

National  
Organization of  
Mothers  
Of  
Twins  
Clubs, Inc.

**SUBJECT: Intervention and Services of Multiple Birth Children with Special Needs**

**RESEARCHER:** National Organization of Mothers of Twins Clubs, Inc.

**DATE:** December 2007 – September 2008

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**PURPOSE:** The purpose of this survey was to gather data regarding issues specific to multiple birth children with special needs.

**METHOD:** A survey consisting of 43 questions was made available online via Survey Monkey. The survey was to be completed by parents of multiple birth children with special needs.

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### BACKGROUND INFORMATION

1. Seventy-two surveys consisting of 43 questions were tabulated with 87.5 % (63) of the responses from twin parents and 9.7 % (7) of the responses from triplet parents. Slightly less than 3 % (2) respondents reported having more than one set of multiples.
2. Twenty point eight percent (15) of respondents reported having monozygotic (identical) multiples, while 79.2 % (57) reported having dizygotic (fraternal) multiples. One respondent each reported having no knowledge of the zygosity type, one set of monozygotic and a dizygotic and one set of trizygotic multiples.
3. Most of the respondents 67.6 % (48) reported their multiples were born early. The remaining respondents 32.4% (23) reported their multiples were not born early.
4. The gestational age of multiples at their birth was reported as 5.6 % (4) for 23 to 25 weeks, 8.3 % (6) for 26 to 28 weeks, 12.5 % (9) for 29 to 31 weeks, 23.6 % (17) for 32 to 34 weeks and 25 % each (18) for both 35 to 37 weeks and greater than 38 weeks.
5. The current grade in school for multiples was reported as the following: 55.6 % of the sample (40) reported that their multiples were in preschool, 9.7 % (7) reported their children were in Kindergarten, 20.8 % (15) reported Grades 1-3, 4.2 % (3) reported Grades 4-5, 2.8 % (2) reported Grades 6-8, and 6.9 % (5) reported Grades 9-12.
6. The age at which many respondents reported their children were diagnosed with special needs was between 0-3 months (16.7 %; 12). Eight point three percent (6) reported their children were aged 4-6 months at diagnosis, 15.3 % (11) reported their children were aged 7-12 months, 13.9 % (10) reported their children were aged 13-18 months and 15.3 % (11) reported their children were aged 19-24 months. Finally, 9.7 % (7) respondents reported their children were aged 25-35 months, 13.9 % (10) reported their children were 3 to 4 years old, 11.1 % (8) reported their children were 5 to 6 years old and 6.9 % (5) reported their children were 7 years or older.

RESULTS

1.

<b>Response</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Developmental delays	37	30	2	48
Physical disabilities	18	12	1	24
Learning disabilities	18	17	0	30
Communicative delays	28	28	3	44
No diagnosis	14	13	3	26

Respondents were asked about the types of special needs that their multiples experienced. Unless otherwise noted, responses were reported as raw counts, with the “Total Count” reflecting the total number in that category. Developmental delays were the highest reported special need for all multiple types, with 69.6 % of respondents reporting that one of their multiples had experienced this delay. This was closely followed by communicative delays, of which 63.8 % of the sample reported their multiples had experienced. The lowest reported special need overall was physical disability, reported by 34.8 % of the sample.

For Multiple A, the highest reported special need was developmental delays (37), with the lowest reported as physical or learning disabilities (18 each). For Multiple B, the highest reported special need was also developmental delays (30), with the lowest reported as physical disabilities (12). For Multiple C, the highest reported category was no diagnosis of special needs and communicative delays (3 responses each), with the least reported category as learning disabilities (no respondents).

Multiple A reported higher numbers in all categories except for communicative delays, where both Multiples A and B were reported at the same rate (28). Seventeen respondents reported that their multiples had other special needs such as speech delays, ADHD, hydrocephalus, cerebral palsy, deafness, seizure disorder, autism spectrum disorder, sensory integration disorder, Asperger’s syndrome, benign congenital hypotonia and mental illness. Three respondents skipped this question.

2. Most respondents 82.1 % (55) reported that their children did receive Early Intervention Services (0-3 years). Ten point four % (7) reported that their children did not receive Early Intervention, while one respondent (1.5 %) reported that services were not available, two respondents each (3.0 %) reported they were unaware of services or that a diagnosis had not been made yet. Five respondents skipped this question.
3. Most respondents 73.8 % (48) reported that their children did receive intervention services in preschool (3-5 years). Fifteen point four percent (10) reported that their children did not receive intervention, while one respondent each, 1.5 %, reported that services were not available, they were unaware of services or that they chose not to participate in services. Finally, 6.2 % (4) reported that a diagnosis had not been made yet. Seven respondents skipped this question.
4. For those children receiving intervention services, a majority of respondents 75.0 % (39) reported that they received these services through the school district. Nine point six percent of respondents (5) reported receiving services through a state agency, 5.8 % each (3) reported receiving services from a local agency or private health care provider, while 3.8 % (2) reported receiving services from a private school. Twenty respondents skipped this question.

