Original Research

Prevalence and Significance of Abnormal Tactile Responses in Young Children with Autism

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With the inclusion of sensory abnormalities in the DSM-V criteria for autism, the multifocal touch/pain abnormalities reported in young children with autism are no longer comorbid symptoms, and it has become an urgent priority to identify their nature and significance. A recent study differentiated children with autism from typical and otherwise developmentally delayed groups on the two-fold basis of mixed allodynia and hypoesthesia, and severe global self-regulatory delay. In this study, we retrospectively analyzed case records for 266 pre-school children with autism and typical development to verify recent findings, assess the prevalence and location of tactile abnormalities in the autism group, and explore the relationship between tactile abnormalities and self-regulatory delay. Results differentiated the autism group by severity of tactile abnormality [$F(1,262) = 172.8$, $p < .001$] and self-regulatory delay [$F(1,262) = 232.8$, $p < .001$]. Allodynia was reported in 100% of the autism group by parent report and 98% by therapist report; hypoesthesia was present in 65% by parent report. Tactile abnormalities were directly, linearly related to self-regulatory delay ($r = .727$, $p < .001$) in both groups. The sense of touch has not been fully evaluated in autism, and there is insufficient quantitative evidence to conclude that it is intact. Mixed allodynia and hypoesthesia are typical signs of sensory neuropathy. Evidence of their near universal presence in young children with autism, and direct relationship to self-regulatory delay underscores the urgent need to fully evaluate the sense of touch in autism and rule out sensory neuropathy.

[N A J Med Sci. 2013;6(3):121-127. **DOI:** *10.7156/najms.2013.0603121]*

Key Words: *autism, autism spectrum disorder, children, hypoesthesia, allodynia, abnormal tactile responses, self-regulatory delay*

INTRODUCTION

Descriptions of unusually high and low touch/pain thresholds abound in the clinical literature describing children with autism,[1] and it is common to read reports of children taking no apparent note of a broken bone or blistering burn; or adamantly refusing gentle touch involved in trimming nails or haircuts. These responses are almost universally present in children with autism and are associated with increased severity of core autism symptoms.[2] With the recent inclusion of sensory abnormalities in the DSM-V criteria for autism, the touch/pain abnormalities reported in young children with autism have become a core feature of autism, and it has become an urgent priority to identify their nature and significance.[34]

What is specifically not known about touch/pain responses in autism is whether the sense of touch is intact. Unlike hearing and vision, exclusion of tactile impairment is not part of the diagnostic work-up for autism, and the sense of touch has not been fully evaluated. The neurological evaluation of touch involves testing responses to touch, vibration, position, pain and temperature, and requires communication about the testing.[5] Psychophysiological testing is not valid in Young children, and has not been done in young children with autism;[6] neither has it been done in older children or adults. The literature reporting evaluation of touch in older children and adults with autism reveals only three small studies evaluating partial aspects of the sense of touch. Contradictory results are reported: one study showed hypersensitivity to touch and vibration in ten adults with Aspergers;[7] a second study showed no difference in touch and vibration in 8 children with autism;[8] and a third study showed no difference in touch and vibration in 8 adults with autism, but differences in thermal thresholds.[9] With so few cases evaluated, it is not possible to conclude that the sense of touch is intact in autism.

For the past decade, our group has researched the effect of treatment of tactile abnormalities in young children with autism on self-regulatory development.[10–12] The theoretical model for treatment is based on Five-Phase Theory of Chinese medicine, which asserts that the five primary senses are connected to five sets of self-regulatory functions underlying development such that impairment of a sense is associated with impairment of a set of self-regulatory functions.[13] There is concordance between self-regulatory functions described in Five-Phase theory and the early self-regulation milestones monitored by pediatricians in the first two years of life. These are: the ability to regulate sleep/ wake cycles, self-regulation of appetite and digestion, self-

Received 05/11/2013; Revised 06/19/2013; Accepted 06/23/2013
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soothing, the ability to orient and regulate attention, and early toilet training abilities.[14,15] Although there is no specific Western medical theory linking sensory abnormalities to self-regulatory delays, Western science is cognizant that untreated hearing or vision loss causes global developmental delay, and that touch deprivation causes social- emotional delay.[16]

