

National Organization of Mothers Of Twins Clubs, Inc.	SUBJECT:	<b>MULTIPLES WITH AUTISM SPECTRUM DISORDERS</b>
	RESEARCHER:	National Organization of Mothers of Twins Clubs, Inc.
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**PURPOSE:** The purpose of this survey was to determine the occurrence of Autism Spectrum Disorders (ASD) in multiples as well as treatment strategies and social and educational impacts.

**METHOD:** A survey consisting of 58 questions was distributed in a national mailing and published online via Survey Monkey. The survey was to be completed by parents of multiples where one or more of the multiples have been diagnosed with an ASD.

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### BACKGROUND INFORMATION

1. Ninety-seven surveys were received and tabulated with 88 percent (81) of respondents having twins; of those, 80.6 percent (75) were fraternal or dizygotic twins. 8.7 percent had triplets. The majority of those diagnosed with ASD were boys (67 out of 77 or 85.7 percent) and 37 were first born.
2. ASD was diagnosed in 68.4 percent (13) of the maternal side of extended family, and 26.3 percent (5) of a paternal relative. None of the biological parents or grandparents were diagnosed with an ASD.
3. The age of the multiples(s) at diagnosis was greatest between 2-3 years in the first three children.

### RESULTS

#### *Diagnosis*

1. Diagnosis was given by a developmental specialist 31.7 percent (20) of the time, neurologist 25.4 percent (16), psychologist 23.8 percent (15), psychiatrist 15.9 percent (10), other 15.9 percent (10), school therapist 14.3 percent (9), pediatrician 7.9 percent (5), and developmental neurologist 4.8 percent (3).
2. Most (41.3 percent or 26) received a definitive diagnosis at the first visit, while 31.7 percent (20) took three months or longer to receive the diagnosis. Nineteen percent (12) received diagnosis within one month of the first visit, and 7.9 percent (5) received the diagnosis between one and three months.
3. Parents listed many factors that they felt contributed to their child(ren) having an ASD. Several listed genetics and immunization as a factor, also problems during pregnancy or birth were listed.
4. When asked whether their multiple(s) exhibited typical behavior prior to the atypical behavior, 71 percent listed the behavior as typical during the first six months, 58 percent stated the behavior was typical during the first 12 months, 29 percent during the first 18 months, 13.3 percent during the first two years, 8.9 percent were typical during the first six years, 4.4 percent were typical during the first three years, and 2 percent were typical both during first four and five years.
5. Fifty-four (55.7 percent) respondents listed other developmental disorders that were also diagnosed. Of these, Pervasive Developmental Disorder, not otherwise specified was the highest at 40.7 percent. Sensory Integration Disorder was listed at 38.9 percent; 5.6 percent listed Mental Retardation, 3.7 percent listed Auditory Processing Disorder. Twenty-four point one percent listed other disorders, including ADHD, Cerebral Palsy and Developmental Delays.
6. The most common complication during birth was premature delivery at 70 percent (35). Labor before delivery was cited at 30 percent (15). Problems during delivery at 14 percent (7), gestational diabetes at 12 percent (6), viral infections or exposure to environmental chemicals / pollutants received at 4 percent (2), and RH factor incompatibility was cited one time or 2 percent. Other factors listed included: pre-eclampsia, TTTS, and HELLP syndrome.
7. Gestational ages of the multiples at birth ranged between 24 and 40 weeks. Twenty-three point nine percent were born at 37 weeks. Eighty-eight percent were born between 33 and 40 weeks, and 12 percent were born from 24 and 31 weeks.

#### *Symptoms*

8. Of symptoms relating to social interaction, 61 responded their multiples exhibit the following: lack of eye contact (72.1 percent), lack of social gestures (70.5 percent), doesn't seek out social interaction (67.2 percent), failure to make friends with peers (63.9 percent), lack of social or emotional response (47.5 percent), and lack of facial expression (32.8 percent).

9. Sixty-three respondents noted their multiples exhibit the following symptoms relating to communication skills: Language, absent or delayed (85.7 percent), inability to initiate and sustain a conversation (76.2 percent), stereotyped, repetitive or atypical use of language (61.9 percent), lack of imaginative or social play (58.7 percent), inappropriate tone or volume level (58.7 percent). Four respondents noted other symptoms including noise sensitivity and articulation issues.
10. Fifty-five respondents noted their multiples exhibit the following other behaviors: Atypical intense preoccupation with certain activities or areas of interest (83.6 percent), stereotyped and repetitive movements (e.g. hand flapping, spinning or preoccupation with parts of objects) (61.8 percent), inflexible insistence on certain nonfunctional rituals or routines (50.9 percent).