5.

<b>Response</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Public preschool	29	26	1	35
Private preschool	29	27	6	36
Public K-2	25	24	2	26
Private K-2	3	5	0	5
Public 3-5	16	15	2	16
Private 3-5	1	2	0	2
Public 6-8	5	4	0	5
Private 6-8	1	2	0	2
Public 9-12	4	3	0	4
Private 9-12	1	2	0	2

Respondents were asked whether their multiples attended public school or private school. Overall, the majority of respondents sent their children to public school for Grades K-12, with the exception of preschool in which more parents overall sent their children to private school. Eleven respondents skipped this question.

6.

<b>Placement: Preschool</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Mainstreamed without aide	33	27	5	35
Mainstreamed with aide	2	4	0	5
Mainstreamed with typical peer/student support	9	10	0	10
Some classes mainstreamed, some not	1	2	0	3
All classes were special needs classes	12	11	1	17

Respondents were asked how their children were placed in preschool. Most respondents 63.6 % (35) reported that their children had been mainstreamed without any aide. Seventeen respondents (30.9 %) reported that their children attended all special needs classes, while 10 respondents (18.2 %) reported that their children were mainstreamed with typical peer/student support. Finally, 5 respondents (9.1 %) reported that their children were mainstreamed with aide, and three respondents (5.4 %) reported that their children attended some mainstreamed classes, and some that were not.

For Multiple A, the highest reported placement was mainstreamed without aide (33), with the lowest reported placement as some classes mainstreamed, some not (1). For Multiple B, the highest reported placement was also mainstreamed without aide (27), with the lowest reported placement as some classes mainstreamed, some not (2). Multiple C's demonstrated the same pattern, with mainstreamed without aide being the highest reported category (5) and no respondents reporting that their children were mainstreamed with aide, mainstreamed with typical peer/student support.

A higher number of Multiple A's reported being mainstreamed without aide or having all special needs classes, while a higher number of Multiple B's reported being mainstreamed with aide, being mainstreamed with typical peer/student support and some classes mainstreamed, some not. Seventeen respondents skipped this question.

7.

<b>Placement: Kindergarten</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Mainstreamed without aide	17	16	0	20
Mainstreamed with aide	6	5	1	9
Mainstreamed with typical peer/student support	4	3	0	4
Some classes mainstreamed, some not	1	3	0	4
All classes were special needs classes	1	3	0	4
Not applicable	27	25	5	30

Respondents were asked how their children were placed in Kindergarten. Most respondents 55.6 % (30) reported that this question was not applicable. For those whose children had received placement, a majority 58.8 % (20) reported that their children had been mainstreamed without aide, followed by 26.5 % (9) who reported their children were mainstreamed with aide. Four respondents each (11.8 %) reported that their children were mainstreamed with typical peer/students support, their children attended some mainstreamed classes and some not, or that their children attended all special needs classes.

For all three multiple types (A, B and C), Kindergarten placement was reported as being not applicable the most frequently. For Multiple A's who had some type of placement, the highest reported category was mainstreamed without aide (17) and the lowest reported placement was some classes mainstreamed, some not or all classes were special needs classes (1 each). For Multiple B's who reported some type of placement, the highest reported category was also mainstreamed without aide (27), with the lowest reported placement as mainstreamed with typical peer/student support, some classes mainstreamed, some not and all classes were special needs classes (3 each). One respondent reported their Multiple C was mainstreamed without aide, making it the highest reported placement type.

Multiple A's reported higher numbers for each category, with the exception of some classes mainstreamed, some not, and all classes were special needs classes, which were reported more often by Multiple B. Eighteen respondents skipped this question.

8.

<b>Placement: Grades 1-3</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Mainstreamed without aide	13	11	1	17
Mainstreamed with aide	3	6	0	8
Mainstreamed with typical peer/student support	5	3	0	5
Some classes mainstreamed, some not	3	3	0	5
All classes were special needs classes	0	3	0	3
Not applicable	27	28	4	31

Respondents were asked how their children were placed in Grades 1-3. Most respondents 60.8 % (31) reported that this question was not applicable. For those whose children had received placement, a majority 85.0 % ( 20) reported that their children had been mainstreamed without aide, followed by 40.0 % (8) who reported their children were mainstreamed with aide. Five respondents each (25.0 %) reported that their children were mainstreamed with typical peer/student support or their children attended some mainstreamed classes and some not. Three respondents (15.0 %) reported that their children attended all special needs classes.