Because there was no existing parent questionnaire eliciting information about sensory and self-regulatory abilities in pre-school children, our research required the development of a parent questionnaire to evaluate treatment outcomes. The resultant questionnaire was called the Sense and Self-Regulation Checklist (SSC).[17] When the SSC was validated in children with autism, typical development and other developmental disabilities, it differentiated the autism group from other groups on the two-fold basis of severe, global delay of early self-regulation milestones and a specific tactile abnormality characterized by the mixed presentation of lack of response to injury (hypoesthesia), and painful response to non-injurious touch on multiple areas of skin (allodynia).[17]

This was the first time that a description of the tactile abnormality in autism was sufficiently detailed to allow consideration of a medical diagnosis. Signs are more significant than symptoms in the evaluation of sensory pathology,[6] and mixed signs of hypoesthesia and allodynia are typical of small fiber neuropathy, a common disorder of sensory nerves in adults involving loss and damage of the small unmyelinated fibers mediating pain and thermal sensation in the skin.[18,19] Normally, signs of hypoesthesia and allodynia would be evaluated with quantitative neurological testing of responses to light touch, pinprick, vibration and thermal thresholds, as well as electro-diagnostic testing and skin biopsy;[6] but as noted above, this has not been reported.

In this study, we wished to further explore the prevalence and significance of tactile abnormalities in young children with autism in our research databases, prior to planning more in-depth neurological studies. We conducted a retrospective review of case records for pre-school children with autism and typical development to answer the following questions:

1. Does parent data describing tactile and self-regulatory symptoms in the present study of 266 pre-school children with autism or typical development confirm our previous report that children with autism are distinguished by hypoesthesia and allodynia and delays of early self-regulation?[17]

2. Are tactile abnormalities related to delays of early self-regulation in the two groups when analyzed separately and together?

3. What is the prevalence and location of tactile abnormality in the autism group by parent report? Do therapist reports confirm parent reports?

METHODS

Research Design

The research design is a retrospective analysis of baseline tactile and self-regulatory data for pre-school children with autism and typical development gathered from the SSC validation study,[17] one previously published randomized control trial,[11] and one on-going randomized control trial evaluating the efficacy of massage for autism (clinical trial number NCT01801696 at clinicaltrials.gov; grant #MCH-HRSA R40MC24945). All studies were carried out with ethics committee approval.

Participants

Children with autism in previous studies were recruited from six regional early-intervention programs in Oregon by invitation letter to children receiving services for autism. Inclusionary criteria for the autism group were 1) age under six; 2) pre-existing diagnosis of autism and confirmation of diagnosis by DSM-IV criteria; 3) receipt of state-sponsored, early-intervention services for autism; 4) absence of other disability; 5) absence of psychotropic medications.

Parents of typically developing children in previous studies were recruited to complete the surveys from one childcare center, three mother support groups, and one toddler drop-in play center. Parents completed the surveys on a convenience basis. Inclusionary criteria for these children included 1) age between three and six, 2) no diagnosis of developmental delay or autism, and 3) no chronic medical condition.

Parent Reports

The Sense and Self-regulation Checklist (SSC) is a parent/caregiver measure of abnormal sensory responses and self-regulatory difficulties in preschool children, developed for use as an outcomes measure.[17] It has demonstrated acceptable levels of internal consistency (alpha = .87) and test-retest reliability (coefficient = .677). The Touch/Pain domain has an internal consistency of alpha = .749. Items are rated as Never (0), Rarely (1), Sometimes (2), or Often (3). The SSC can be viewed in its entirety online at http://www.qsti.org/QSTSensorySystemChecklist.pdf.

The touch/pain section consists of questions that gather information relative to unusually high pain thresholds to injury (hypoesthesia), and withdrawal/avoidance of gentle touch (allodynia) on six areas of skin (face, scalp, hands, feet diaper area and body skin). The questions are shown in **Table 1**.

The self-regulatory section asks for a rating of self-regulatory difficulties/delays relative to foundational self-regulatory milestones: regular sleep/wake cycles, regular appetite and digestion, regulation of orientation/attention, and the ability to self-soothe. There are 30 questions rated Never (0), Rarely (1), Sometimes (2), or Often (3). Scores of 'Sometimes' reflect self-regulatory difficulty; scores of 'Often' reflect self-regulatory delay.

Table 1. Touch/pain questions on the Sense and Self-regulation Checklist.

