child was invited to and attended.

Fourteen through twenty-one: Forty respondents (32%) had children aged 14-21; 33 of which were in school (83%). Child's health was described as excellent (8%), very good (50%), good (35%), fair (3%), and poor (5%). Twenty-three percent of participants described their child as needing total assistance, sixty percent as needing some assistance, and eighteen percent as independent. The following results are based only on the children aged 14-21 who attended school (N = 33). The majority of children participated in SLT (53%), special instruction (38%), OT (28%), and/or PT (23%). Other therapies/services children received included behavior management (20%), nursing (18%), service coordination (13%), social work (8%), art therapy (8%), vision and mobility (5%), oral motor (5%), aqua therapy (5%), sensory integration therapy (3%), hippotherapy (3%), and pet therapy (3%).

For each therapy a child receives, participants were asked to respond to the length, frequency, location, and setting of the therapy/service; as well as the role the parent plays in the sessions and who provides the therapy/service. Table 14 shows the number of responses for each item by the therapy/service. Across all therapies/services, the majority of children received therapy/service sessions that were 30 minutes or less in length (43%) or 31-60 minutes (32%) and most often occurred in school – in the classroom (56%) or out of the classroom (33%), with the largest number of children receiving a therapy/service everyday (29%) or two or three times a week (28%). Fifty-three percent of children received therapy/service one-on-one and the school provided the majority (70%) of the therapies/services. Parents most often (29%) described their role in the therapy/service as receiving regular updates from the provider.

The next few questions focused on educational and therapeutic experiences including the individualized education program (IEP). The majority of respondents indicated that providers met together to discuss the child's goals (79%) and the majority of respondents were invited to these meetings all the time (53%) or sometimes (43%). Progress updates from providers occurred quarterly (33%), after each session (27%), and once a week (9%). Thirty percent of respondents indicated "other;" responses included as needed, communication varies with each provider, and daily. Communication from providers occurs through a communication notebook (30%), in person (27%), by email (9%), and over the phone (9%). Twenty-four percent indicated "other," with the majority of participants indicating that they received communication through multiple methods.

Respondents had children in public schools (78%), private schools (9%), and other (13%). Participants listed other responses such as the child is educated in the home, child attends a state school, and child attends a transition program. The highest percentage of respondents indicated their child spent none of their time in a regular classroom (46%); other responses included the child spent most (18%), a little bit (18%), half (12%), or all (5%) of their time in a regular classroom. Ninety-seven percent of children had an IEP. Fifty-five percent of respondents indicated their child was given a label for eligibility, while 35% indicated they did not know. Disabilities indicated are as follows: developmental delay (48%), intellectual disability (48%), speech/language impairment (30%), multiple disabilities (23%), other health impairment (20%), hearing impairment (18%), visual impairment (10%), orthopedic impairment (8%), specific learning disability (8%), deaf-blindness (8%), autism (5%), and emotional disturbance (5%). Some of the adaptations being used by these children and their caregivers included modified curriculum (48%), communication notebook (40%), classroom aide (33%), picture communication system (33%), sign language (25%), individual programming (25%), adaptive PE (23%), behavior intervention plan (20%), special equipment for sitting, standing or walking (20%), resource room (18%), computer program (15%), other special equipment (13%), visual adaptation (10%), computer assisted communication (10%), auditory amplification (3%), and tape recorder (3%). Forty-seven percent of students participate in state assessments. Modifications used for participation in states' assessments were alternative assessment (18%), modified presentation (18%), extended time (10%), additional materials (8%), alternative setting (8%), other timing/scheduling practices (5%), alternative response methods (3%), and personal assistant (3%). See Table 15 for participants' responses to items assessing their experience with educational and therapeutic activities.

Participants were also asked about their experiences with care coordination for their child's services. Sixty-one percent of participants reported needing care coordination among health care providers and services in the past 12 months, yet only 45% felt they had received the care coordination that was needed. Participants reported receiving care coordination never (59%), sometimes (30%), and always (11%). Caregivers were very satisfied (31%), somewhat satisfied (27%), somewhat dissatisfied (8%), or very dissatisfied (19%) with the care coordination they received. Caregivers were also asked about the communication between various doctors and health care providers about the child's care, as well as the communication between health care providers and the child's educational and therapeutic providers. Table 16 illustrates the variation of responses.

Finally, participants were asked about their child's social experiences. Table 17 shows the percentage of responses to the number of friends who were invited and attended the child's birthday party, as well as the number of birthday parties the child was invited to and attended.

For participants whose child was no longer in school, items on the survey focused on the child's participation in the community. The following results are for the seven children aged 14-21 who were no longer in school (N = 7). All indicated the child's living arrangement was at home with the parent(s). Of these, two work in the community, both in special workshops doing assembly line work. One works in a small group (under 5) with a supervisor and one works in a large group with a supervisor. Table 18 shows participants' responses to items assessing the child's transition to community life and their participation in the community.

CONCLUSION

The results of this survey provide a large amount of information on the educational and therapeutic experiences of children with Cornelia de Lange syndrome and their families. Future research needs to look at some of the findings of this study in more depth. For example, these results showed that children with CdLS typically spend half or less than half of their school day in a regular education classroom. Future research should focus on the reasons for this as well as how it compares to students with other types of disabilities. Also, more research should look at the transition from school to adult life including how these students are prepared for the transition, the options that are explored, and the satisfaction of both the child with CdLS and his/her family. Overall, this survey provides a wealth of information from which to plan future research and provide support to families and professionals of children with CdLS.

Appendix A

Educational Research Opportunity for Parents with Children Ages Birth to 21

The University of Connecticut's Center for Developmental Disabilities (UCEDD) invites parents to participate in a survey to share their perspectives on their child's experiences. Topics covered include therapies, social interactions, and the educational system.

With information gained from this survey, researchers hope to develop educational guidelines for parents, as well as professionals working in the school arena. This project is a follow-up to a broader survey in 2007, which saw overwhelming support from parents.

The survey can be accessed online at http://www.surveymonkey.com/s.aspx?sm=556cwt76DDNZ9Tt2rbVFLg_3d_3d; for a paper copy, contact Cristina Wilson, Ph.D., at 860-679-1500 or cmwilson@uchc.edu.

Appendix B

Parent Survey of Children with Cornelia de Lange Syndrome

Background Information

1. What is your relation to this child?
    - ☐ Mother
    - ☐ Father
    - ☐ Family member
    - ☐ Other (please specify:____)

2. What is the sex of your child?
    - ☐ Male
    - ☐ Female

3. How would you rate your child's general health?
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor

4. How would you rate your child's functioning in everyday activities? Would you say he/she...
    - ☐ Is independent
    - ☐ Needs some assistance
    - ☐ Needs total assistance

    Please describe further

5. What is your child's race/ethnicity? (You may check all that apply)
    - ☐ White

☐ Latino/Hispanic
☐ African-American
☐ Asian
☐ Other (please specify:____)

6. How old is your child?
   ☐ 0-2 years
   ☐ 3-5 years
   ☐ 6-13 years
   ☐ 14-21 years

Birth through Two

1. Which of the following therapies/services does your child currently receive (select ALL that apply)?
   - ☐ Art therapy
   - ☐ Aqua therapy
   - ☐ Behavior management
   - ☐ Hippotherapy
   - ☐ Music therapy
   - ☐ Nursing
   - ☐ Occupational therapy
   - ☐ Oral motor (feeding) therapy
   - ☐ Pet therapy
   - ☐ Physical therapy
   - ☐ Sensory integration therapy
   - ☐ Service coordination
   - ☐ Social work
   - ☐ Special instruction
   - ☐ Speech-language therapy
   - ☐ Vision and mobility
   - ☐ Other (Please specify: ____)

2. If you selected aqua therapy, hippotherapy, or pet therapy, please describe in detail what a typical therapy session looks like.