For all three multiple types (A, B and C), Grades 1-3 placement was reported as being not applicable the most frequently. For Multiple A's who reported some placement type, the highest reported category was mainstreamed without aide (13) and the lowest reported placement was all classes were special needs classes (no respondents reported this). For Multiple B's who were placed, the highest reported placement was also mainstreamed without aide (11), with the lowest reported placement as mainstreamed with typical peer/student support, some classes mainstreamed, some not and all classes were special needs classes (3 each). One respondent reported their Multiple C was mainstreamed without aide, making it the highest reported placement type.

Multiple A's reported higher numbers for placement categories of mainstreamed without aide or mainstreamed with typical peer/student support, while Multiple B had the highest reported number of mainstreamed with aide and all classes were special needs classes. Multiples A and B reported the same frequency on the category some classes mainstreamed, some not. Twenty-one respondents skipped this question.

9.

<b>Placement: Grades 4-5</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Mainstreamed without aide	3	5	0	6
Mainstreamed with aide	0	0	0	0
Mainstreamed with typical peer/student support	2	0	0	2
Some classes mainstreamed, some not	2	3	0	3
All classes were special needs classes	2	1	0	4
Not applicable	41	41	6	44

Respondents were asked how their children were placed in Grades 4-5. Most respondents 88.0 % (44) reported that this question was not applicable. For those whose children had received placement, all 100.0 % (6) reported that their children had been mainstreamed without aide, followed by 66.7 % (4) who reported all their child’s classes were special needs classes. Three respondents (50.0 %) reported that some of their child’s classes were mainstreamed, and some were not, while 30.0 % (2) reported their children were mainstreamed with typical peer/student support. Zero respondents reported that their children were mainstreamed with aide.

For all three multiple types (A, B and C), Grades 4-5 placement was reported as being not applicable the most frequently. For Multiple A’s who reported some placement, the highest reported category was mainstreamed without aide (3) and the lowest reported placement was mainstreamed with aide (no respondents reported this). For Multiple B’s who were placed, the highest reported category was also mainstreamed without aide (5), with the lowest reported placement as mainstreamed with aide or mainstreamed with typical peer/student report (no respondents). For Multiple C, the highest reported placement type was mainstreamed without aide (5), with no other placement types reported.

Multiple A’s reported higher numbers for placement categories of mainstreamed with typical peer/student support and all classes were special needs classes, while Multiple B had the highest reported number of mainstreamed without aide and some classes special needs, some not. All three multiple types failed to report mainstreamed with aide as a placement type. Twenty-two respondents skipped this question.

10.

<b>Placement: Grades 6-8</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Mainstreamed without aide	1	1	0	2
Mainstreamed with aide	1	0	0	1
Mainstreamed with typical peer/student support	2	0	0	2
Some classes mainstreamed, some not	2	1	0	3
All classes were special needs classes	1	3	0	3
Not applicable	39	40	5	42

Respondents were asked how their children were placed in Grades 6-8. Most respondents 91.3 % (42) reported that this question was not applicable. For those whose children had received placement, 75.0 % each (3) reported that some of their children's classes were mainstreamed and some were not or all classes were special needs classes, 50.0 % each (2) reported that their children had been mainstreamed without aide or mainstreamed with typical peer/student support and 25.0 % (1) reported their children were mainstreamed with aide.

For all three multiple types (A, B and C), Grades 6-8 placement was reported as being not applicable the most frequently. For Multiple A's who reported placement, the highest reported category was mainstreamed with typical peer/student support or some classes mainstreamed, some not (2 each), with the remaining placement types reporting 1 each. For Multiple B's who were placed, the highest reported category was all classes were special needs classes (3), with the lowest reported placement as mainstreamed with aide or mainstreamed with typical peer/student support (no respondents reported this). For Multiple C, there were no placement types reported.

Multiple A's reported higher numbers for placement categories of mainstreamed with aide, mainstreamed with typical peer/student support and some classes mainstreamed, some not, while Multiple B had the highest reported number of all classes were special needs classes. Both multiple types A & B reported mainstreamed without aide with the same frequency (1 each). Twenty-six respondents skipped this question.

11.

<b>Placement: Grades 9-12</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Mainstreamed without aide	2	2	0	3
Mainstreamed with aide	1	0	0	1
Mainstreamed with typical peer/student support	1	0	0	1
Some classes mainstreamed, some not	0	1	0	1
All classes were special needs classes	1	2	0	2
Not applicable	42	41	5	43

Respondents were asked how their children were placed in Grades 9-12. Most respondents 91.5 %, (43) reported that this question was not applicable. For those whose children had received placement, 75.0 % (3) reported that their children were mainstreamed without aide, followed by 50.0 % (2) reporting all classes were special needs classes. Twenty-five % each (1) reported that their children had been mainstreamed with aide, mainstreamed with typical peer/student support, or some classes mainstreamed and some not.