Question	Hypoesthesia	Allodynia	Skin area
Head bangs on a hard surface	√		Scalp
Head bangs on a soft surface	√		Scalp
Does not notice if the diaper is wet or dirty	√		Buttocks
Does not cry tears when hurt	√		
Cries tears when falls, scrapes skin, or gets hurt (this question is scored when answered in the negative)	√		
Face washing is difficult		√	Face
Haircuts are difficult		√	Scalp
Refuses to wear a hat		√	Scalp
Prefers to wear a hat		√	Scalp
Cutting fingernails is difficult		√	Fingers
Prefers to wear one or two gloves		√	Fingers/hands
Avoids wearing gloves		√	Fingers/hands
Cutting toenails is difficult		√	Toes
Will only wear certain footwear (e.g., loose shoes, no socks)		√	Toes/feet
Prefers to wear the same clothes day after day		√	Body
Will only wear certain clothes (e.g., no elastic, not tight, no tags, long or short sleeves or pants)		√	Body

Therapist Reports

Case records were completed by 27 therapists who had graduated from, or were enrolled in a training program in our qigong massage methodology for autism. The therapist massage provides organized tactile stimulation to the skin in a series of 12 movements that sequentially stimulate the back and sides of the head and body, followed by the torso, arms, fingers, legs, toes and soles. The face is not massaged. A full description of massage procedures can be found in the book.[20] Therapists were trained to closely observe the child's responses to touch on each part of the body, and modify the technique in the event of withdrawal or avoidance. Records were kept at the end of each visit to document specific areas of avoidance/withdrawal from touch on eight areas of the body: the scalp, fingers, toes, chest, abdomen, thighs, calves and soles.

Data Collection

Children with autism and typical development were identified from previous studies as described above, and SSC data collected from case records. Parent data reporting on hypoesthesia and allodynia by area was extracted from the SSC. If the item was marked 'never' or 'rarely', no tactile abnormality was noted. If the item was marked 'sometimes' or 'often', hypoesthesia or allodynia was noted. For the autism group, therapist data reporting on allodynia was extracted from treatment data sheets reporting withdrawal from touch by skin area at each massage visit. A positive result for allodynia on a given area was given if withdrawal was recorded on two out of three of the first treatment visits. Two therapist case records were incompletely filled out and were dropped from the analysis.

Statistical Analysis

Analysis of variance and post-hoc Scheffe test comparisons were used to determine whether parent data describing tactile and self-regulatory symptoms differentiated the autism group from the typical group on the basis of tactile abnormalities and self-regulatory delay. Scatter plots and regression analyses were used to determine whether tactile abnormalities were related to self-regulatory delay in both groups, analyzed separately and together. Simple descriptive statistics were used to assess the prevalence and location of hypoesthesia and allodynia in the autism group and to determine whether therapist reports confirmed parent reports.

RESULTS

Case records from a total of 266 pre-school children were identified from previous research studies. Of these, there were 128 case records for children with autism, and 138 for typically developing children. Ages of the autism group ranged from 2 through 5 years with a mean of 3.90 (SD = 1.14). Ages of the typical group ranged from 2 through 5 years with a mean of 3.89 (SD = 0.89). Of the autism group, 83.6% were male and 16.7% were female. Of the typical group children, 50.7% were male and 49.3% were female. Previous analyses using these data found no relationship between age or gender and the variables of interest here.[17]

1. Does parent data describing tactile and self-regulatory symptoms in the present study of 266 pre-school children with autism or typical development confirm our previous report that children with autism are distinguished by hypoesthesia and allodynia and delays of early self-regulation?[17]

Table 2 shows the MANOVA results for the two groups of pre-school children on the SSC. Overall differences in scores for Abnormal Touch/Pain response [F(1,264) = 204.3] and Self-Regulatory delay [F(1,264) = 254.4] are highly significant. Mean tactile scores for the two groups were Autism 21.81 (SD 7.97), and Typically Developing 9.91 (SD 5.47). Mean self-regulatory scores for the two groups were Autism 46.89 (SD 13.82), and Typically Developing 20.59 (SD 9.97).[17] Higher scores mean greater dysfunction. The two groups were significantly different from each other on all variables.

Table 2. Significant group differences between tactile and self-regulatory symptoms.