3. On average, how long does each of the following therapy/service sessions last?

	30 minutes or less	31-60 minutes	More than 60 minutes	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

4. How often does your child receive each of the following therapies/services?

	Everyday	2 or 3 times a week	Once a week	2 or 3 times a month	About once a month	Every 2 to 3 months	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

5. Where does your child receive each of the following therapies/services (select ALL that apply)?

	Home	School	Child care	Clinical setting (therapy room, hospital)	Community setting (playground, pool)	Other	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

6. How are the following therapies/services provided?

	Group setting (more than 2 children)	With one other child	One-on-one	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

7. Do your child's providers meet together and discuss your child's goals?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

8. If yes, how often are you invited?
    - ☐ Never
    - ☐ Sometimes
    - ☐ All the time

9. Which of your child's providers meet together?

10. How are you (the parent[s]) included in each of the following therapy/service sessions?

	When my child receives services I am not present	I watch the provider work with my child	Provider explains what she/he is doing with my child to me	Provider shows me how to do the interventions	Provider helps me learn how to do interventions without his or her help	Does not receive
Art therapy						
Aqua therapy						
Behavior management						
Hippotherapy						
Music therapy						
Nursing						
Occupational therapy						
Oral motor (feeding)						
Pet therapy						
Physical therapy						
Sensory integration therapy						
Service coordination						
Social work						
Special instruction						
Speech-language therapy						
Vision and mobility						
Other						

11. Who provides the following therapies/services?

	Early intervention (EI) system	Private	Other	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

The Individualized Family Service Plan (IFSP) is the document that is used by families and professionals to support the developmental needs of a young child from birth to age three with special needs and includes the family's concerns, priorities, and resources as well as the goals for the child and family and the supports needed to reach those goals.

12. Does your child have an IFSP?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

13. If your child has an IFSP, please describe the skills that are currently being worked on with your child (goals on the IFSP).

14. What adaptations are being used to meet your child's needs (select ALL that apply)?
    - ☐ Sign language
    - ☐ Picture communication system
    - ☐ Computer-assisted communication
    - ☐ Auditory amplification
    - ☐ Behavior intervention plan
    - ☐ Special equipment for sitting, standing, or walking
    - ☐ Other special equipment such as adapted toys or feeding utensils
    - ☐ Other (please specify: ___________________________________)

15. Please select the rating that best fits for each item

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning			
I am involved in deciding what my child's goals should be			
My child's goals are objective and measurable			
My child is making progress towards his/her goals			
I am satisfied with the amount of progress my child is making			
My child's behavioral challenges are being addressed (if applicable)			
My child participates in groups/activities outside the home			
My child participates in activities that include both children with special needs and typically developing children			
There is a transition plan in place for when my child turns 3			
I am satisfied with the transition process (if applicable)			

A case manager or a case coordinator is a person who assists in coordinating care to make sure that your child gets the services that he/she needs.

16. During the past 12 months, was there any time when your child needed care coordination among different health care providers and services that your child uses?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

17. If yes, did you or your family receive all the professional care coordination that was needed?
    - ☐ Yes
    - ☐ No

☐ I don’t know

18. If you have a care coordinator, what is their title/position?

19. How often does a person help you coordinate your child’s care among his/her different providers and services?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always
    - ☐ I don’t know

20. Overall, how satisfied are you with the help you have received in coordinating your child’s care?
    - ☐ Very satisfied
    - ☐ Somewhat satisfied
    - ☐ Somewhat dissatisfied
    - ☐ Very dissatisfied
    - ☐ I don’t know

21. How well do you think your child’s doctors and other health care providers communicate with each other about your child’s care? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor
    - ☐ Communication is not needed
    - ☐ I don’t know

22. How well do you think your child’s doctors and other health care providers communicate with your child’s school, early intervention program, child care providers, or vocational rehabilitation program? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor

- ☐ Communication is not needed
- ☐ I don't know

By "friends" we mean that the children like each other and play together.

23. How many friends did you invite to your child's last birthday party?

Total number of friends ☐

Number of friends with disabilities ☐

Number of friends without disabilities ☐

24. How many friends attended your child's last birthday party?

Total number of friends attended ☐

Number of friends with disabilities ☐

Number of friends without disabilities ☐

25. How many birthday parties was your child invited to last year?

☐

26. How many birthday parties did your child attend last year?

☐

Preschool (3-5)

1. Which of the following therapies/services does your child currently receive (select ALL that apply)?
   - ☐ Art therapy
   - ☐ Aqua therapy
   - ☐ Behavior management
   - ☐ Hippotherapy
   - ☐ Music therapy
   - ☐ Nursing
   - ☐ Occupational therapy
   - ☐ Oral motor (feeding) therapy
   - ☐ Pet therapy
   - ☐ Physical therapy
   - ☐ Sensory integration therapy
   - ☐ Service coordination
   - ☐ Social work
   - ☐ Special instruction
   - ☐ Speech-language therapy
   - ☐ Vision and mobility
   - ☐ Other (Please specify: ____)

2. If you selected aqua therapy, hippotherapy, or pet therapy, please describe in detail what a typical therapy session looks like.

3. On average, how long does each of the following therapy/service sessions last?

	30 minutes or less	31-60 minutes	More than 60 minutes	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

4. How often does your child receive each of the following therapies/services?

	Everyday	2 or 3 times a week	Once a week	2 or 3 times a month	About once a month	Every 2 to 3 months	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

5. Where does your child receive each of the following therapies/services (select ALL that apply)?

	Home	Public preschool	Other preschool (Head Start, private, community)	Child care (family, in-home)	Clinical setting (therapy room, hospital)	Community activity (playground, pool)	Other	Does not receive
Art therapy								
Aqua therapy								
Behavior management								
Hippotherapy								
Music therapy								
Nursing								
Occupational therapy								
Oral motor (feeding)								
Pet therapy								
Physical therapy								
Sensory integration therapy								
Service coordination								
Social work								
Special instruction								
Speech-language therapy								
Vision and mobility								
Other								

6. How are the following therapies/services provided?

	Group setting (more than 2 children)	With one other child	One-on-one	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

7. Do your child's providers meet together and discuss your child's goals?
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

8. If yes, how often are you invited?
   - ☐ Never
   - ☐ Sometimes
   - ☐ All the time

9. Which of your child's providers meet together?

10. How are you (the parent[s]) included in each of the following therapy/service sessions?

	When my child receives services I am not present	I watch the provider work with my child	Provider explains what she/he is doing with my child to me	Provider shows me how to do the interventions	Provider helps me learn how to do interventions without his or her help	Does not receive
Art therapy						
Aqua therapy						
Behavior management						
Hippotherapy						
Music therapy						
Nursing						
Occupational therapy						
Oral motor (feeding)						
Pet therapy						
Physical therapy						
Sensory integration therapy						
Service coordination						
Social work						
Special instruction						
Speech-language therapy						
Vision and mobility						
Other						

11. Who provides the following therapies/services?

	School	Private	Other	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

12. How often do you receive updates on your child's progress from his/her service providers?

☐ Quarterly
☐ Once a month
☐ Once a week
☐ After each session
☐ Other (please specify: ____)

13. How do you typically communicate with your child's service providers?
    ☐ In person
    ☐ Phone
    ☐ E-mail
    ☐ Communication notebook
    ☐ Other (please specify:____)

14. What type of educational setting does your child attend?
    ☐ Public school
    ☐ Private school
    ☐ Community child care program
    ☐ Head Start program
    ☐ Other (please specify: ____)

The Individualized Education Program (IEP) is a document used by the family and school personnel to support the educational needs of children aged three through twenty-one and includes a description of the child's current performance, annual goals, educational and related services, participation with non-disabled peers, etc.

