DEVELOPMENTAL SCREENING PRACTICES AND AUTISM AWARENESS
OF UTAH’S PRIMARY CARE PHYSICIANS: 2004 SURVEY RESULTS

Abstract
We conducted a mail survey of Utah family physicians (FPs) and pediatricians (Peds) asking about developmental screening and referral practices, autism spectrum disorder (ASD) awareness, and interest in Continuing Medical Education (CME) about ASDs. The response rate was 38% (35% for FPs, 41% for Peds). Most, but not all, respondents reported using an instrument to conduct developmental screening, and tended to refer children identified with delays for further evaluation. Few respondents were familiar with autism screening tools, and most respondents rated their knowledge of ASDs and comfort in identifying a child with an ASD as low to moderate. Nearly all respondents were interested in CME about ASDs. The results of this survey, even with its inherent limitations, can provide useful information for developing future CME programs for FPs and Peds.

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Background

Scientific literature regarding physician screening and referral patterns for developmental delays in children, including autism spectrum disorders (ASDs), is sparse. ASDs include classic autism, Asperger Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). A recent national survey of primary care physicians who see children in their practices (i.e., family physicians and pediatricians) asked how they identify and manage children with developmental delays (Sices, Feudtner, & McLaughlin, 2003; Sices, Feudtner, & McLaughlin, 2004). A similar survey of family physicians (FPs) and pediatricians (Peds) in Utah was conducted to assess their screening and referral practices, ASD awareness, and interest in continuing medical education (CME) regarding ASDs.

Approximately one in five children aged 0 through 17 years of age in the United States will have at least one developmental disability which is defined as hearing or vision loss, epilepsy or seizures, speech deficits, cerebral palsy, delayed development, learning disabilities, and emotional or behavioral problems (Boyle, Decoufle, & Yeargin-Allsopp, 1994). Children with developmental delays, including ASDs, can benefit from receiving early intervention services that promote their developmental progress and help to prepare them for school (American Academy of Pediatrics [AAP] Committee on Children with Disabilities, 2001). Children with the most severe delays are frequently identified early, but children with less obvious delays, including ASDs, are often not recognized until they are in school (Baird, Charman, & Cox, 2001; Filipek, Accardo, & Ashwal, 2000; King & Glascoe, 2003; Palfrey, Singer, & Walker, 1987; Smith, 2004; Sonnander, 2000; Yeargin-Allsopp, Rice, & Karapurkar, 2003).

While early intervention can be beneficial for children with developmental delays, including ASDs, it can be challenging to accurately identify such children, especially those with mild symptoms. It can be especially difficult to distinguish mild, temporary delays from similar, seemingly insignificant symptoms that are an early signal of a more critical problem. While no perfect developmental screening tool has yet been developed, there are many that have been tested for sensitivity, specificity, validity and reliability in diverse populations. Physicians do not always use screening tools for a number of reasons. Some physicians believe their clinical
impressions are adequate to identify children with delays even though the research on this issue finds that clinical impressions alone can miss children with developmental delays (AAP, 2001; Glascoe & Dworkin, 1993). Some physicians are hesitant to mention concerns, especially about mild delays, for fear that they will generate “overreferrals” or unnecessarily alarm parents (Glascoe, 2001; King & Glascoe, 2003). Finally, most third-party payers do not currently reimburse physicians for the total costs of their time, expertise and effort that are involved with screenings (AAP, 2001; Glascoe, Foster, & Wolraich, 1997; Halfon, Hochstein, & Harvinder, 2001).

Methods

A three-page, fourteen-question survey was designed that asked questions about the physicians’ training, practice location, screening practices (for overall development and emotional/behavioral health), awareness of autism screening tools, number of children seen and referred with developmental delays, number of children with ASDs in their practices, comfort and knowledge levels about ASDs, and interest in continuing medical education (CME) on ASDs. This survey was reviewed internally for clarity and content by the co-authors and other healthcare professionals, including two pediatricians. It was further pre-tested by a practicing pediatrician for usability. A copy of the cover letter and survey is included as an Appendix (See Appendix).