Tactile and Early Self-Regulation Domain	Autism (n=128) Mean (SD)	Typical (n=138) Mean (SD)	F (df)
Overall			54.94*** (4,261)
Total Tactile Mean (SD)	21.81 7.97	9.91 5.47	204.27*** (1,264)
Allodynia Mean (SD)	15.91 6.18	7.67 5.00	143.93*** (1,264)
# areas with allodynia Mean (SD)	3.65 1.28	1.79 1.36	131.63*** (1,264)
Hypoesthesia Mean score (SD)	2.69 1.74	1.33 1.22	61.83*** (1,264)
Overall			55.39*** (5,260)
Total Self-Regulation Mean (SD)	46.89 13.82	20.59 9.97	254.43*** (1,264)
Sleep Mean (SD)	6.15 2.79	3.50 2.16	67.97*** (1,264)
Digestion Mean (SD)	12.44 4.77	6.30 4.52	101.58*** (1,264)
Orientation/Attention Mean (SD)	8.62 3.74	2.99 2.48	193.63*** (1,264)
Self-soothing Mean (SD)	8.29 2.96	5.09 2.56	79.01*** (1,264)

*** $p < .001$

2. Are tactile abnormalities related to delays of early self-regulation in the two groups when analyzed separately and together?

The relationship between tactile and self-regulatory variables is shown graphically in the figures below. There was a direct linear relationship between tactile and self-regulatory variables in the two groups analyzed separately and together. In **Figure 1**, each of the two groups is shown separately, with the accompanying regression equation. The slopes do not differ significantly between the two groups. The interaction

term between group and Abnormal Tactile Response was not significant [F (1,265) = 0.180, p = .672). The constant for the autism group is significantly higher than that for the typical group, reflecting the more severe levels of abnormal touch/pain and self-regulatory scores. The R^2 value for each equation is significant. For the typically developing group, R^2 = .286 with F (1,136) = 42.57, p < .001. For the autism group, R^2 = .214 with F (1,126) = 34.41, p < .001.

Figure 2 displays the overall pattern of relationship between the two variables when both groups are included. The equation fits the data from both groups very well, with R^2 = .529 with F(1,264) = 296.10, p < .001.

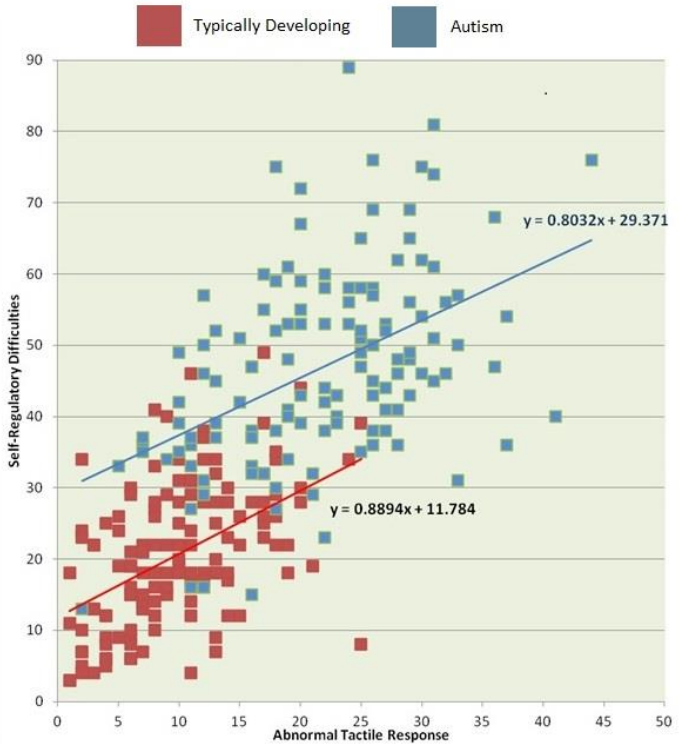

Figure 1. Relationship between abnormal tactile responses and self-regulatory difficulties by group.