15. Does your child have an IEP?
    ☐ Yes
    ☐ No
    ☐ I don't know

16. If your child has an IEP, please describe the skills that are currently being worked on with your child (goals on the IEP).

The Individuals with Disabilities Education Act (IDEA) is the law that ensures services are provided to children with disabilities throughout the nation, including early intervention, special education and related services.

17. If your child is receiving IDEA services, has a label for eligibility been given?

☐ Yes
☐ No
☐ I don't know

18. What is your child's educational disability (select ALL that apply)?

☐ Autism
☐ Deaf-blindness
☐ Developmental delay
☐ Hearing impairment (including deafness)
☐ Emotional disturbance
☐ Intellectual disabilities (mental retardation)
☐ Multiple disabilities
☐ Orthopedic impairment
☐ Other health impairment
☐ Specific learning disability
☐ Speech-language impairment
☐ Traumatic brain injury
☐ Visual impairment (including blindness)
☐ I don't know
☐ Other (please specify:____)

19. What adaptations are being used to meet your child's needs (select ALL that apply)?

☐ Sign language
☐ Picture communication system
☐ Computer-assisted communication
☐ Auditory amplification
☐ Behavior intervention plan
☐ Communication book between home and school
☐ Modified curriculum
☐ Individual programming
☐ Classroom aide specifically for your child
☐ Computer educational programs
☐ Special equipment for sitting, standing, or walking
☐ Other special equipment such as adapted feeding utensils
☐ Visual adaptations (special print material, large print, Braille)
☐ Use of tape recorder
☐ Other (please specify: ______________________________________)

20. Please select the rating that best fits for each item.

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning			
I am involved in deciding what my child's goals should be			
My child's goals are objective and measurable			
My child is making progress towards his/her goals			
I am satisfied with the amount of progress my child is making			
Skills that are being taught in the classroom are also being taught at home			
My child's behavioral challenges are being addressed (if applicable)			
My child participates in groups/activities outside the home			
My child participates in groups/activities that include both children with special needs and typically developing children			
There was a transition plan in place for when my child moved from early intervention (birth to three) to public education			
My child was adequately prepared for the transition			
I was satisfied with the transition process			
My child's classroom promotes social skills			
My child's school/center provides activities outside of school time to help develop social relationships			
My child has a way to communicate both at home and at school			
My child's therapies involve social interactions with peers			
The skills my child is learning in therapy promote independence			
My child has a 1-on-1 paraprofessional at school			

A case manager or a case coordinator is a person who assists in coordinating care to make sure that your child gets the services that he/she needs.

21. During the past 12 months, was there any time when your child needed care coordination among different health care providers and services that your child uses?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

22. If yes, did you or your family receive all the professional care coordination that was needed?
    - ☐ Yes
    - ☐ No
    - ☐ I don’t know

23. If you have a care coordinator, what is their title/position?

24. How often does a person help you coordinate your child’s care among his/her different providers and services?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always
    - ☐ I don’t know

25. Overall, how satisfied are you with the help you have received in coordinating your child’s care?
    - ☐ Very satisfied
    - ☐ Somewhat satisfied
    - ☐ Somewhat dissatisfied
    - ☐ Very dissatisfied
    - ☐ I don’t know

26. How well do you think your child’s doctors and other health care providers communicate with each other about your child’s care? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor
    - ☐ Communication is not needed
    - ☐ I don’t know

27. How well do you think your child’s doctors and other health care providers communicate with your child’s school, early intervention program, child care providers, or vocational rehabilitation program? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor
    - ☐ Communication is not needed
    - ☐ I don’t know

By “friends” we mean that the children like each other and play together.

28. How many friends did you invite to your child’s last birthday party?

    Total number of friends ☐

    Number of friends with disabilities ☐

    Number of friends without disabilities ☐

29. How many friends attended your child’s last birthday party?

    Total number of friends attended ☐

    Number of friends with disabilities ☐

    Number of friends without disabilities ☐

30. How many birthday parties was your child invited to last year?

    ☐

31. How many birthday parties did your child attend last year?

    ☐

Ages 6-13

1. Which of the following therapies/services does your child currently receive (select ALL that apply)?
    - ☐ Art therapy
    - ☐ Aqua therapy
    - ☐ Behavior management
    - ☐ Hippotherapy
    - ☐ Music therapy
    - ☐ Nursing
    - ☐ Occupational therapy
    - ☐ Oral motor (feeding) therapy
    - ☐ Pet therapy
    - ☐ Physical therapy
    - ☐ Sensory integration therapy
    - ☐ Service coordination
    - ☐ Social work
    - ☐ Special instruction
    - ☐ Speech-language therapy
    - ☐ Vision and mobility
    - ☐ Other (Please specify: ____)

2. If you selected aqua therapy, hippotherapy, or pet therapy, please describe in detail what a typical therapy session looks like.

3. On average, how long does each of the following therapy/service sessions last?

	30 minutes or less	31-60 minutes	More than 60 minutes	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

4. How often does your child receive each of the following therapies/services?

	Everyday	2 or 3 times a week	Once a week	2 or 3 times a month	About once a month	Every 2 to 3 months	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

5. Where does your child receive each of the following therapies/services (select ALL that apply)?

	Home	School-in the classroom	School-out of the classroom	Clinical setting (therapy room, hospital)	Community activity (playground, pool)	Other	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

6. How are the following therapies/services provided?

	Group setting (more than 2 children)	With one other child	One-on-one	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

7. Do your child’s providers meet together and discuss your child’s goals?
   - ☐ Yes
   - ☐ No
   - ☐ I don’t know

8. If yes, how often are you invited?
   - ☐ Never
   - ☐ Sometimes
   - ☐ All the time

9. Which of your child’s providers meet together?

10. How are you (the parent[s]) included in each of the following therapy/service sessions?

	When my child receives services, I am not involved	I receive quarterly updates from the provider	I receive regular updates that include what is being worked on and any problems	I receive regular updates and consultation including things I can do at home	I participate in therapy sessions by observing and/or interacting with my child	Does not receive
Art therapy						
Aqua therapy						
Behavior management						
Hippotherapy						
Music therapy						
Nursing						
Occupational therapy						
Oral motor (feeding)						
Pet therapy						
Physical therapy						
Sensory integration therapy						
Service coordination						
Social work						
Special instruction						
Speech-language therapy						
Vision and mobility						
Other						

11. Who provides the following therapies/services?

	School	Private	Other	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

12. How often do you receive updates on your child's progress from his/her service providers?
    - ☐ Quarterly
    - ☐ Once a month
    - ☐ Once a week
    - ☐ After each session
    - ☐ Other (please specify:____)

13. How do you typically communicate with your child's service providers?
    - ☐ In person
    - ☐ Phone
    - ☐ E-mail
    - ☐ Communication notebook
    - ☐ Other (please specify: ____)

14. What type of educational settings does your child attend?
    - ☐ Public school
    - ☐ Private school
    - ☐ Other (please specify: ____)

15. How much of your child's day is spent in a regular classroom?
    - ☐ All of it
    - ☐ Most of it
    - ☐ Half of it
    - ☐ A little bit of it
    - ☐ None of it

The Individualized Education Program (IEP) is a document used by the family and school personnel to support the educational needs of children aged three through twenty-one and includes a description of the child's current performance, annual goals, educational and related services, participation with non-disabled peers, etc.