#### *Treatment*

11. Most parents started treatment before ASD diagnosis was made (67.2 percent). Thirty-two point eight percent started treatment immediately after diagnosis. Fourteen point eight percent started treatment less than six months after diagnosis, and only 4.9 percent started treatment more than six months after diagnosis.
12. When asked who helped determine what type of treatment to begin with, 75 percent stated an early intervention specialist and 43.5 percent stated doctor/specialist. Thirty-seven point one percent stated school district, and 24.2 percent said other, which included: psychologist, themselves and occupational therapist, or themselves.
13. Seventy-six point two percent of respondents stated there were treatment options available in their community. Only 6.3 percent stated there were not. Seventeen point five percent stated, “some, not all” options were available.
14. An overwhelming 95.2 percent stated they did not relocate to accommodate a treatment strategy. Four point eight percent of respondents said they did relocate. Of those that relocated, one went to a different school district, one to another county, and the other relocated to a different state.
15. There were many different treatments utilized. Eighty-three point nine percent had speech therapy, 80.6 percent occupational therapy, 53.2 percent Applied Behavior Analysis (ABA). Thirty point six percent had floor time or Play and Language for Autistic Youngsters (PLAY), 8.1 percent Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH), 3.2 percent Social Communication, Emotional Regulation and Transactional Support (SCERTS), and 40.3 percent utilized other treatments including: RDI (Relationship Development Intervention) and developmental therapy.
16. Of the treatments used, the strategy that was found to have the greatest impact was speech therapy (55.7 percent), occupational therapy (44.3 percent), ABA (47.5 percent), PLAY (21.3 percent), TEACCH (6.6 percent), and other (24.6 percent) which included RDI, physical therapy, and developmental therapy.
17. Eighty-five point seven percent stated that there was no treatment strategy that was not helpful. Eight respondents stated that the following treatments were not helpful: floor time, ABA, BIP (Behavior Intervention Plan), and speech therapy.
18. When asked how the cost of treatment strategies were covered, 61.3 percent stated insurance paid for them. Fifty-nine point seven percent answered private pay, 45.2 percent other, and 6.5 percent used scholarship funds.
19. Forty-eight point four percent of respondents stated they have not tried any alternative treatments or treatments not recommended by their primary care physician. Of those who tried alternative treatments, 40.3 percent tried dietary treatment, 16.1 percent medications, and 21 percent chose “other” including audio, music, vitamin therapy, talk therapy, acupuncture, and use of a chiropractor. Of those that tried alternative treatments, 41.9 percent felt they were successful, 35.5 percent felt they were somewhat successful, and 22.6 percent felt they were not successful.

#### *Schooling/education*

20. Eighty-one point three percent of the respondents have multiples, pre-school aged or older.
21. Those that are in school attend the following: public school - mainstreamed (42.3 percent), self contained program within public school (21.2 percent), parochial or private school (11.5 percent), both public and special school concurrently (11.5 percent), special school (7.7 percent), and 5.8 percent are home schooled.
22. Fifty-one percent stated that their school offers special classes for children with ASD. Thirty-eight point eight percent stated their schools did not, and 10.2 percent were not sure.
23. Forty point four percent stated their child did not qualify for a full-time aide in the classroom. Thirty-eight point five percent stated they did qualify, and 21.2 percent were not sure if their child qualified.
24. When asked whether their school has separate classes based on the different levels of ASD – high functioning and low functioning, 43.1 percent stated they did not. Nineteen point six percent stated they did, and 37.3 percent were not sure if there were separate classrooms available.