The surveys were mailed in February 2004 from the Utah Department of Health to current members of Utah’s chapter of the American Academy of Pediatrics, the Intermountain Pediatric Society, and to current members of Utah’s chapter of the American Academy of Family Physicians. The survey mailing included a cover letter, the survey, and a postage paid return envelope. If the respondent completed the bottom portion of the back page of the survey to request ASD information, this portion was removed prior to data entry to maintain the respondent’s confidentiality. Survey responses were then entered into an Epi-Info 2000 database, and statistical calculations were performed using Epi-Info 2000 statistical software (CDC, Atlanta, GA).

Results

Part I. Who Responded to the Survey?

Of the 916 surveys mailed out, 885 (97% of the total) were deliverable (Table 1). The response rate for physicians who received the survey was 38% (35% of FPs and 41% of Peds). While our response rate was lower than that cited in a national survey where 49.3% responded, we did experience a similar higher response rate from Peds versus FPs (Sices, et al, 2003). Responses from physicians who see only adults or specialists of any kind were considered ineligible because many of the questions were not applicable to their practices which left 247 eligible responses, 135 from FPs and 112 from Peds. The only information we had about non-responders was their name and address from the mailing lists.

Table 1
Number Of Completed Survey Responses And Response Rate By Specialty

<table>
<thead>
<tr>
<th>Number of surveys</th>
<th>Total</th>
<th>Family Physicians (FPs)</th>
<th>Pediatricians (Peds)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mailed</td>
<td>916</td>
<td>529</td>
<td>387</td>
</tr>
<tr>
<td>Undeliverable</td>
<td>31 (3% of total)</td>
<td>9 (2% of total)</td>
<td>22 (6% of total)</td>
</tr>
<tr>
<td>Delivered</td>
<td>885</td>
<td>520</td>
<td>365</td>
</tr>
<tr>
<td>Completed</td>
<td>335</td>
<td>184</td>
<td>151</td>
</tr>
<tr>
<td>(% response rate*)</td>
<td>(38% response rate)</td>
<td>(35% response rate)</td>
<td>(41% response rate)</td>
</tr>
<tr>
<td>Ineligible</td>
<td>88</td>
<td>49</td>
<td>39</td>
</tr>
<tr>
<td>Eligible responses</td>
<td>247</td>
<td>135</td>
<td>112</td>
</tr>
</tbody>
</table>

*Response rate is calculated based on the number of surveys delivered.

Table 2 shows the regions where the respondents practice medicine. The majority of both FP and Ped respondents practice medicine in the metropolitan Wasatch Front (i.e., Davis, Salt Lake, Utah and Weber Counties). The distribution of FPs’ practices differs from that of Peds’ practices; FPs’ practices are more widely distributed through the state (Chi-square for linear trend = 16.12; p<0.0001). This distribution is similar to that from the national study where FPs were more likely than Peds to practice in non-metropolitan areas (Sices, et al, 2003). The distribution of FPs and Peds by region did not differ significantly between respondents and non-respondents, based on a comparison of the counties where respondents reported practicing medicine versus the counties of the respondents’ and non-respondents’ mailing addresses (data not shown).

Table 2

<table>
<thead>
<tr>
<th>Region</th>
<th>Total (n=246)*</th>
<th>FPs (n=135)</th>
<th>Peds (n=111)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wasatch Front: Salt Lake, Utah, Davis, and Weber Counties</td>
<td>193 (78%)</td>
<td>93 (69%)</td>
<td>100 (90%)</td>
</tr>
<tr>
<td>Northern Utah: Box Elder, Cache, Morgan, Rich, Summit, Wasatch, and Tooele Counties</td>
<td>20 (8%)</td>
<td>14 (10%)</td>
<td>6 (5%)</td>
</tr>
<tr>
<td>Central and Southern Utah: Beaver, Carbon, Daggett, Duchesne, Emery, Iron, Juab, Garfield, Grand, San Juan, Sanpete, Sevier, Uintah, Kane, Millard, Piute, Washington, and Wayne Counties</td>
<td>29 (12%)</td>
<td>25 (19%)</td>
<td>4 (4%)</td>
</tr>
<tr>
<td>Multiple regions**</td>
<td>4 (2%)</td>
<td>3 (2%)</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

*1 Ped response missing  
**Physicians’ practice area includes counties in more than one region as defined in the above table.

Table 3 shows when the respondents graduated from medical school. The distribution of responses differed between FPs and Peds; FPs were more likely to be recent graduates than were Peds (Chi-square for linear trend = 15.55; p<0.0001). This difference may be attributable, in part, to 22 responses received from FP residents versus six responses received from Ped residents.