For all three multiple types (A, B and C), Grades 9-12 placement was reported as being not applicable the most frequently. For Multiple A's who reported placement, the highest reported category was mainstreamed without aide (2), with zero respondents reporting their Multiple A attended some mainstreamed classes, some not. For Multiple B's who were placed, the highest reported categories were mainstreamed without aide or all classes were special needs classes (2 each), with the lowest reported placement as mainstreamed with aide or mainstreamed with typical peer/student support (no respondents). For Multiple C, there were no placement types reported.

Multiple A's reported higher numbers for placement categories of mainstreamed with aide and mainstreamed with typical peer/student support, while Multiple B reported higher numbers for some classes mainstreamed, some not and all classes were special needs classes. Both multiple types A & B reported mainstreamed without aide with the same frequency (2 each). Twenty-five respondents skipped this question.

12.

<b>Intervention Type</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
Occupational therapy	28	25	1	40
Physical therapy	16	15	2	24
Speech/language therapy	33	28	3	46
Vision therapy	5	6	1	11
Sensory motor therapy	6	12	0	17
Deaf/hard of hearing therapy	0	2	0	2
Learning delay therapy	6	9	0	12
Paraprofessional/aide	7	9	1	13
Classroom modifications	7	14	0	18
Classroom accommodations	13	17	0	25
Curriculum modifications	8	9	0	16
Curriculum accommodations	9	12	0	17
Assistive technology	4	8	1	10
Other	3	5	0	7
None	13	14	3	26

Respondents were asked about the types of intervention that their children received. Just over three-quarters of respondents reported that their children had received speech/language therapy (78.0 %), while 67.8 % received occupational therapy. Nearly half of all respondents (44.1 %) reported that their children received classroom accommodations (42.3 %) and physical therapy (40.7 %). Less than one-third of respondents reported that their children received classroom modifications (30.5 %), curriculum modifications or sensory motor therapy (28.8 %), curriculum accommodations (27.1 %), paraprofessional/aides (22.0 %) or learning delay therapy (20.3 %). Less than one-fifth of respondents reported that their children received vision therapy (18.6 %), assistive technology (16.9 %) or deaf/hard of hearing therapy (3.4 %).

For Multiple A, the most frequently reported intervention type was speech/language therapy (33), and the least reported intervention was deaf/hard of hearing therapy (none reported). Similarly, for Multiple B, the most frequently reported intervention was speech/language therapy (28), and the least frequently reported intervention was deaf/hard of hearing therapy (2). For Multiple C, the most frequently reported intervention was also speech/language therapy and no therapy (3 each), and the least frequently reported were sensory motor therapy, deaf/hard of hearing therapy, learning delay therapy, classroom modifications, classroom accommodations, curriculum modifications, curriculum accommodations or other (no respondents).

Multiple A reported higher numbers in the categories of occupational therapy, physical therapy and speech/language therapy. Multiple B reported higher numbers in the categories of vision therapy, sensory motor therapy, deaf/hard of hearing therapy, learning delay therapy, paraprofessional/aide, classroom modifications, classroom accommodations, curriculum modifications, curriculum accommodations, assistive technology, other and no interventions. Both multiple types had the same percentage of mainstreamed without aide. Thirteen respondents skipped this question.

13.

<b>Special Needs</b>	<b>Multiple A</b>	<b>Multiple B</b>	<b>Multiple C</b>	<b>Total Count</b>
ADD/ADHD	11	12	0	17
Developmental delay	29	23	2	37
Hearing impairment	0	2	0	2
Learning disabilities	11	9	0	16
Mental retardation	0	3	0	3
Physical disabilities	12	6	2	17
Sensory motor impairment	10	9	0	16
Speech/language disorders/delays	34	24	3	43
Visual impairment	4	4	1	8
Other	11	11	1	18

Respondents were asked about the types of special needs that their children had. More than half of respondents reported that their children had speech/language disorders/delays (69.4 %) and developmental delays (59.7 %). Slightly less than one-third of respondents reported their children had other special needs (29.0 %), ADD/ADHD (29.0 %), physical disabilities (29.0 %), and learning disabilities (25.8 %). Finally, 12.9 % of respondents reported their children had visual impairments, 4.8 % reported their children had mental retardation and 3.2 % reported their children had a hearing impairment.

For Multiple A, the most frequently reported special need was speech/language disorder/delays (34), and the least frequently reported was hearing impairment and mental retardation (no respondents). For Multiple B, the most frequently reported special need was also speech/language disorder/delays (24), and the least frequently reported was hearing impairment (2). For Multiple C, the most frequently reported special need was speech/language disorders/delays and the least frequently reported were ADD/ADHD, hearing impairment, learning disabilities, mental retardation and sensory motor impairment (no respondents).