25. Sixty-eight point six percent of the children were mainstreamed into regular classes with typical peers while 31.4 percent were not. Of those that were mainstreamed, 55.3 percent were mainstreamed for the full day, 26.3 percent for a few hours daily, 15.8 percent for a half day, and 2.6 percent only weekly.
26. When asked whether the class used task boxes or work baskets in their learning techniques, 38.5 percent stated they did not, 34.8 stated they did, and 26.9 percent stated they were not sure. (A task box helps a child with hand-eye coordination, matching pictures, matching/learning of colors and letters, recognizing/counting money, identifying food and drinks from pictures, reading and writing, and household chores.)
27. An overwhelming 80.8 percent of the schools offer speech therapy to children with ASD. Nine point six percent responded that their school did not offer speech therapy, and 9.6 percent were not sure.
28. When asked whether or not their multiples had communication materials/devices to help communicate within the classroom, 46.2 percent stated they did not. Thirty-six point five percent stated there were devices available, and 17.3 percent said they were not sure. Devices available that were listed included: PECS, Alpha Smart, picture cards, voice output device, and keyboard. When asked who provided the communication devices, 77.8 percent responded the school district, 40.7 percent had to purchase the devices personally, 7.4 percent were through Medicaid or private donation, and a state or city organization paid for 3.7 percent of the devices.

#### *Emotional impact*

29. When asked which feelings were experienced immediately after their child was diagnosed, 58.3 percent stated that they were relieved to have a definite diagnosis. Fifty-six point seven percent felt helpless, and suffered depression or anxiety, 51.7 percent felt frustration, and 43.3 percent felt anger, guilt or failure and inadequacy. Forty-one point seven percent felt confident that the child would have the best possible future due to treatment and education, and 28.3 percent felt shock. Finally, 13.3 percent felt other emotions including confusion, sadness, and a strong desire to learn more.
30. When asked whether or not they experienced emotional distress or sought out professional counseling after the diagnosis of their child, 46.7 percent of respondents experienced some emotional distress, but were able to manage without counseling. Twenty-three point three percent experienced great emotional distress, but did not seek counseling, 15 percent experienced great emotional distress and received counseling, and 15 percent did not experience emotional distress.
31. Spouses or significant others reacted differently to the diagnosis. Sixty percent reacted with denial, 36.7 percent showed relief to have a definite diagnosis, 33.3 percent showed frustration, 30 percent experienced anxiety, 31.7 percent felt confidence that the child would have the best possible future due to treatment and education, 21.7 percent showed helplessness, anger or guilt, 20 percent reacted with shock, and 23.3 percent with depression. Fifteen point five percent felt feelings of failure and inadequacy, and 5 percent stated other reactions.
32. When asked whether or not their spouses or significant other experienced emotional distress and/or sought professional treatment after the diagnosis of their child, 48.3 percent experienced some emotional distress but were able to manage without counseling. Twenty-eight point percent did not experience emotional distress, 18.3 percent experienced emotional distress but did not seek counseling, and 5 percent experienced great emotional distress and received counseling.
33. When asked about siblings without ASD, 58.5 percent of the respondents stated the siblings without ASD are protective of the siblings with ASD. Thirty-two point one percent said the siblings without ASD display resentment that the parents spend more time with the siblings with ASD. And 9.4 percent stated the siblings without ASD experience teasing from their peers. Eleven point three percent of the respondents do not have children without ASD.
34. When asked which aspects of life were negatively affected by the diagnosis of a child with ASD, marriage or relationship with significant other was noted at 59.3 percent. Fifty-two point five percent responded that their relationships with other family members suffered, 54.2 percent remarked that social interaction with other adults diminished, and 39 percent said their career was affected. Eleven point nine percent responded there were no aspects of life that were negatively affected. Of those that had discord in their marriage or relationship, it was split 50/50 between, "they addressed and solved the conflict on their own," and "the issues are ongoing and unresolved."

#### *Social Impact*

35. The respondents stated their multiples with ASD display a lack of interest in social interaction 41.7 percent of the time. Twenty-one point seven percent stated, "No, they don't display a lack of interest" and 36.7 percent stated sometimes.
36. When asked what type of social ramifications the children with ASD experience, the responses varied. Fifty-seven point thirty-nine percent stated isolation was a factor, 42.1 percent of the children act out