Table 3

<table>
<thead>
<tr>
<th>Year indicated on survey</th>
<th>Total (n=246)*</th>
<th>FPs (n=134)*</th>
<th>Peds (n=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995-2003</td>
<td>89 (36%)</td>
<td>61 (46%)</td>
<td>28 (25%)</td>
</tr>
<tr>
<td>1985-1994</td>
<td>83 (34%)</td>
<td>43 (32%)</td>
<td>40 (36%)</td>
</tr>
<tr>
<td>1975-1984</td>
<td>55 (22%)</td>
<td>26 (19%)</td>
<td>29 (26%)</td>
</tr>
<tr>
<td>Before 1975</td>
<td>19 (8%)</td>
<td>4 (3%)</td>
<td>15 (13%)</td>
</tr>
</tbody>
</table>

*1 FP response missing

Part II. Developmental and Autism Screening Knowledge and Practices

When asked if they routinely used developmental screening tools (including tools designed by themselves or by their practices), 86% of respondents said ‘Yes’ with no statistically significant difference between FPs and Peds (84% versus 88%, respectively) (Table 4).

Respondents were asked to indicate which screening tool (or tools) that they used from a list (See Appendix under Question 5). The most frequently chosen developmental screening tool

was the Denver II Developmental Screening Test (DDST): 48 FPs (36%) and 34 Peds (31%) selected it as their only choice; an additional 23 physicians selected it along with other choices. Other screening tools selected less frequently included the Pre-screening Developmental Questionnaire, Ages and Stages Questionnaire, and Child Development Inventories. Twenty-five physicians (14 FPs and 11 Peds) described screening tools that were designed either by themselves or by their practice.

Table 4
Responses To Screening Practices And Autism Screening Tools Awareness Questions By Specialty

<table>
<thead>
<tr>
<th>Survey question</th>
<th>Respondents replying ‘Yes’</th>
<th>FPs compared to Peds</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Do you routinely use developmental screening tools for well-child exams?” or “Have you and/or others in your practice constructed your own developmental screening methods that you routinely use for well-child exams?”</td>
<td>211 (86%) 113 (84%) 98 (88%)</td>
<td>0.97 (0.57, 1.68)</td>
</tr>
<tr>
<td>“Do you routinely screen for emotional or behavioral concerns in children from birth to five years of age?”</td>
<td>172 (70%) 77 (57%) 95 (86%)</td>
<td>0.23 (0.12, 0.43)</td>
</tr>
<tr>
<td>“Are you familiar with any tools designed to specifically screen for autism?”</td>
<td>50 (20%) 8 (6%) 42 (38%)</td>
<td>0.11 (0.05, 0.24)</td>
</tr>
</tbody>
</table>

*1 FP and 1 Ped response missing
**CI = Confidence Interval

Screening for emotional or behavioral concerns was reported less frequently (by 70% of respondents), and FP respondents were less likely than Ped respondents to report doing this type of screening (57% versus 86%, respectively) (Table 4). Respondents who indicated that they conducted emotional or behavioral screening were asked to describe how they did this. Responses to the question included combinations of taking a history; observing the child and parent; asking questions designed to address emotional and/or behavioral issues; and, assessing developmental screening results from the well-child examination. Three FP respondents and three Ped respondents named a specific instrument that they used to conduct emotional and behavioral screening.

Only 20% of the respondents reported that they were familiar with autism screening tools. FP respondents were less likely than Ped respondents to report familiarity with such tools (6% versus 38%, respectively) (Table 4). Respondents who indicated that they were familiar with autism screening tools were asked to select which tools from a list (See Appendix under Question 7). The most frequently recognized autism-screening tools reported by the respondents were the Autism Behavior Checklist, Checklist for Autism in Toddlers, and the Pervasive Developmental Disorders Screening Test.

Part III. Screening and Referral Practices

When asked to estimate the percentage of children six months to five years of age that they had seen in the past three months with delays in speech, language and/or social skills, most respondents selected either “0-1%” or “2-5%” (Table 5). After excluding the “Not sure” responses from comparison, FP respondents differed from Ped respondents, and reported seeing a lower percentage of young children with delays than Ped respondents (Chi-square = 54.01, p<0.0001) (Table 5). When asked to estimate what percentage of these children with delays that they had referred for further evaluation, 67% of all respondents reported that they referred at least 25% of such children for further evaluation (64% of FPs and 69% of Peds, respectively) (Table 6).