16. Does your child have an IEP?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

17. If your child has an IEP, please describe the skills that are currently being worked on with your child (goals on the IEP).

The Individuals with Disabilities Education Act (IDEA) is the law that ensures services are provided to children with disabilities throughout the nation, including early intervention, special education and related services.

18. If your child is receiving IDEA services, has a label for eligibility been given?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

19. What is your child's educational disability (select ALL that apply)?
    - ☐ Autism
    - ☐ Deaf-blindness
    - ☐ Developmental delay
    - ☐ Hearing impairment (including deafness)
    - ☐ Emotional disturbance
    - ☐ Intellectual disabilities (mental retardation)
    - ☐ Multiple disabilities
    - ☐ Orthopedic impairment
    - ☐ Other health impairment
    - ☐ Specific learning disability
    - ☐ Speech-language impairment
    - ☐ Traumatic brain injury
    - ☐ Visual impairment (including blindness)
    - ☐ I don't know
    - ☐ Other (please specify: ____)

20. What adaptations are being used to meet your child’s needs (select ALL that apply)?

- ☐ Adaptive PE
- ☐ Sign language
- ☐ Picture communication system
- ☐ Computer-assisted communication
- ☐ Auditory amplification
- ☐ Behavior intervention plan
- ☐ Communication book between home and school
- ☐ Modified curriculum
- ☐ Individual programming
- ☐ Classroom aide specifically for your child
- ☐ Computer educational programs
- ☐ Special equipment for sitting, standing, or walking
- ☐ Other special equipment such as adapted feeding utensils
- ☐ Resource room
- ☐ Visual adaptations (special print material, large print, Braille)
- ☐ Use of tape recorder
- ☐ Other (please specify: ____)

21. Does your child participate in your state assessment? (No Child Left Behind yearly assessment)?

- ☐ Yes
- ☐ No
- ☐ I don’t know

22. What modifications or accommodations does your child use in order to participate in state assessment (select ALL that apply)?

- ☐ No modifications or accommodations
- ☐ Child does not participate in state assessment
- ☐ Use of an alternative assessment
- ☐ Modified presentation of assessment (ex. Braille, large print, read aloud)
- ☐ Use of additional materials (ex. calculator, manipulatives, amplification)
- ☐ Alternative response methods (ex. pointing, use of a scribe)
- ☐ Alternative setting (ex. separate room, at home)
- ☐ Extended time to complete assessment
- ☐ Use of other timing/scheduling practices (ex. frequent breaks)
- ☐ Use of a personal assistant
- ☐ Other (please specify:____)

23. Please select the rating that best fits for each item.

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning			
I am involved in deciding what my child’s goals should be			
My child’s goals are objective and measurable			
My child is making progress towards his/her goals			
I am satisfied with the amount of progress my child is making			
My child’s behavioral challenges are being addressed (if applicable)			
My child participates in groups/activities outside the home			
My child participates in groups/activities that include both children with special needs and typically developing children			
There is/was a transition plan in place for moving from elementary to Jr. High/Middle/High school			
My child is/was adequately prepared for the transition			
I am satisfied with the transition process			
My child’s classroom promotes social skills			
My child’s school provides activities outside of school time to help develop social relationships			
My child has a way to communicate both at home and at school			
My child’s therapies involve social interactions with peers			
The skills my child is learning in therapy are functional for home, community, and school			
The skills my child is learning in therapy promote independence			
My child has a 1-on-1 paraprofessional at school			

A case manager or a case coordinator is a person who assists in coordinating care to make sure that your child gets the services that he/she needs.

24. During the past 12 months, was there any time when your child needed care coordination among different health care providers and services that your child uses?
    - ☐ Yes
    - ☐ No
    - ☐ I don’t know

25. If yes, did you or your family receive all the professional care coordination that was needed?
    - ☐ Yes
    - ☐ No
    - ☐ I don’t know

26. If you have a care coordinator, what is their title/position?

27. How often does a person help you coordinate your child’s care among his/her different providers and services?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always
    - ☐ I don’t know

28. Overall, how satisfied are you with the help you have received in coordinating your child’s care?
    - ☐ Very satisfied
    - ☐ Somewhat satisfied
    - ☐ Somewhat dissatisfied
    - ☐ Very dissatisfied
    - ☐ I don’t know

29. How well do you think your child’s doctors and other health care providers communicate with each other about your child’s care? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor
    - ☐ Communication is not needed
    - ☐ I don’t know

30. How well do you think your child’s doctors and other health care providers communicate with your child’s school, early intervention program, child care providers, or vocational rehabilitation program? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good

☐ Good
☐ Fair
☐ Poor
☐ Communication is not needed
☐ I don't know

By "friends" we mean that the children like each other and play together.

31. How many friends did you invite to your child's last birthday party?

Total number of friends

Number of friends with disabilities

Number of friends without disabilities

32. How many friends attended your child's last birthday party?

Total number of friends attended

Number of friends with disabilities

Number of friends without disabilities

33. How many birthday parties was your child invited to last year?

34. How many birthday parties did your child attend last year?

Ages 14-21

1. Is your child currently in school?
   - ☐ Yes
   - ☐ No

If you answered yes to question number 1, complete questions 2-36. If you answered no, only answer questions 37-42.

2. Which of the following therapies/services does your child currently receive (select ALL that apply)?
   - ☐ Art therapy
   - ☐ Aqua therapy
   - ☐ Behavior management
   - ☐ Hippotherapy
   - ☐ Music therapy
   - ☐ Nursing
   - ☐ Occupational therapy
   - ☐ Oral motor (feeding) therapy
   - ☐ Pet therapy
   - ☐ Physical therapy
   - ☐ Sensory integration therapy
   - ☐ Service coordination
   - ☐ Social work
   - ☐ Special instruction
   - ☐ Speech-language therapy
   - ☐ Vision and mobility
   - ☐ Other (Please specify: ____)

3. If you selected aqua therapy, hippotherapy, or pet therapy, please describe in detail what a typical therapy session looks like.

4. On average, how long does each of the following therapy/service sessions last?

	30 minutes or less	31-60 minutes	More than 60 minutes	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

5. How often does your child receive each of the following therapies/services?

	Everyday	2 or 3 times a week	Once a week	2 or 3 times a month	About once a month	Every 2 to 3 months	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

6. Where does your child receive each of the following therapies/services (select ALL that apply)?

	Home	School-in the classroom	School-out of the classroom	Clinical setting (therapy room, hospital)	Community activity (playground, pool)	Other	Does not receive
Art therapy							
Aqua therapy							
Behavior management							
Hippotherapy							
Music therapy							
Nursing							
Occupational therapy							
Oral motor (feeding)							
Pet therapy							
Physical therapy							
Sensory integration therapy							
Service coordination							
Social work							
Special instruction							
Speech-language therapy							
Vision and mobility							
Other							

7. How are the following therapies/services provided?

	Group setting (more than 2 children)	With one other child	One-on-one	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

8. Do your child's providers meet together and discuss your child's goals?
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

9. If yes, how often are you invited?
   - ☐ Never
   - ☐ Sometimes
   - ☐ All the time

10. Which of your child's providers meet together?

11. How are you (the parent[s]) included in each of the following therapy/service sessions?

	When my child receives services, I am not involved	I receive quarterly updates from the provider	I receive regular updates that include what is being worked on and any problems	I receive regular updates and consultation including things I can do at home	I participate in therapy sessions by observing and/or interacting with my child	Does not receive
Art therapy						
Aqua therapy						
Behavior management						
Hippotherapy						
Music therapy						
Nursing						
Occupational therapy						
Oral motor (feeding)						
Pet therapy						
Physical therapy						
Sensory integration therapy						
Service coordination						
Social work						
Special instruction						
Speech-language therapy						
Vision and mobility						
Other						