Multiple A reported higher numbers in the categories of developmental delays, learning disabilities, physical disabilities, sensory motor impairment and speech/language disorders/delays. Multiple B reported higher numbers in the categories of ADD/ADHD, hearing impairment and mental retardation. Respondents reported Multiples A and B experienced visual impairments or other delays at the same frequency. Ten respondents skipped this question.

14. Respondents were asked if they received any type of training or information to assist them in dealing with their child’s special needs. Most respondents, 71.0 % (44) reported that they did, while 29.0 % (18) reported that they did not. Ten respondents skipped this question.
15. Respondents were asked where they received their information or training and were instructed to select all that applied. The most frequently reported category was school 58.1 % (25), closely followed by therapy 53.5 % (23). Respondents also reported they received information from other parents of children with special needs, 41.9 % (18) or other sources 34.9 % (15) such as reading books, the library, internet and self taught. Finally, respondents also reported receiving information from government agencies, 30.2 % (13), the doctor’s office, 25.6 % (11) or hospital, 14.0 % (6). Twenty-nine respondents skipped this question.
16. Respondents were asked if they were provided with information on how to access therapy or services that their children may need. A majority of respondents, 66.1 % (41) reported that they had, while 33.9 % (21) reported that they had not. Ten respondents skipped this question.
17. Respondents were asked whether they utilized the services. All respondents 100 % (36) reported that they had, however a few clarified that they had not started services yet, or the types of services that were offered were not beneficial to their child or not necessary. Thirty six respondents skipped this question.
18. Respondents were asked how they paid for the therapy or services that their children used and were instructed to select all that applied. The most frequently reported source was insurance, 68.3 % (41), closely followed by the school system, 61.7 % (37). Respondents also reported they paid for services out of pocket, 45.0 % (27) or governmental agencies/public assistance, 36.7 % (22). Finally, respondents also reported receiving assistance for services from a charitable organization such as Easter Seals or the March of Dimes, 11.7 % (7) or other sources, 5.0 % (3) such as federal government programs or savings. Twelve respondents skipped this question.

19. Respondents were asked whether they were satisfied that their children's teachers were adequately trained to address their special needs. Most respondents, 67.7 % (42) reported that they were. Twenty respondents, 32.2 % provided information on why they were not satisfied with the services their child had received. Answers ranged from being satisfied with some services and not with others, having therapists or other professionals not listen to their concerns, poor quality of teachers available in public schools, lack of training or qualifications of teachers or lack of time for teachers to spend with their child. Ten respondents skipped this question.
20. Respondents were asked whether they felt welcome observing their children in the classroom. Most respondents, 78.3 % (48) reported that they did, while 21.7 % (13) reported they did not. Twelve respondents skipped this question.
21. Respondents were asked if they received an inter-district transfer to accommodate their children's needs. Most respondents, 65.5 % (38) reported that this was not applicable, while 19.0 % (11) reported that they did and 15.5 % (9) reported that they did not. Fourteen respondents skipped this question.
22. Respondents were asked if their children had an Individualized Education Plan (IEP) or Section 504 Plan. A majority of respondents 87.1 % (54) reported that their children had an IEP, while 3.2 % of respondents (2) reported that their children had a Section 504 Plan. Six and a half % of respondents (4) reported that their children did not have a plan, while one person each (1.6 %) reported that they were unsure if their children had a plan or they were unaware of any programs. Three respondents (4.8 %) reported that their children had other programs, such as a Student Study Team. Ten respondents skipped this question.
23. Respondents were asked whether they felt their opinions and contributions to the IEP/Section 504 Plan were valued and respected. Half of the respondents, 50.0 % (30) reported that they were, while 28.3 % (17) reported sometimes. Eleven point seven % of respondents (7) reported that they were not sure and 10.0 % (6) reported no. Twelve respondents skipped this question.
24. Respondents were asked whether they felt pressure to accept a specific IEP/Section 504 Plan for their children that they were not comfortable with. Most respondents, 64.4 % (38) reported that they did not, while 25.4 % (15) reported sometimes and 10.2 % (6) reported yes. Thirteen respondents skipped this question.
25. Respondents were asked how their child progressed with this plan. Just over one-quarter of respondents 27.3 % (6) reported that they progressed and did well, 18.2 % (4) reported they struggled but progressed as expected and 9.1 % (2) reported that their child struggled and did not progress as expected. Most respondents, 45.5 % (10) reported other, with explanations such as it is too early to tell, lack of progress reports from school and inappropriate accommodations provided by school. Fifty respondents skipped this question.
26. When asked whether respondents felt their concerns had been addressed, half (6) reported they had been addressed and half (6) reported they had not. Sixty respondents skipped this question.
27. Respondents were asked whether they were informed or aware of the process to have their child's IEP/Section 504 Plan re-evaluated. Most respondents, 76.3 % (45) reported they were, and 23.7 % (14) reported they were not. Thirteen respondents skipped this question.
28. When respondents were asked whether they took an active part in writing their child's IEP/Section 504 Plan, nearly three quarters, 72.9 % (43) reported they did. Fifteen point three % of respondents (9) reported no and 11.9 % (7) reported they wished they were more active. Thirteen respondents skipped this question. Respondents were asked to describe their involvement in the process and provided a variety of responses such as attending meetings, responding to surveys, helped set up modifications for the classroom, hired an advocate, classroom observation and contributing to goals writing.
29. Respondents were asked whether they were a member of a local parents of multiples club. Nearly all respondents, 96.6 % (56) reported they were, and 3.4 % (2) reported they were not. Fourteen respondents skipped this question.