Table 5

Responses To The Following Question By Specialty: “Please estimate what percentage of all the young children (from six months to five years of age) that you have seen in the past three months for well-child exams that have presented with delays in speech, language, and/or social skills.”

<table>
<thead>
<tr>
<th>Answer selected</th>
<th>Total (n=241)*</th>
<th>FPs (n=133)*</th>
<th>Peds (n=108)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not sure</td>
<td>9 (4%)</td>
<td>6 (5%)</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>0-1%</td>
<td>85 (35%)</td>
<td>70 (53%)</td>
<td>15 (14%)</td>
</tr>
<tr>
<td>2-5%</td>
<td>117 (49%)</td>
<td>54 (41%)</td>
<td>63 (58%)</td>
</tr>
<tr>
<td>5-10%</td>
<td>27 (11%)</td>
<td>3 (2%)</td>
<td>24 (22%)</td>
</tr>
<tr>
<td>&gt;10%</td>
<td>3 (1%)</td>
<td>0 (0%)</td>
<td>3 (3%)</td>
</tr>
</tbody>
</table>

*2 FP and 4 Ped responses missing
Table 6

Responses To The Following Question By Specialty: “Of the young children with delays in speech, language and/or social skills, please estimate what percentage you referred for further evaluation.”

<table>
<thead>
<tr>
<th>Answer selected</th>
<th>Total (n=227)*</th>
<th>FPs (n=119)*</th>
<th>Peds (n=108)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>0% referred, but the physician completed the evaluation</td>
<td>20 (9%)</td>
<td>15 (13%)</td>
<td>5 (5%)</td>
</tr>
<tr>
<td>0% with no further evaluation reported</td>
<td>7 (3%)</td>
<td>6 (5%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>&lt;25%</td>
<td>48 (21%)</td>
<td>21 (18%)</td>
<td>27 (25%)</td>
</tr>
<tr>
<td>25% - 75%</td>
<td>69 (30%)</td>
<td>29 (24%)</td>
<td>40 (37%)</td>
</tr>
<tr>
<td>&gt;75%</td>
<td>83 (37%)</td>
<td>48 (40%)</td>
<td>35 (32%)</td>
</tr>
</tbody>
</table>

*16 FP and 4 Ped responses missing

When asked to “Please check all that apply” from a list of referral choices to indicate where they would refer children with delays who were between six months and five years of age for further evaluation, a majority of respondents selected “Early Intervention Program” (59%) and “Physician Specialist” (53%). FP respondents were more likely than Ped respondents to choose only one referral option versus more than one referral option; 60 of the 131 FP respondents chose one option while 20 of the 110 Ped respondents chose one option (OR = 3.80; 95% CI = 2.02, 7.21). The remaining 71 FP respondents and 90 Ped respondents chose more than one option. FP respondents were less likely than Ped respondents to select “Early Intervention Program”, “Special Education Program”, and “Children with Special Health Care Needs”, and were more likely to select “Not sure” (although only 14 FP respondents and two Ped respondents chose this option). There was no statistical difference between FP and Ped respondents for “Physician Specialists” and “Other Developmental Specialists” (Table 7). Respondents who chose to name “Other” referral options listed hospital-based programs, audiologists, public assistance programs, and programs for children with ASDs.
Table 7
Where Physicians Refer Children With Delays By Specialty

<table>
<thead>
<tr>
<th>Resource/Program selected†</th>
<th>Total (n=241)*</th>
<th>FPs (n=131)*</th>
<th>Peds (n=110)*</th>
<th>FPs compared to Peds</th>
<th>Odds Ratio (95% CI**)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Intervention Program</td>
<td>141 (59%)</td>
<td>49 (37%)</td>
<td>92 (84%)</td>
<td>0.11 (0.05, 0.23)</td>
<td></td>
</tr>
<tr>
<td>Special Education Program</td>
<td>24 (10%)</td>
<td>5 (4%)</td>
<td>19 (17%)</td>
<td>0.20 (0.06, 0.68)</td>
<td></td>
</tr>
<tr>
<td>Children with Special Health Care Needs</td>
<td>62 (26%)</td>
<td>13 (10%)</td>
<td>49 (45%)</td>
<td>0.16 (0.07, 0.33)</td>
<td></td>
</tr>
<tr>
<td>Physician Specialist</td>
<td>127 (53%)</td>
<td>65 (50%)</td>
<td>62 (56%)</td>
<td>0.79 (0.43, 1.42)</td>
<td></td>
</tr>
<tr>
<td>Other Developmental Specialist</td>
<td>108 (45%)</td>
<td>47 (36%)</td>
<td>61 (55%)</td>
<td>0.57 (0.31, 1.03)</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td>16 (7%)</td>
<td>14 (11%)</td>
<td>2 (2%)</td>
<td>7.98 (1.66, 52.36)</td>
<td></td>
</tr>
</tbody>
</table>