12. Who provides the following therapies/services?

	School	Private	Other	Does not receive
Art therapy				
Aqua therapy				
Behavior management				
Hippotherapy				
Music therapy				
Nursing				
Occupational therapy				
Oral motor (feeding)				
Pet therapy				
Physical therapy				
Sensory integration therapy				
Service coordination				
Social work				
Special instruction				
Speech-language therapy				
Vision and mobility				
Other				

13. How often do you receive updates on your child’s progress from his/her service providers?
    - ☐ Quarterly
    - ☐ Once a month
    - ☐ Once a week
    - ☐ After each session
    - ☐ Other (please specify: ____)

14. How do you typically communicate with your child’s service providers?
    - ☐ In person
    - ☐ Phone
    - ☐ E-mail
    - ☐ Communication notebook
    - ☐ Other (please specify: ___________________________________)

15. What type of educational settings does your child attend?
    - ☐ Public school
    - ☐ Private school
    - ☐ Other (please specify:____)

16. How much of your child’s day is spent in a regular classroom?
    - ☐ All of it
    - ☐ Most of it
    - ☐ Half of it
    - ☐ A little bit of it
    - ☐ None of it

The Individualized Education Program (IEP) is a document used by the family and school personnel to support the educational needs of children aged three through twenty-one and includes a description of the child’s current performance, annual goals, educational and related services, participation with non-disabled peers, etc.

17. Does your child have an IEP?
    - ☐ Yes
    - ☐ No
    - ☐ I don’t know

18. If your child has an IEP, please describe the skills that are currently being worked on with your child (goals on the IEP).

The Individuals with Disabilities Education Act (IDEA) is the law that ensures services are provided to children with disabilities throughout the nation, including early intervention, special education and related services.

19. If your child is receiving IDEA services, has a label for eligibility been given?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

20. What is your child's educational disability (select ALL that apply)?
    - ☐ Autism
    - ☐ Deaf-blindness
    - ☐ Developmental delay
    - ☐ Hearing impairment (including deafness)
    - ☐ Emotional disturbance
    - ☐ Intellectual disability (mental retardation)
    - ☐ Multiple disabilities
    - ☐ Orthopedic impairment
    - ☐ Other health impairment
    - ☐ Specific learning disability
    - ☐ Speech-language impairment
    - ☐ Traumatic brain injury
    - ☐ Visual impairment (including blindness)

☐ I don’t know
☐ Other (please specify: _______________________________________)

21. What adaptations are being used to meet your child’s needs (select ALL that apply)?
   ☐ Adaptive PE
   ☐ Sign language
   ☐ Picture communication system
   ☐ Computer-assisted communication
   ☐ Auditory amplification
   ☐ Behavior intervention plan
   ☐ Communication book between home and school
   ☐ Modified curriculum
   ☐ Individual programming
   ☐ Classroom aide specifically for your child
   ☐ Computer educational programs
   ☐ Special equipment for sitting, standing, or walking
   ☐ Other special equipment such as adapted feeding utensils
   ☐ Resource room
   ☐ Visual adaptations (special print material, large print, Braille)
   ☐ Use of tape recorder
   ☐ Other (please specify: ____)

22. Does your child participate in your state assessment? (No Child Left Behind yearly assessment)?

   ☐ Yes
   ☐ No
   ☐ I don’t know

23. What modifications or accommodations does your child use in order to participate in state assessment (select ALL that apply)?
   ☐ No modifications or accommodations
   ☐ Child does not participate in state assessment
   ☐ Use of an alternative assessment
   ☐ Modified presentation of assessment (ex. Braille, large print, read aloud)
   ☐ Use of additional materials (ex. calculator, manipulatives, amplification)
   ☐ Alternative response methods (ex. pointing, use of a scribe)
   ☐ Alternative setting (ex. separate room, at home)
   ☐ Extended time to complete assessment
   ☐ Use of other timing/scheduling practices (ex. frequent breaks)
   ☐ Use of a personal assistant
   ☐ Other (please specify: _____________________________________)

24. Please select the rating that best fits for each item.

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning			
I am involved in deciding what my child's goals should be			
My child's goals are objective and measurable			
My child is making progress towards his/her goals			
I am satisfied with the amount of progress my child is making			
My child's behavioral challenges are being addressed (if applicable)			
My child participates in groups/activities outside the home			
My child participates in groups/activities that include both peers with and without disabilities			
There is/was a transition plan in place for transitioning to adult life after school			
My child is/was adequately prepared for the transition			
I am satisfied with the transition process			
Higher education and/or technical schools were discussed as options for my child during the transition process			
My child's classroom promotes social skills			
My child's school provides activities outside of school time to help develop social relationships			
My child has a way to communicate both at home and at school			
My child's therapies involve social interactions with peers			
The skills my child is learning in therapy are functional for home, community, and school			
The skills my child is learning in therapy promote independence			
My child has a 1-on-1 paraprofessional at school			

A case manager or a case coordinator is a person who assists in coordinating care to make sure that your child gets the services that he/she needs.

25. During the past 12 months, was there any time when your child needed care coordination among different health care providers and services that your child uses?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know

26. If yes, did you or your family receive all the professional care coordination that was needed?
    - ☐ Yes
    - ☐ No
    - ☐ I don’t know

27. If you have a care coordinator, what is their title/position?

28. How often does a person help you coordinate your child’s care among his/her different providers and services?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always
    - ☐ I don’t know

29. Overall, how satisfied are you with the help you have received in coordinating your child’s care?
    - ☐ Very satisfied
    - ☐ Somewhat satisfied
    - ☐ Somewhat dissatisfied
    - ☐ Very dissatisfied
    - ☐ I don’t know

30. How well do you think your child’s doctors and other health care providers communicate with each other about your child’s care? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good
    - ☐ Good
    - ☐ Fair
    - ☐ Poor
    - ☐ Communication is not needed
    - ☐ I don’t know

31. How well do you think your child’s doctors and other health care providers communicate with your child’s school, early intervention program, child care providers, or vocational rehabilitation program? Would you say their communication is...
    - ☐ Excellent
    - ☐ Very good

☐ Good
☐ Fair
☐ Poor
☐ Communication is not needed
☐ I don't know

By "friends" we mean your child's peers who like each other and hang out together.

32. How many friends did your child invite to his/her last birthday party?

Total number of friends ☐

Number of friends with disabilities ☐

Number of friends without disabilities ☐

33. How many friends attended your child's last birthday party?

Total number of friends attended ☐

Number of friends with disabilities ☐

Number of friends without disabilities ☐

34. How many birthday parties was your child invited to last year?

☐

35. How many birthday parties did your child attend last year?

☐

36. How many social gatherings/activities, not affiliated with school or disability organizations, does your child attend each month (i.e. going to the movies, having dinner with friends)?

☐

Complete the following questions if your child is no longer in school.