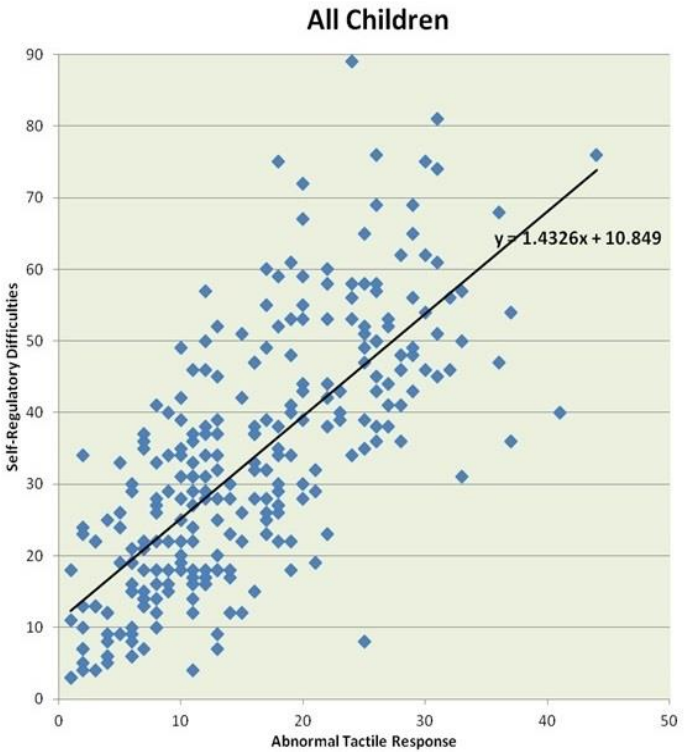

Figure 2. Relationship between abnormal tactile responses and self-regulatory difficulties for both groups.

3. What is the prevalence and location of tactile abnormality in the autism group by parent report? Do therapist reports confirm parent reports?

Prevalence of hypoesthesia and allodynia by parent report was calculated from SSC data for 128 children with autism. Parents reported signs of hypoesthesia in 65% of the sample, and signs of allodynia in 100% of the sample, confirming the presence of mixed hypoesthesia and allodynia. Therapist data for signs of allodynia were available for 121 children with autism; therapists did not evaluate hypoesthesia. Prevalence of therapist-reported allodynia was 98%, thus confirming parent-reported prevalence. Allodynia was multi-focal by both parent report and therapist exam in 91% of children. Parent and therapist data for prevalence of allodynia by specific location was highly correlated, e.g. for the scalp both reported a prevalence of 93%, and for the feet both reported a prevalence of 76%. Results are shown in **Table 3**.

DISCUSSION

This paper is the second report using the Sense and Self-Regulation Checklist that children with autism were distinguished by a severity of tactile abnormalities and delay of early self-regulation milestones. Parent-reported prevalence of tactile abnormality was 100%; therapist-reported prevalence was 98%. These rates are similar to an earlier study reporting 95% prevalence of tactile abnormalites using the Sensory Profile.[21] Confirmation of parent reports with therapist reports, and with two different evaluation instruments, mitigates bias introduced by parent reporting and supports the finding that the tactile abnormality was nearly universally present in the children with autism.

In order to assess the presence of allodynia on different skin locations in young children with autism, it was necessary to surmount the main obstacle that has prevented evaluation of abnormal tactile responses with quantitative sensory testing in this population, i.e. it is not a valid procedure to ask young children with autism to verbally describe symptoms of pain in response to testing. Instead, we used parent reports describing signs of allodynia - withdrawal/avoidance of non-injurious touch - relative to daily activities (e.g. cutting hair, nails, washing face), and withdrawal/avoidance responses relative to putting on specific articles of clothing (e.g. hats, shoes, gloves). This provided us with information about

withdrawal/avoidance of touch by skin area, in the context of daily life. To mitigate against misinterpretation of allodynia, we confirmed parent reports with therapist observations of withdrawal from touch on specific areas of the body in the context of massage. With this, we were able to confirm parent reports with therapist reports by area. The use of signs of allodynia, rather than symptoms and signs, is a limitation of the study that is imposed by the nature of the disability.

Table 3. Prevalence and location of abnormal tactile responses in the autism group by parent report and therapist exam.