†Please note that respondents could select more than one choice
*4 FP and 2 Ped responses missing
**CI = Confidence Interval

Part IV. Experience with Autism Spectrum Disorders in Your Practice

When asked if any parents had expressed concern about the possibility of an ASD in their child in the past year, FP respondents were less likely than Ped respondents to indicate “Yes” (39% versus 88%, respectively; OR = 0.09, 95% CI = 0.04, 0.17). When asked to estimate the number of children they had seen in the past year who have an ASD, the distribution of responses differed between FPs and Peds; FP respondents tended to report seeing fewer children with an ASD than did Ped respondents (Chi-square for linear trend = 87, p<0.0001; responses of “Not sure” were not included in this calculation) (Table 8).

Table 8
Response To The Following Question By Specialty: “Please estimate the number of children you have seen in the past year who have an autism spectrum disorder.”

<table>
<thead>
<tr>
<th>Response selected</th>
<th>Total (n=240)*</th>
<th>FPs (n=131)*</th>
<th>Peds (n=109)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>99 (41%)</td>
<td>88 (67%)</td>
<td>11 (10%)</td>
</tr>
<tr>
<td>2-10</td>
<td>115 (48%)</td>
<td>34 (26%)</td>
<td>81 (74%)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>13 (5%)</td>
<td>1 (1%)</td>
<td>12 (11%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>13 (5%)</td>
<td>8 (6%)</td>
<td>5 (5%)</td>
</tr>
</tbody>
</table>

*4 FP and 3 Ped responses missing

When asked to rate both their current knowledge level about ASDs and their degree of comfort in identifying a child with an ASD on scales from 1 (low) to 10 (high), respondents tended to rate themselves in the 4-6 range for both categories. FP respondents gave themselves lower
ratings than did Ped respondents (Two-way ANOVA T statistic for Knowledge level = 9.3, p<0.0001; for Comfort level = 8.6, p<0.0001) (Table 9).

Table 9
Self-Reported Knowledge Level And Comfort Level By Specialty

<table>
<thead>
<tr>
<th></th>
<th>FPs (n=133)*</th>
<th>Peds (n=110)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge level about ASDs</td>
<td>Mean score of 3.7 (range 1-10)</td>
<td>Mean score of 5.8 (range 2-9)</td>
</tr>
<tr>
<td>Degree of comfort in identifying a child as having an ASD</td>
<td>Mean score of 3.4 (range of 1-9)</td>
<td>Mean score of 5.6 (range 2-9)</td>
</tr>
</tbody>
</table>

*2 FP and 2 Ped responses missing

Part V. Continuing Medical Education (CME) Preferred Topics and Formats

Nearly all respondents (except for two FPs and two Peds) were interested in CME that provided information on ASDs. "How to screen children for ASDs and refer for further evaluation" was the most popular topic. “Lecture or presentation at local conference” was the most popular format. The 1-2 hour length of presentation was the most popular for a majority of both FP and Ped respondents; a half-day or longer was selected by approximately one-fifth of Ped respondents.