- physically, and 10.5 percent reacted with embarrassment, 21.1 percent with teasing, and 28.1 percent with no social ramifications. One other ramification listed was biting.
37. Of those children that display severe ASD symptoms, the unpredictability of the behavior limits the respondent's social interactions with others 43.5 percent of the time. Twenty-one point eight percent stated it did not limit interactions, and 34.5 percent remarked that this was not applicable.
  38. Fifty-one point seven percent of families experienced financial difficulties due to their child's treatment while 48.3 percent did not.
  39. When asked if they take time for themselves, 64.4 percent stated they did so infrequently, 22 percent frequently, and 13.6 percent never took time for themselves. Date nights, volunteering and going to the gym were some of the activities the respondents mentioned they did to get away.
  40. Respite care is available in 58.6 percent of the respondents' area. Respite was not available in 10.3 percent of the respondents' area. Thirty-one percent did not know if it was available.
  41. When asked if the families engaged in activities without the children with ASD, 55 percent stated they never did, 35 percent stated sometimes, and 10 percent stated they did.
  42. When asked what their greatest sources of support were, 73.3 percent stated it was their spouse or significant other. Sixty-one point seven percent leaned on their friends for support, 56.7 percent relied on other immediate family members, 31.7 percent listed education professionals, 25 percent listed Internet groups/chat rooms, 20 percent listed local support groups, 16.7 percent listed health care professionals, 11.7 percent found support at their place of worship, and 11.7 percent found support through other avenues, including other parents with children with ASD.

## CONCLUSION

The effort to determine the occurrence of multiples with ASD, strategies, social, and educational impacts, yielded a total of ninety-seven responses. All questions except for those dealing with demographics were consistently skipped by at least 34 respondents, which leads to the conclusion that 63 respondents took the survey and fully completed it. Percentages were adjusted to accommodate this number.

Demographics show that 88.0 percent have twins; 80.6 percent are dizygotic or fraternal. It is also interesting to note that 67 out of 77 or 85.7 percent diagnosed were boys, and of those, 37 were first born. ASD was diagnosed within 68.4 percent of a maternal extended family member, and 26.3 percent of a paternal relative. The age of the multiple(s) at diagnosis was greatest between 2-3 years in the first three children. Diagnosis was made in 31.7 percent of the cases by a developmental specialist, with 41.3 percent diagnosed at first visit.

Responses (62) showed a wide range of *symptoms* which included: speech, slow development, repetitive behaviors, lack of eye contact, misbehavior, and non-socialization. Approximately 50.0 percent reported their multiple(s) exhibited typical behavior from birth to three years. In developmental symptoms, the following responses were given: lack of social/emotional response (72.4 percent), language absent or delayed (66.7 percent), and inflexibility in routines (75.0 percent).

With the help of early intervention specialists, treatment began before diagnosis in approximately 60.1 percent of the multiple(s). Speech therapy was the number one treatment (83.9 percent) and had the greatest impact (55.7 percent). Insurance covers most of the cost of treatment (61.3 percent) however, 51.7 percent reported family financial difficulties due to the treatments. Most of the children with ASD are mainstreamed full day into regular classes in public school (42.3 percent). These schools also offer speech therapy to children with ASD (80.8 percent), while school districts provide communication materials/devices (77.8 percent).

The emotional impact experienced immediately after diagnosis yielded a wide range of responses, with "relief to finally have a diagnosis" being number one (58.3 percent). The spouse/significant other reaction was "denial" in 60.0 percent. Most couples (46.7 percent) experienced some emotional distress but were able to manage without counseling. Relationship with spouse/significant other was affected by 59.3 percent after diagnosis of a child with ASD. Half the conflicts were addressed and solved on their own (50.0 percent), 50.0 percent reported issues ongoing and unresolved, yet spouse/significant other was given as the greatest source of support (73.3 percent).

Social impact on the multiple(s) shows 41.7 percent display a lack of interest in social interaction. Isolation (57.9 percent) is the uppermost social ramification for the child(ren). If the multiple(s) display severe/unpredictable symptoms of ASD, 43.6 percent of parents report the behavior puts severe limits on their social interactions with others. When surveyed if the parent(s) take time out for themselves, 64.4 percent responded "infrequently."

Although 58.6 percent reported having respite care available in their area, 55.0 percent said they do not engage in family activities without the multiple(s) with ASD.

Autism Spectrum Disorders cut across all lines of race, class, and ethnicity. Autism impacts millions of children, adults, and their families around the world. Autism Spectrum Disorders affect not only the person diagnosed with the disorder, but also have a significant impact on the entire family with a variety of social, financial, and other practical demands. It is important to diagnose and obtain treatment of ASD early. There is research that believes there is a genetic link with ASD. It is also felt that siblings of a child with autism have a greater chance of being diagnosed with an Autism Spectrum Disorder. However, this survey did not address this subject. It may be of benefit to do a survey on this subject in the future.