37. Does your adult child work in the community?
    - ☐ Yes
    - ☐ No

38. The type of job my son/daughter has is:
    - ☐ Volunteer – not paid
    - ☐ Full time – paid
    - ☐ Part time – paid
    - ☐ Other (please specify:________________________________)

39. Please describe the kind of work your son/daughter does (Ex: cleaning, clerical, assembly, etc.)

40. The level of support my son/daughter receives in this job is:
    - ☐ 1-on-1 support
    - ☐ Small group (under 5) with a supervisor
    - ☐ Large group (6+) with a supervisor
    - ☐ Other (please specify: ____)

41. My son/daughter lives:
    - ☐ At home with us (parents)
    - ☐ With a sibling
    - ☐ In a group home
    - ☐ In another facility
    - ☐ Independently
    - ☐ In his/her own home, with support

42. Please select the rating that best fits for each item.

	Not at all	Somewhat	As expected
My child participates in groups/activities in the community			
My child has opportunities to participate in activities/groups with his/her peers with and without disabilities			
There was a transition plan in place for transitioning to adult life after school			

Higher education and/or technical schools were discussed as options for my child during the transition process			
I was satisfied with the transition process			

Final Section

1. Would you be willing to share a copy of your child’s IFSP or IEP with our research staff? All identifiers will be removed (all names, addresses, dates). It will be kept completely confidential and there will be no link between your identity as a parent or your child and the IFSP/IEP document.

   ☐ Yes
   ☐ No
   ☐ My child does not have an IFSP or IEP

   If you would be willing to share a copy of your child’s most recent IFSP/IEP, please make a copy and enclose it with your survey in the pre-paid postage envelope provided.

2. Is there anything else you would like to tell us about your child’s development, learning, health care, or school support?

3. What is your current marital status?
    - ☐ Married
    - ☐ Never married
    - ☐ Co-parenting relationship
    - ☐ Divorced/separated
    - ☐ Widowed/spouse passed away

4. Are you currently employed?
    - ☐ Yes - full-time
    - ☐ Yes - part-time
    - ☐ No

5. Is your spouse/partner currently employed?
    - ☐ Yes - full-time
    - ☐ Yes - part-time
    - ☐ No
    - ☐ NA

6. What is your highest educational attainment?
    - ☐ Less than high school
    - ☐ High school
    - ☐ Some college
    - ☐ 2 year degree
    - ☐ 4 year degree
    - ☐ Master's degree
    - ☐ Doctorate/Ph.D./M.D./J.D./Ed.D

7. In 2008, what was your approximate combined gross household income in U.S. dollars?

    - ☐ Less than $19,999
    - ☐ $20,000-$29,999
    - ☐ $30,000-$39,999
    - ☐ $40,000-$49,999
    - ☐ $50,000-$59,999
    - ☐ $60,000-$69,999
    - ☐ $70,000-$79,999
    - ☐ $80,000-$89,999
    - ☐ $90,000-$99,999
    - ☐ $100,000-$109,999
    - ☐ $110,000-$119,999
    - ☐ $120,000-$129,999
    - ☐ $130,000-$139,999
    - ☐ $140,000-$149,999
    - ☐ More than $150,000

8. What state/territory do you currently live in?

☐ Alabama
☐ Alaska
☐ Arizona
☐ Arkansas
☐ California
☐ Colorado
☐ Connecticut
☐ Delaware
☐ District of Columbia
☐ Florida
☐ Georgia
☐ Guam
☐ Hawaii
☐ Idaho
☐ Illinois
☐ Indiana
☐ Iowa
☐ Kansas
☐ Kentucky
☐ Louisiana
☐ Maine
☐ Maryland
☐ Massachusetts
☐ Michigan
☐ Minnesota
☐ Mississippi
☐ Missouri
☐ Montana
☐ Nebraska
☐ Nevada
☐ New Hampshire
☐ New Jersey
☐ New Mexico
☐ New York
☐ North Carolina
☐ North Dakota
☐ Ohio
☐ Oklahoma
☐ Oregon
☐ Pennsylvania
☐ Puerto Rico
☐ Rhode Island
☐ South Carolina
☐ South Dakota
☐ Tennessee
☐ Texas
☐ Utah
☐ Vermont
☐ Virgin Islands
☐ Virginia
☐ Washington
☐ West Virginia
☐ Wisconsin
☐ Wyoming
☐ Other (please specify): ___________________

Contact Information

1. If you would like to participate in any of our follow up surveys or receive a copy of our results from this study please provide your contact information. We will also post our results on our web site: http://www.uconnucedd.org/index.htm

   Your contact information will not be connected to any of the information you have provided; it will be kept separate from your responses and will be kept confidential.

Name	
Address	
City, State	
Zip	
Email	
Phone	

2. Would you like to be contacted for other studies?
   ☐ Yes
   ☐ No

3. Would you like to receive the results of this study?
   ☐ Yes
   ☐ No

Thank you for completing this survey. Please return the survey (along with a copy of your child's IFSP or IEP if you agree to share it with our research staff) in the enclosed pre-paid postage envelope.

Appendix C

Table 1. Demographic and background information for all participants (N = 125)

	%		%
Relation to child		Employment status	
Mother	90.4	*Full-time*	41.2
Father	5.6	*Part-time*	23.5
Family member	1.6	*Not employed*	35.3
Other	2.4	Partner’s employment status	
Sex of child		*Full-time*	65.5
Male	44.0	*Part-time*	5.9
Female	56.0	*Not employed*	15.1
Child’s general health		*NA*	13.4
Excellent	11.2	Highest education	
Very good	44.0	*Less than high school*	1.7
Good	34.4	*High school*	5.0
Fair	8.8	*Some college*	29.8
Poor	1.6	*2 year degree*	14.0
Child’s functioning		*4 year degree*	29.8
Is independent	12.8	*Master’s degree*	14.9
Needs some assistance	58.4	*Doctorate/Ph.D./M.D.*	5.0
Needs total assistance	28.8	Household income	
Child’s race/ethnicity		*< $50,000*	39.3
White	84.8	*$50,000 - $100,000*	35.6
Latino/Hispanic	10.4	*> $100,000*	25.1
African-American	4.8	Region of U.S.	
Asian	4.0	*Northeast*	25.8
Age of child		*Southeast*	15.8
0-2 years	14.4	*Midwest*	31.4
3-5 years	20.0	*Southwest*	8.3
6-13 years	33.6	*West*	18.2
14-21 years	32.0		
Marital status			
Married	75.2		
Never married	7.4		
Co-parenting	3.3		
Divorced/separated	13.2		
Widowed	.8		

Table 2. Number of responses for each item by therapy/service (birth-2)

	OT (N = 14)	PT (N = 13)	SLT (N = 10)	OM (N = 7)	SC/SW (N = 5)	SI (N = 3)	Nursing (N = 2)
Session length							
More than 60 minutes	--	--	--	--	--	1	2
31-60 minutes	11	9	6	5	1	2	--
30 minutes or less	3	3	3	2	2	--	--
Frequency of sessions							
Every day	1	1	--	1	--	--	2
2 or 3 times a week	3	4	3	3	--	--	--
Once a week	3	5	--	3	--	--	--
2 or 3 times a month	6	3	3	6	--	--	--
Once a month	1	--	--	1	2	1	--
Every 2 to 3 months	--	1	1	--	2	2	--
Location							
Home	12	11	7	5	4	1	2
School	2	2	1	--	--	1	--
Clinical setting	--	--	1	1	--	--	--
Setting							
One-on-one	12	11	8	7	3	1	2
With one other child	2	2	1	--	--	1	--
Group setting	--	--	--	--	--	1	--
Parent Role							
Provider helps me learn how to do the interventions	1	2	--	3	2	--	--
Provider shows me how to do interventions	4	4	3	1	1	1	1
Provider explains interventions to me	5	5	3	3	--	1	1
I watch the provider work with my child	3	1	2	--	--	--	--
I am not present	1	1	1	--	--	1	--
Service provider							
Early intervention	12	11	8	5	2	3	--
Private	1	1	1	1	--	--	--
Other	--	--	--	--	1	--	1

Table 3. Percentage of responses selected for each item (birth-2).