Discussion

To the best of our knowledge, this survey is the first study of Utah primary care physicians’ developmental screening and referral practices, and autism awareness. We were encouraged to learn that 86% of Utah respondents (84% of FPs and 88% of Peds) use some tool to conduct general developmental screening of young children in their practices. A recent national survey found that 47% of primary care physicians (46% of FPs and 47% of Peds) indicated that they used a standardized screening instrument for developmental assessments (Sices, et al, 2003). The consistent use of a developmental screening instrument should assist with the early identification of children with developmental delays, including ASDs. The reported rate of use of any screening tool by Utah primary care physicians was high, but the figures include physicians who use standardized screening instruments as well as those who use practice- or self-designed instruments. The reported use of self- or practice-designed screening tools would indicate that some providers might not be using clinically validated tools. Similar to the national trend, the DDST remains the first choice of Utah primary care physicians (Sices, et
It is possible, because of the time involved with the administration of the DDST, that some providers might be using this screening tool in a non-standardized manner (Sices et al, 2003). There are parent-completed questionnaires that require less provider time than physician-administered tools, such as the Parents' Evaluation of Developmental Status, and Ages and Stages Questionnaire, among others (AAP, 2001). Few respondents reported using these tools.

It may be worthwhile for Utah primary care physicians to consider the use of parent-completed questionnaires; these clinically validated instruments are able to identify children with developmental delays and require less physician time than provider-administered examinations (AAP, 2001). Emotional and behavioral screening was less commonly reported than general developmental screening. The reported difference between FPs and Peds in this area may be due to their perception of the question. Peds spend more time in their professional training than FPs studying the emotional and behavioral development of children and, thus, may have placed a different emphasis on this issue. The majority of responses from those who reported conducting such screening suggested that they integrate this screening into their general developmental screening. Since some general developmental screening instruments are not designed to specifically identify children with emotional or behavioral problems, this approach could miss some children. Screening tools are available, such as the Child Behavioral Checklist, and The Carey Temperament Scales, among others (AAP, 2001). There appears to be a genuine need in Utah for primary care physicians to receive education about the use of clinically validated screening tools that can identify children at risk for emotional or behavioral problems.

A majority of respondents reported a willingness to refer children with developmental delays for further evaluation, although the referral patterns to community resources differed significantly between FPs and Peds. We did not ask respondents if they thought the resources in their communities were adequate or effective in addressing the needs of children with delays. This information may have been useful to better understand why some physicians may not prefer to use certain resources (Cunningham, 2004). There does appear to be a need for education and
outreach efforts, particularly by Early Intervention Programs, Special Education Programs, and Children with Special Health Care Needs targeted especially towards FPs.

The nearly universal interest in CME focusing on “How to screen children for ASDs and refer for further evaluation” was very encouraging, especially in light of the generally limited self-reported awareness of autism screening tools and ASDs. While it is likely that most children suspected of having an ASD would eventually be referred to specialists for further evaluation, an understanding by primary care physicians about autism screening tests may help them to better and more quickly identify children who need such a referral. This limited awareness of autism screening tools also means that the specialists who conduct evaluations for ASDs should anticipate questions from both primary care physicians and families. While nearly all respondents were interested in CME focusing on ASDs, more Peds were interested in longer programs than FPs. This is likely a reflection of their respective practice compositions, as Peds were more likely to report being asked about ASDs in the past year and to report caring for a higher number of children with ASDs than were FPs.

Our study has the expected limitations of a survey conducted by mail. We have limited information about non-responders; we do know, however, that the geographic distribution of responders’ practices does not differ from the distribution of non-responders and responders’ mailing addresses. This limited geographic comparison cannot exclude the possibility of a bias among responders versus non-responders being responsible for at least some of the differences between FPs and Peds. We also used the membership lists from Utah’s chapters of the AAFP and the AAP; we do not know if their members are necessarily representative of all practicing primary care physicians. Plus, our results are based on survey responses, and not direct observation of physician practices or direct evaluation of physician knowledge. While we did pre-test the questions, it seems in retrospect that at least one of the questions may have provided more useful information had it been written differently. The first part of the screening and referral question (Question 8, Part 1) asked respondents to indicate a percentage of children seen with developmental delays within an expressed time frame, but the second part of the screening and referral question (Question 8, Part 2) did not provide a clear option for some respondents who
reported seeing zero children with developmental delays. The 16 Family Physician and 4 Pediatrician responses that were missing to the second part of the question may have represented practitioners who had not identified a child with developmental delays in the past three months. In retrospect, we also would have liked to include two additional questions. One would have asked the ages at which children routinely received developmental screenings, and the other would have asked about the physicians’ belief in the usefulness/effectiveness of their community resources for children with delays.