30. Most respondents, 84.2 % (48) reported that their local parents of multiples club did not address special needs issues at their regular meetings, while 15.8 % (9) reported they did. Fifteen respondents skipped this question. Respondents reported that this information was presented at their meetings 1 to 2 times per year, 66.7 % (6), 3 to 4 times per year, 22.2 % (2) and one respondent, 11.1 % reported this information was presented once every few years. No respondents reported this information was presented 5 or more times per year or never. Sixty-three respondents skipped this question.
31. Respondents were asked for ways in which their local clubs could provide support to multiples families with special needs children. Thirty-two respondents provided a variety of responses such as providing more information on early intervention, setting up a “big sister” type of program where mothers who are further along in the process could help mothers who are new to the process, providing additional information on services or how to work with the school district, or having additional meetings, speakers or support groups specifically for special needs. Forty respondents skipped this question.
32. Respondents were asked whether they were a member of the National Organization of Mothers of Twins Clubs, Inc. (NOMOTC). Nearly all respondents, 86.0 % (49) reported they were, 8.8 % (5) reported that they were not, and 5.3 % (3) reported they were not currently, but were a member in the past. Fifteen respondents skipped this question.
33. Respondents were asked for ways in which NOMOTC could provide support to multiples families with special needs children. Twenty-four respondents provided a variety of responses, including many that were similar to recommendations for local clubs such as providing more networking and resource information. Some ideas specific to NOMOTC were to provide information on current scientific research related to special needs, provide information on current legislation relating to special needs, special sessions at conferences related to special needs and articles in the *Notebook* related to special needs. Forty-eight respondents skipped this question.
34. Respondents were asked to share any issues they had experienced with their multiples with special needs at any age. Seventeen respondents shared their experiences. Some responses were light hearted, such as how every day is a new adventure, while others were more about the difficulties of having a child with special needs and the special challenges of having one multiple with special needs and other multiple(s) that do not. Respondents again voiced their frustration dealing with schools or professionals who are not receptive the day to day challenges such as cost and feeling alone in their situation. Fifty-five respondents skipped this question.
35. Finally, respondents were asked if they had any additional comments relating to the survey. Fourteen respondents provided information, many of whom were pleased that NOMOTC was taking the time to ask questions about this population and that they hoped the information would be published on the website or shared with school district personnel. Fifty-eight respondents skipped this question.

## CONCLUSION

The effort to collect data regarding issues facing multiples with special needs yielded 72 surveys comprised of 43 questions each. Twins accounted for the highest percentage of multiple types at 87.5 %, followed by 9.7 % for triplets and less than 3 % for multiple multiples. Just over three quarters, 79.2 %, were dizygotic (fraternal) multiples, 20.8 % were monozygotic (identical) multiples, and the remaining multiples were either unknown zygosity or a combination of dizygotic and monozygotic for higher order multiples (HOMs). Nearly seventy % of respondents reported that their multiples were born early, although half of the sample reported that their multiples were born at 35 weeks or later. Overall the multiples in the sample were young, with nearly 85 % of the respondents reporting that their multiples were in 3<sup>rd</sup> grade or under, with just over half reporting that their children were currently in preschool.

Forty point three % of the sample reported that their children were between birth and age 12 months when they were diagnosed with special needs, while 29.2 % reported their children were between 13 months to two years when they were diagnosed. Nearly 10 % of respondents reported their children were between ages two to three, 13.9 % reported their children were 3 to 4 years old, 11.1 % reported their children were 5 to 6 years old and 6.9 % reported their children were 7 years or older when diagnosed.