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning	--	29	71
I am involved in deciding what my child’s goals should be	--	11	89
My child’s goals are objective and measurable	--	6	94

My child is making progress towards his/her goals	6	22	72
I am satisfied with the amount of progress my child is making	6	50	44
My child's behavioral challenges are being addressed (if applicable)	36	18	46
My child participates in groups/activities outside the home	53	24	24
My child participates in activities that include both children with special needs and typically developing children	53	12	35
There is a transition plan in place for when my child turns 3	50	17	33
I am satisfied with the transition process (if applicable)	25	38	38

Table 4. Percentage of responses for communication of health care providers (birth-2).

	Excellent	Very good	Good	Fair	Poor	Not needed	I don't know
Among various health care providers	6	18	24	18	24	6	6
Between health care providers and child's educational or therapeutic providers	--	22	11	11	22	22	11

Table 5. Percentage of responses for invites and attendance at birthday parties (birth-2).

	Zero	1-4	5-10	More than 10
Total friends invited to child's party	36	14	21	29
Friends with disabilities	71	14	7	7
Friends without disabilities	36	14	29	21
Total friends attended child's party	36	14	29	21
Friends with disabilities	77	8	8	8
Friends without disabilities	54	8	23	15
Birthday parties child was invited to	33	17	28	--
Birthday parties child attended	39	22	17	--

Table 6. Number of responses for each item by therapy/service (3-5)

	SLT N = 24	OT N = 21	PT N = 18	OM N = 8	SI N = 6	SIT N = 4	BM N = 3	SC/SW N = 3	VM N = 3	Nursing N = 2	HT N = 1	Art N = 1
Session length												
More than 60 minutes	2	1	2	1	4	1	--	1	2	3	--	--
31-60 minutes	10	8	7	4	--	2	2	2	2	--	1	--
30 minutes or less	12	13	8	2	1	1	1	1	--	--	--	1
Frequency of sessions												
Every day	--	--	--	2	5	1	--	--	--	1	--	--
2 or 3 times a week	14	9	7	3	2	1	1	1	1	--	--	1
Once a week	7	12	6	3	--	2	--	2	2	--	1	--
2 or 3 times a month	--	1	4	--	--	--	--	--	--	2	--	--
Once a month	2	--	--	--	--	--	2	1	1	--	--	--
Every 2 to 3 months	--	--	--	--	--	--	--	--	--	--	--	--
Location												
Home	4	5	4	2	2	1	1	1	1	3	--	1
Public preschool	12	12	10	2	4	2	1	2	1	--	--	1
Other preschool	6	5	3	3	2	2	--	--	1	--	--	--
Child care	1	1	1	1	--	--	1	2	--	--	--	1
Clinical setting	7	7	6	5	--	2	2	--	1	--	--	--
Setting												
One-on-one	24	21	16	6	1	4	2	4	4	3	1	--
With one other child	--	--	--	--	--	--	--	--	--	--	--	--
Group setting	--	1	1	1	6	--	1	1	--	--	--	1
Parent Role												
Provider helps me learn how to do the interventions	1	--	--	--	1	--	1	1	--	--	--	--
Provider shows me how to do interventions	1	1	4	3	--	--	1	--	--	--	--	--
Provider explains interventions to me	4	4	3	1	1	--	1	--	--	--	--	--
I watch the provider work	4	2	1	1	--	--	--	2	2	--	1	--

with my child												
I am not present	13	15	8	2	5	4	--	1	3	1	--	--
Service provider												
School	16	18	14	5	6	3	1	3	2	--	--	1
Private	6	3	3	2	--	1	--	1	1	3	1	--
Other	1	1	1	--	1	--	2	--	1	--	--	--

Table 7. Percentage of responses selected for each item (3-5)

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning	8	33	58
I am involved in deciding what my child’s goals should be	--	24	76
My child’s goals are objective and measurable	8	24	68
My child is making progress towards his/her goals	4	44	52
I am satisfied with the amount of progress my child is making	4	48	48
Skills that are being taught in the classroom are also being taught at home	--	44	56
My child’s behavioral challenges are being addressed (if applicable)	15	25	60
My child participates in groups/activities outside the home	24	32	44
My child participates in groups/activities that include both children with special needs and typically developing children	17	42	42
There was a transition plan in place for when my child moved from early intervention (birth to three) to public education	14	26	57
My child was adequately prepared for the transition	17	39	44

I was satisfied with the transition process	17	35	48
My child's classroom promotes social skills	5	24	71
My child's school/center provides activities outside of school time to help develop social relationships	24	48	29
My child has a way to communicate both at home and at school	8	46	46
My child's therapies involve social interactions with peers	25	42	33
The skills my child is learning in therapy promote independence	8	32	60
My child has a 1-on-1 paraprofessional at school	41	32	27

Table 8. Percentage of responses for communication of health care providers (3-5).

	Excellent	Very good	Good	Fair	Poor	Not needed	I don't know
Among various health care providers	12	16	20	24	20	8	--
Between health care providers and child's educational or therapeutic providers	8	12	4	12	40	20	4

Table 9. Percentage of responses for invites and attendance at birthday parties (3-5).

	Zero	1-4	5-10	More than 10
Total friends invited to child's party	27	24	29	19
Friends with disabilities	72	22	6	--
Friends without disabilities	30	20	35	15
Total friends attended child's party	29	29	29	14

Friends with disabilities	78	22	--	--
Friends without disabilities	30	30	30	10
Birthday parties child was invited to	32	36	24	--
Birthday parties child attended	36	44	12	--

Table 10. Number of responses for each item by therapy/service (6-13)

	SLT N = 36	OT N = 31	PT N = 20	SI N = 13	BM N = 8	SC/SW N = 7	OM N = 5	SIT N = 5	Nursing N = 4	VM N = 2	HT N = 2	Art N = 1	Pet N = 1
Session length													
More than 60 minutes	--	--	--	13	3	1	1	--	3	--	--	--	--
31-60 minutes	22	13	11	1	3	2	1	1	--	1	1	--	--
30 minutes or less	15	19	11	1	2	3	3	4	1	2	1	1	1
Frequency of sessions													
Every day	4	2	1	14	4	--	2	1	3	--	--	--	1
2 or 3 times a week	24	16	13	3	2	4	3	1	--	--	--	1	--
Once a week	9	9	6	--	--	--	--	2	--	--	2	--	--
2 or 3 times a month	--	3	1	--	--	--	--	1	--	1	--	--	--
Once a month	--	--	--	--	1	1	--	--	1	--	--	--	--
Every 2 to 3 months	--	--	1	--	1	--	--	--	--	--	--	--	--
Location													
Home	5	3	1	4	5	2	2	1	4	1	--	1	1
School – in classroom	20	17	9	16	6	3	3	1	1	--	--	--	--
School – out of classroom	18	17	11	4	3	--	2	1	--	--	--	--	--
Clinical setting	8	7	6	--	1	--	1	3	--	--	--	--	--
Community	--	--	2	--	1	--	--	--	--	--	1	--	--
Setting													
One-on-one	27	25	18	5	8	2	4	4	4	1	3	1	1
With one other child	1	1	--	1	--	--	--	--	--	--	--	--	--
Group setting	9	5	4	12	--	3	--	1	--	--	--	--	--
Parent Role													
I participate by observing or	6	4	6	1	3	1	1	1	3	1	2	--	1

interacting													
I receive updates and consultation	14	8	3	7	1	--	2	1	1	1	--	1	--
I receive regular updates	6	8	4	1	1	--	1	--	--	--	--	--	--
I receive quarterly updates	8	12	9	7	2	3	--	2	--	--	--	--	--
I am not involved	1	1	--	2	1	--	--	--	--	--	--	--	--
Service provider													
School	27	26	16	17	3	3	2	2	--	3	--	--	--
Private	8	7	5	1	4	--	2	2	2	--	2	--	--
Other	1	--	1	--	1	2	1	--	2	--	--	--	1