Even with the above limitations, we believe this survey can be a useful tool in understanding the screening and referral practices and autism awareness of FPs and Peds in Utah. This information could be particularly useful in designing future CME programs that focus on: the benefits of developmental screening; the expanded use of screening for emotional and behavioral concerns; awareness of and access to community referral resources; and, awareness of autism screening tools and ASDs. Programs targeting either FPs or Peds could be further focused based on each group’s unique needs. Projected future analyses of the survey data that compare rural versus urban physicians, or more recent versus less recent medical school graduates may provide additional information to assist with CME planning. Children with developmental delays, including ASDs, who are identified early and receive appropriate therapies have a better chance of meeting their maximum potential in the long run (AAP, 2001; Baird, et al, 2001; Filipek, et al, 2000; King & Glascoe, 2003). Physicians who see these young children for routine care are in an excellent position to identify and refer them, and should not miss the opportunity to do so.

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References


Appendix. Cover Letter and Survey

Cover Letter

Dear Health Care Provider,

Autism is generating a lot of interest lately, primarily because of widespread concern about the increase in the number of children who are affected. While our understanding of autism has improved since the first description of the condition was published, much remains unknown. The Utah Department of Health is collaborating with the University of Utah Department of Psychiatry to study the epidemiology of autism spectrum disorders (i.e., Autism, Asperger Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified) in Utah. The project will involve conducting a prevalence study of autism spectrum disorders, establishing a statewide registry of affected persons, and conducting a campaign to enhance awareness of these conditions.

An integral part of the awareness campaign will be to sponsor continuing education programs for health care providers. These will focus on autism spectrum disorders and other issues related to the development and mental health of infants and children. This brief survey was sent to you to help us better understand your needs for information on developmental screening, including screening for autism. We would also like to know what sort of educational programs you would prefer and in what format(s).

The enclosed survey should take no more than 10 minutes of your time. Your answers will help us plan for future continuing education programs. Your responses will be kept confidential and we will not disclose your personal information to others. A postage-paid, self-addressed envelope is included for you to return the survey. We hope you will take the time to fill out and return the survey and want to thank you in advance for your participation.

AUTISM AWARENESS SURVEY FOR HEALTH CARE PROVIDERS

1. Are at least 10% of the patients you see younger than 19 years of age?
   [ ] Yes
   [ ] No  If ‘No’, please STOP HERE. Thank you for your participation.

2. Which of these best describes your current primary profession? (Please choose one.)
   [ ] Physician – If so, what is your specialty? _________________________________
   [ ] Nurse Practitioner
   [ ] Physician’s Assistant
   [ ] Nurse
   [ ] Psychologist – If so, what is your specialty? _______________________________
   [ ] Other – If so, please specify: ___________________________________________ 

3. In which county or counties do you practice? (Please check all that apply.)
   [ ] Beaver  [ ] Box Elder  [ ] Cache  [ ] Carbon  [ ] Davis
   [ ] Daggett  [ ] Duchesne  [ ] Emery  [ ] Garfield  [ ] Grand
   [ ] Iron  [ ] Juab  [ ] Kane  [ ] Millard  [ ] Morgan
   [ ] Piute  [ ] Rich  [ ] San Juan  [ ] Salt Lake  [ ] Sanpete
   [ ] Sevier  [ ] Summit  [ ] Tooele  [ ] Uintah  [ ] Utah

4. In what year did you graduate from medical, nursing, or PA school? ________________

5. Do you routinely use developmental screening tools for well-child exams?
   [ ] Yes  [ ] No
   If ‘Yes’, please indicate which tool(s) you use. (Please check all that apply.)
   [ ] Ages and Stages Questionnaire (ASQ)
   [ ] Brigance Screens
   [ ] Clinical Development Inventories (CDI)
   [ ] Clinical Adaptive Test/Clinical Linguistic Adaptive Milestone Scale (CAT/CLAMS)
   [ ] Denver II Developmental Screening Test (DDST)
   [ ] Minnesota Child Developmental Inventory (MCDI)
   [ ] Parent’s Evaluations of Developmental Status (PEDS)
   [ ] Pre-Screening Developmental Questionnaire (PDQ)
   [ ] Other – Please specify: _________________________________________________

Have you and/or others in your practice constructed your own developmental screening methods that you routinely use for well-child exams?
   [ ] Yes  [ ] No

6. Do you routinely screen for emotional or behavioral concerns in children from birth to five years of age?
   [ ] Yes  [ ] No
   If so, how do you do this? ________________________________________________

(Please continue your answer on the back of the page if needed.)
7. Are you familiar with any tools designed to specifically screen for autism?  
   [ ] Yes  [ ] No  

If 'Yes', please indicate which tools you are familiar with. (Please check all that apply.)