Developmental delays were the highest reported special need for all multiple types, with 69.6 % of respondents reporting that one of their multiples had experienced this delay. This was closely followed by communicative delays, of which 63.8 % of the sample reported their multiples had experienced. The lowest reported special need overall was physical disability, reported by 34.8 % of the sample. Seventeen respondents reported that their multiples had other special needs such as speech delays, ADHD, hydrocephalus, cerebral palsy, deafness, seizure disorder, autism spectrum disorder, sensory integration disorder, Asperger's syndrome, benign congenital hypotonia and mental illness. For Multiple A, the highest reported special need was developmental delays (37), with the lowest reported as physical or learning disabilities (18 each). For Multiple B, the highest reported special need was also developmental delays (30), with the lowest reported as physical disabilities (12). For Multiple C, the highest reported category was no diagnosis of special needs and communicative delays (3 responses each), with the least reported category as learning disabilities (no respondents).

Most respondents (82.1 %) reported that their children did receive Early Intervention Services (0-3 years) and received intervention services in preschool (73.8 %). Three quarters of children receiving intervention services received these services through the school district. The majority of respondents sent their children to public school for Grades K-12, with the exception of preschool in which more parents overall sent their children to private school.

Most respondents reported that their children had been mainstreamed without any aide in preschool (63.6 %), Kindergarten (58.8 %), Grades 1-3 (85.0 %), Grades 4-5 (100.0 %) and Grades 9-12 (75.0 %). For Grades 6-8, the most frequently reported placement type was some of their children's classes were mainstreamed and some were not or all classes were special needs classes (75.0 %, 3 each).

Looking at the placements by grade and multiple types, by far the most reported placement category was "not applicable", however this would be an expected response since half of the sample was reported to be in preschool or younger. For Multiple A's who reported a placement type, the highest reported was mainstreamed without aide for preschool (33), Kindergarten (17), Grades 1-3 (13), Grades 4-5 (3) and Grades 9-12 (2). Multiple A's in Grades 6-8 reported the highest placement as mainstreamed with typical peer/student support or some classes mainstreamed, some not (2 each). For Multiple B's, the highest reported placement type was mainstreamed without aide for preschool (27), Kindergarten (27), Grades 1-3 (11) and Grades 4-5 (5). For Grades 6-8, the highest reported placement type for Multiple B was all special needs classes (3), with Multiple B's in Grades 9-12 reporting mainstreamed without aide or all classes were special needs classes (2 each). For Multiple C's, the highest reported category was mainstreamed without aide for preschool (5), Kindergarten (1), Grades 1-3 (1) and Grades 4-5 (5). There were no placement types reported for Multiple C's in Grades 6-8 or 9-12.

The most frequently reported intervention type was speech/language therapy, reported by 78.0 % of respondents. The least frequently reported interventions were vision therapy (18.6 %), assistive technology (16.9 %) or deaf/hard of hearing therapy (3.4 %). For Multiple A, the most frequently reported intervention type was speech/language therapy (33), and the least reported intervention was deaf/hard of hearing therapy (none reported). Similarly, for Multiple B, the most frequently reported intervention was speech/language therapy (28), and the least frequently reported intervention was deaf/hard of hearing therapy (2). For Multiple C, the most frequently reported intervention was also speech/language therapy and no therapy (3 each), and the least frequently reported were sensory motor therapy, deaf/hard of hearing therapy, learning delay therapy, classroom modifications, classroom accommodations, curriculum modifications, curriculum accommodations or other (no respondents).

Similar to findings on intervention types, the greatest majority of respondents (69.4 %) reported that their children had speech/language disorders/delays (69.4 %), closely followed by developmental delays (59.7 %). Slightly less than one-third of respondents reported their children had other special needs (29.0 %), ADD/ADHD (29.0 %), physical disabilities (29.0 %), and learning disabilities (25.8 %). Finally, 12.9 % of respondents reported their children had visual impairments, 4.8 % reported their children had mental retardation and 3.2 % reported their children had a hearing impairment.

For Multiple A, the most frequently reported special need was speech/language disorder/delays (34), and the least frequently reported was hearing impairment and mental retardation (no respondents). For Multiple B, the most frequently reported special need was also speech/language disorder/delays (24), and the least frequently reported was hearing impairment (2). For Multiple C, the most frequently reported special need was speech/language disorders/delays and the least frequently reported were ADD/ADHD, hearing impairment, learning disabilities, mental retardation and sensory motor impairment (no respondents).