Abnormal touch/pain response in autism group	Prevalence by Parent report (n=128)	Prevalence by Therapist exam (n= 121)
Hypoesthesia	64.8%	n/a
Allodynia of one or more areas	100%	98%
# of Areas with allodynia		
0	0%	2.3%
1	9.1%	6.3%
2	30.6%	7.8%
3	29.8%	20.3%
4	30.6%	34.4%
5	--	28.9%
Allodynia by area		
Face	65.6%	n/a
Scalp	93.0%	93.4%
Oral	93%	n/a
Hands/fingers	88.3% (hands)	52.1% (fingers)
Feet	75.8%	76.0%
Body skin:	42.2%	60.3%
Chest		30.6%
Abdomen		34.7%
Thighs		24.8%
Calves		32.2%

There can be little doubt that the severity of tactile abnormalities in the autism group is due to a pathological, rather than a physiological process. Evidence of pathological impairment of the sense of touch is particularly relevant to the study of autism, firstly because a normal sense of touch is of critical importance to social development,[22,23] and secondly because, of the triad of core features characteristic of autism. It is *social delay*, rather than communication delay or behavioral abnormalities, that distinguishes autism from the other neurodevelopmental disorders.[24] As such, determining the nature and etiology of tactile abnormalities in autism is likely to assist in unraveling the cause, treatment and prevention of social delay in autism.

As shown in **Table 2**, the mean severity of tactile scores for the autism group was more than twice that of the typical group, and the range of severity characterizing the autism group was quite neatly separated from the typical group. As previously reported,[17] the data showed hypoesthesia and allodynia on multiple areas of skin including face and hands. Although it is possible that mixed signs of tactile hypo and hyper-sensitivity were due to an unknown form of central processing disorder, as may be the case with auditory abnormalities[25] these are typical signs of a form of multifocal sensory neuropathy that is common in adults - small fiber neuropathy, in which there is damage to the small unmyelinated sensory fibers mediating pain and temperature.[19] The diagnosis of small fiber neuropathy can be made with 50% accuracy with psycho-physiological testing in adults, 80% accuracy with sweat testing,[26] and 90% accuracy with skin biopsy.[19] Data listed in Table 3 describing the most common locations of allodynia may help guide future researchers undertaking sweat testing or skin biopsy. Certainly, sensory neuropathy as an explanation for near universal tactile abnormalities in young children with autism should be urgently ruled out.

The finding that early self-regulation abilities were severely delayed in the autism group, proportional to severity of tactile abnormality, suggests that tactile impairment may have been sufficiently severe to pose a barrier to touch-mediated stimulation of early self-regulation abilities. The vast amount of attuned parent touch involved in infant and childcare provides the main impetus towards stimulation and maturation of early self-regulation.[16] In children with predominant allodynia, such touch would be likely to stimulate a withdrawal response and sympathetic nervous system activity, whereas in children with predominant hypoesthesia, it would be likely not register a response. Either way, tactile impairment would pose a barrier to touch-mediated stimulation of parasympathetic nervous system maturation.

The strong association between tactile abnormality and self-regulatory delay in the data, in view of the importance of touch to early self-regulation, introduces the possibility that tactile impairment may be a primary contributing cause of self-regulatory delay in autism. A recent study reporting significant improvement of self-regulatory delay following successful treatment of tactile abnormalities in 128 pre-school children lends preliminary support to this thesis.[27] Further study investigating the possibility that treatment of tactile abnormalities will improve the developmental base and lessen the severity of the autism in young children is ongoing.

Lastly, from a developmental perspective, it is important to consider the effect that severe global delay of self-regulation milestones in the first year would be expected to have on social and language development in the second and third years. The early self-regulation milestones form the foundation for the timely unfolding of development[15] and are required for the learning of language and social skills.[28,29] As such, severe global delay of first-year self-regulation milestones would be expected to result in delays of social and language development by the age of three.

In summary, while it is known that hearing and vision are normal in autism, there is no clear evidence that the sense of touch is normal in autism. This paper presents evidence that signs of tactile impairment suggestive of sensory neuropathy are nearly universally present in young children with autism, and directly related to severe delays of early self-regulation milestones needed for social development. A call to definitively evaluate the sense of touch in autism and rule out sensory neuropathy is made.

CONFLICT OF INTEREST

None.

ACKNOWLEDGEMENTS

This study was supported in part by grant R40 MC24945 from the MCH Autism Intervention Research Program, Maternal and Child Health Bureau (Combating Autism Act, 2006), Health Resources and Services Administration, Department of Health and Human Services. We wish to thank Kristen Gabrielsen for her work on editing this article.

FUNDING SOURCES

Curry Stone Foundation; Maternal and Child Health Bureau (Combating Autism Act, 2006), Health Resources and Services Administration, Department of Health and Human Services.

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