[ ] Autism Behavior Checklist (ABC)  
[ ] Autism Diagnostic Interview-Revised (ADI-R)  
[ ] Autism Screening Questionnaire (ASQ)  
[ ] Checklist for Autism in Toddlers (CHAT)  
[ ] Childhood Autism Rating Scale (CARS)  
[ ] Gilliam Autism Rating Scale (GARS)  
[ ] Modified Checklist for Autism in Toddlers (M-CHAT)  
[ ] Parent Interview for Autism (PIA)  
[ ] Pervasive Developmental Disorders Screening Test (PDDST)  
[ ] Autism Diagnostic Observation Schedule (ADOS)  
[ ] Screening Tool for Autism in Two-Year-Olds (STAT)  
[ ] Other – Please specify: __________________________________________________

8. Please estimate what percentage of all the young children (from eighteen months to five years of age) that you have seen in the past three months for well-child exams that have presented to you with delays in language and/or social skills. (Please choose one.)  
   [ ] 0-1%  [ ] 2-5%  [ ] 5-10%  [ ] Greater than 10%  [ ] I am not sure  

Of the young children with delays in language and/or social skills, please estimate what percentage you referred for further evaluation? (Please choose one.)  

[ ] 0%  If '0%', did you complete the further evaluation?  [ ] Yes  [ ] No  
[ ] Less than 25%  [ ] 25-75%  [ ] Greater than 75%  

9. If you were to refer a child between eighteen months and five years of age for further evaluation, where would you refer them? (Please check all that apply.)  
   [ ] I am not sure where to refer children for further developmental evaluations.  
   [ ] Early Intervention Program  
   [ ] Special Education Program  
   [ ] Children with Special Health Care Needs Program  
   [ ] Physician Specialist (i.e., Psychiatrist, Developmental Pediatrician, Neurologist, etc.)  
   [ ] Other Developmental Specialist (i.e., Child Psychologist, Speech Pathologist, etc.)  
   [ ] Other – Please specify: _____________________________________________

10. Have any parents of the children you have seen in the past year expressed concern about the possibility of an autism spectrum disorder in their child?  
    [ ] Yes  [ ] No  

11. Please estimate the number of children that you have seen in the past year who have an autism spectrum disorder? (Please choose one.)  
    [ ] 0-1  [ ] 2-10  [ ] Greater than 10  [ ] I am not sure
12. Please rate your current knowledge level about autism spectrum disorders and your degree of comfort in identifying a child with an autism spectrum disorder. (Please circle the corresponding number at the place along the spectrum that best describes you.)

Your knowledge level about autism spectrum disorders:
Low---------------------------------Medium---------------------------------High
1  2  3  4  5  6  7  8  9  10

Your degree of comfort in identifying a child as having an autism spectrum disorder:
Low---------------------------------Medium---------------------------------High
1  2  3  4  5  6  7  8  9  10

13. In which continuing education topic(s) on autism spectrum disorders (ASDs) might you be interested? (Please check all that apply.)
[ ] Basic information about ASDs
[ ] How to screen children for ASDs and refer for further evaluation
[ ] How to diagnose ASDs
[ ] How to treat children with ASDs
[ ] Other – If so, please specify: __________________________________________
[ ] I am not interested at this time

14. How do you prefer to receive continuing education? (Please check all that apply.)
[ ] Web-based program over the Internet
[ ] Lecture or presentation at local conference
[ ] Information sent by mail
[ ] Other – If so, please specify: __________________________________________

What length of lecture or presentation would you most prefer? (Please choose one.)
[ ] One to two hours
[ ] One-half day (Four hours)
[ ] Full day (Eight hours)
[ ] Other – If so, please specify: __________________________________________

If you would like to receive informational materials on ASDs, please complete the information below:

Name: __________________________________________________________________
Mailing address: __________________________________________________________
City: ____________________________ Zip: __________

Thank you for your participation! Please place the completed survey in the postage-paid, self-addressed envelope and return it to the Utah Department of Health.