Table 11. Percentage of responses selected for each item (6-13)

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning	13	41	46
I am involved in deciding what my child’s goals should be	8	18	74
My child’s goals are objective and measurable	--	40	61
My child is making progress towards his/her goals	3	31	67
I am satisfied with the amount of progress my child is making	11	34	55
My child’s behavioral challenges are being addressed (if applicable)	3	33	64
My child participates in groups/activities outside the home	18	28	54
My child participates in groups/activities that include both children with special needs and typically developing children	15	33	51
There is/was a transition plan in place for moving from elementary to Jr. High/Middle/High school	53	24	24

My child is/was adequately prepared for the transition	57	30	13
I am satisfied with the transition process	52	29	19
My child’s classroom promotes social skills	11	27	62
My child’s school provides activities outside of school time to help develop social relationships	43	29	29
My child has a way to communicate both at home and at school	11	29	61
My child’s therapies involve social interactions with peers	17	36	47
The skills my child is learning in therapy are functional for home, community, and school	6	22	72
The skills my child is learning in therapy promote independence	--	22	78
My child has a 1-on-1 paraprofessional at school	49	19	32

Table 12. Percentage of responses for communication of health care providers (6-13).

	Excellent	Very good	Good	Fair	Poor	Not needed	I don’t know
Among various health care providers	13	21	18	15	18	8	8
Between health care providers and child’s educational or therapeutic providers	5	13	13	18	16	24	11

Table 13. Percentage of responses for invites and attendance at birthday parties (6-13).

	Zero	1-4	5-10	More than 10
Total friends invited to child’s party	32	30	30	8
Friends with disabilities	52	41	7	--
Friends without disabilities	19	52	22	7
Total friends attended child’s party	32	30	30	8
Friends with disabilities	48	44	7	--
Friends without disabilities	19	50	23	8
Birthday parties child was invited to	26	62	13	--
Birthday parties child attended	28	61	10	--

Table 14. Number of responses for each item by therapy/service (14-21).

	SLT N = 21	SI N = 15	OT N = 11	PT N = 9	BM N = 8	SC/SW N = 8	Nursing N = 7	Art N = 3	Aqua N = 2	VM N = 2	OM N = 2	HT N = 1	Pet N = 1	SIT N = 1
Session length														
More than 60 minutes	1	11	1	--	2	2	4	--	--	1	--	--	1	--
31-60 minutes	10	2	4	4	1	3	--	2	--	--	1	--	--	2
30 minutes or less	10	1	8	6	3	5	2	--	2	1	1	1	--	--
Frequency of sessions														
Every day	2	14	1	--	4	1	4	--	--	--	--	--	1	--
2 or 3 times a week	7	1	4	4	2	4	1	1	--	1	--	--	--	1
Once a week	8	--	6	3	1	1	--	--	1	--	1	1	1	1
2 or 3 times a month	4	--	2	1	--	2	--	--	--	--	--	--	--	--
Once a month	--	--	1	1	--	1	--	--	--	1	--	--	--	--
Every 2 to 3 months	--	--	--	--	--	3	--	--	--	--	--	--	--	--
Location														
Home	--	2	1	--	4	3	3	--	--	--	1	--	1	--

School – in classroom	10	15	8	4	5	4	1	1	--	2	--	--	--	1
School – out of classroom	12	3	3	3	2	3	2	--	1	1	--	--	--	1
Clinical setting	2	--	2	2	1	--	1	--	--	--	--	--	--	1
Community	--	1	--	--	2	1	1	--	2	--	--	--	--	--
Setting														
One-on-one	10	4	6	6	6	6	6	--	1	1	2	--	1	1
With one other child	3	--	1	--	--	--	--	--	--	--	--	1	--	1
Group setting	8	11	5	2	1	4	--	2	2	1	1	--	--	1
Parent Role														
I participate by observing or interacting	2	2	--	1	1	2	4	--	1	--	1	--	1	--
I receive updates and consultation	4	5	3	1	4	4	1	1	--	--	--	--	--	--
I receive regular updates	3	5	4	2	2	3	2	1	1	1	1	1	--	2
I receive quarterly updates	4	4	3	4	--	--	--	--	--	2	--	--	--	--
I am not involved	6	1	3	2	--	--	--	--	--	--	--	--	--	1
Service provider														
School	20	11	11	9	3	4	2	2	2	2	1	--	--	2
Private	1	4	3	1	3	2	1	--	--	--	--	1	1	1
Other	--	--	--	--	1	6	3	--	--	--	1	--	--	--

Table 15. Percentage of responses selected for each item (14-21).

	Not at all	Somewhat	As expected
Assessments of my child accurately reflect his/her level of functioning	6	41	53
I am involved in deciding what my child’s goals should be	--	28	72
My child’s goals are objective and measurable	--	40	60
My child is making progress towards his/her goals	6	46	49
I am satisfied with the amount of progress my child is making	9	50	41
My child’s behavioral challenges are being addressed (if applicable)	4	39	58
My child participates in groups/activities outside the home	18	36	46
My child participates in groups/activities that include both peers with and without disabilities	30	24	46
There is/was a transition plan in place for transitioning to adult life after school	28	47	25
My child is/was adequately prepared for the transition	38	45	17
I am satisfied with the transition process	31	38	31
Higher education and/or technical schools were discussed as options for my child during the transition process	47	30	23
My child’s classroom promotes social skills	9	28	63
My child’s school provides activities outside of school time to help develop social relationships	31	31	38
My child has a way to communicate both at home and at school	6	30	64

My child's therapies involve social interactions with peers	23	32	45
The skills my child is learning in therapy are functional for home, community, and school	6	34	59
The skills my child is learning in therapy promote independence	9	41	50
My child has a 1-on-1 paraprofessional at school	55	7	38

Table 16. Percentage of responses for communication of health care providers (14-21).

	Excellent	Very good	Good	Fair	Poor	Not needed	I don't know
Among various health care providers	6	21	27	18	18	9	--
Between health care providers and child's educational or therapeutic providers	3	13	13	9	31	22	9

Table 17. Percentage of responses for invites and attendance at birthday parties (14-21).

	Zero	1-4	5-10	More than 10
Total friends invited to child's party	41	19	22	19
Friends with disabilities	46	33	13	8
Friends without disabilities	40	28	16	16
Total friends attended child's party	39	19	23	19
Friends with disabilities	50	29	13	8
Friends without disabilities	40	32	8	20
Birthday parties child was invited to	39	33	8	--
Birthday parties child attended	38	35	5	--
Social gatherings attended	43	20	13	5

Table 18. Percentage of responses selected for each item (14-21 not in school)

	Not at all	Somewhat	As expected
My child participates in groups/activities in the community	71	14	14
My child has opportunities to participate in activities/groups with his/her peers with and without disabilities	43	57	--
There was a transition plan in place for transitioning to adult life after high school	57	14	29
Higher education and/or technical schools were discussed as options for my child during the transition process	86	14	--
I was satisfied with the transition process	17	33	50