Fortunately, when asked if they received any type of training or information to assist them in dealing with their child's special needs, most respondents (71.0 %) reported that they had, although 29.0 % reported that they did not. For those that had received training and information, the most frequently cited source of this information was the child's school (58.1 %), closely followed by therapy (53.5 %). Respondents also reported they received information from other parents of children with special needs (41.9 %) or other sources (34.9 %) such as reading books, the library, internet and self taught. Finally, respondents also reported receiving information from government agencies (30.2 %), the doctor's office (25.6 %) or hospital (14.0 %). When asked if they were provided information on how to access services, most reported they had (66.1 %), although 33.9 % reported they had not. All respondents reported that they had utilized the services referred to them, however a few clarified that they had not started services yet, or the types of services that were offered were not beneficial to their child or not necessary. The most frequently cited way that families reported paying for these services via insurance (68.3 %), closely followed by the school system (61.7 %). The least reported forms of service payments were via assistance from a charitable organization such as Easter Seals or the March of Dimes (11.7 %) or other sources such as federal government programs or savings (5.0 %).

Several questions relating to school were asked next. While nearly 3 out of 4 respondents reported that they believed their child's teachers were adequately trained to address their special needs, 32.2 % reported they did not believe so. Concerns raised about staff preparation included respondents being satisfied with some services and not with others, having therapists or other professionals not listen to their concerns, poor quality of teachers available in public schools, lack of training or qualifications of teachers or lack of time for teachers to spend with their child. Most respondents (78.3 %) reported that they felt welcome to observe their child in the classroom. When respondents were asked if they received an inter-district transfer to accommodate their children's needs, most respondents (65.5 %) reported that this was not applicable, while 19.0 % reported that they did and 15.5 % reported that they did not.

Respondents were asked if their children had an Individualized Education Plan (IEP) or Section 504 Plan. A majority of respondents (87.1 %) reported that their children had an IEP, while 3.2 % of respondents reported that their children had a Section 504 Plan. Six and a half % of respondents reported that their children did not have a plan, while one person each reported that they were unsure if their children had a plan or they were unaware of any programs. When asked whether they felt their opinions and contributions to the IEP/Section 504 Plan were valued and respected, half of the respondents (50.0 %) reported that they were, while 28.3 % reported sometimes, 11.7 % stated that they were not sure and 10.0 % reported no. While most respondents (64.4 %) reported they did not feel pressure to accept a specific IEP/Section 504 Plan for their children that they were not comfortable with, 25.4 % reported sometimes and 10.2 % reported yes. When asked how their child progressed with this plan, nearly half of families (45.5 %) reported that they progressed and did well or struggled but progressed as expected. Less than 10 % (9.1 %) reported that their child struggled and did not progress as expected, while many respondents (45.5) reported other, with explanations such as it is too early to tell, lack of progress reports from school and inappropriate accommodations provided by school.

When asked whether respondents felt their concerns had been addressed, 50.0 % reported they had been addressed and 50.0 % reported they had not. Most respondents (76.3 %) reported that they were informed or aware of the process to have their child's IEP/Section 504 Plan re-evaluated, although 23.7 % reported they were not. When respondents were asked whether they took an active part in writing their child's IEP/Section 504 Plan, nearly three quarters 72.9 % reported they did, while 15.3 % reported they did not and 11.9 % reported they wished they were more active. Parents described their involvement in the process in a variety of responses such as attending meetings, responding to surveys, helped set up modifications for the classroom, hired an advocate, classroom observation and contributing to goals writing.

Nearly all respondents (96.6 %) reported they were members of a local mothers of multiples club, although most respondents (84.2 %) reported that their local parents of multiples club did not address special needs issues at their regular meetings. Members reported it was most often presented at their meetings 1-2 times per year (66.7 %). When asked how their local clubs could provide support to multiples families with special needs children, a variety of responses were provided such as offering more information on early intervention, setting up a "big sister" type of program where mothers who are further along in the process could help mothers who are new to the process, providing additional information on services or how to work with the school district, or having additional meetings, speakers or support groups specifically for special needs.

Similarly, nearly all respondents (86.0 %) reported they were members of the National Organization of Mothers of Twins Clubs (NOMOTC). Respondents suggested that NOMOTC could provide support to multiples families with special needs children, including many that were similar to recommendations for local clubs such as providing more

networking and resource information. Some ideas specific to NOMOTC were to provide information on current scientific research related to special needs, provide information on current legislation relating to special needs, special sessions at conferences related to special needs and articles in the *Notebook* related to special needs. Forty-eight respondents skipped this question.

Finally, respondents were asked to share any issues they had experienced with their multiples with special needs at any age. Seventeen respondents shared their experiences. Some responses were light hearted, such as how every day is a new adventure, while others were more about the difficulties of having a child with special needs and the special challenges of having one multiple with special needs and other multiple(s) that do not. Respondents again voiced their frustration dealing with schools or professionals who are not receptive the day to day challenges such as cost and feeling alone in their situation. Many respondents reported being pleased that NOMOTC was taking the time to ask questions about this population and that they hoped the information would be published on the website or shared with school district personnel.