Early Identification of Developmental Delays Through Surveillance, Screening, and Diagnostic Evaluation

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Developmental and behavioral problems in young children are prevalent in the United States. While young children experience an increased prevalence of such problems, a lack of early identification services continues to exist. Not only are early identification services required under American law, such as the Individual with Disabilities Education Improvement Act, these services increase access to appropriate care and improve developmental outcomes. The purpose of this manuscript is to describe the range of early identification services available during early childhood. These services include surveillance, screening, and developmental and medical diagnostic evaluation. Findings from a web-based survey are summarized to illustrate screening practices of community health care providers in a Midwestern state. Recommendations to improve early identification practices on the basis of the literature and the findings from the survey are discussed. Key words: child find activities, developmental delays, early childhood, early identification

The American Academy of Pediatrics (AAP, 2006) recommends that all children receive early identification services including surveillance, screening, and, if needed, developmental or medical diagnostic evaluation. Consistent with the AAP recommendations are Child Find activities as outlined in the American law also known as the Individuals with Disabilities Education Improvement Act (IDEA, 2004). Child Find activities are methods and procedures utilized by service providers to locate and identify children who are in need of early intervention Part C services and are required under the law (Dunst, Trivette, Appl, & Bagnato, 2004). The emphasis on early identification of developmental concerns and referral to early intervention services is based on the mounting evidence indicating that early identification leads to improved outcomes for children (AAP, 2006).

Surveillance, a useful early identification method, can be performed by a wide range of service providers who are trained in health-related disciplines. When conducting developmental surveillance, providers use a systematic means of discerning developmental risk (trauma, violence, abuse) and protective factors (nurturing relationships, adequate nutrition, safe environment). Surveillance is less formal when compared with the screening and includes listening to familial concerns, maintaining an accurate history and record of concerns, and using observations...
Surveillance does not entail the use of a standardized instrument to determine whether further diagnostic evaluation is warranted (AAP, 2006). While health care providers such as physicians most commonly engage in surveillance activities, surveillance alone is not the most effective in detecting developmental delays and is associated with poor sensitivity (Rydz, Shevell, Majner, & Oskoui, 2005). To augment surveillance, developmental screening is recommended. Screening differs from surveillance in that screening involves the use of a standardized instrument to determine whether further diagnostic evaluation is warranted. Screening does not result in a diagnosis or a definitive treatment plan; however, when screening is paired with surveillance methods, there is an improvement in referral rates for diagnostic evaluation and subsequent intervention (Hix-Small, Marks, Squires, & Nickel, 2007). All children should be formally screened using a standardized instrument (AAP, 2006). The AAP recommends that the physicians conduct general developmental screening at 9, 18, 24/30 months. Autism-specific screening should be completed at 18 and 24 months, respectively. These ages correspond to well-child visits and represent a period when developmental milestones should be observed. Despite the recommendations of the AAP and the availability of cost-free screening, the detection of developmental disorders is significantly lower than the actual prevalence (AAP, 2006; Riportella-Muller et al., 1996).

To address the gap between the prevalence of developmental disorders and actual screening practices, the AAP (2006) published a comprehensive list of instruments that accurately identify children at risk for developmental delays. Among the comprehensive list of recommended screening instruments are parent-completed screening questionnaires and provider-administered screening instruments. An example of a parent-completed screening instrument is the Ages and Stages Questionnaire (ASQ) (Bricker & Squires, 1999). This instrument is norm referenced and provides information about a child’s communication, gross motor, fine motor, problem-solving, and personal adaptive skills. In addition, the AAP (2006) recommends autism-specific parent-completed questionnaires, including the Checklist for Autism in Toddlers (Baird et al., 2000) and the Modified Checklist for Autism in Toddlers (Dumont-Mathieu & Fein, 2005). While the Checklist for Autism in Toddlers and Modified Checklist for Autism in Toddlers are both parent-completed instruments, they differ from the ASQ in that they do not screen for global or broad developmental delays. The main advantage of parent-completed questionnaires is their versatility and cost-effectiveness (Dobrez et al., 2001). Parents can complete the questionnaires on their own time and then discuss the results with a provider. Providers need to spend time with the parents reviewing the results of the screening to understand their concerns and link parents to resources if a formal evaluation is needed. A main disadvantage of parent-completed questionnaires is that the provider may not have the opportunity to directly observe the child’s behaviors.

In contrast to the parent-completed instruments are provider-administered instruments. The Battelle Developmental Inventory (Newborg, 2005) and Denver II Development Screening Test (Frankenburg, Camp, & van Natta, 1971) are examples of provider-administered instruments recommended by the AAP (2006). These instruments are designed to screen personal, social, adaptive, motor, communication, and cognitive development, and allow the provider to directly observe a child’s behavior. Provider-administered instruments are less versatile in that they require certain materials, space, and administration time (Dobrez et al., 2001).

Developmental and medical diagnostic evaluations differ from surveillance and screening as these evaluations confirm or rule out a diagnosis and provide the basis for an intervention plan. For example, at 18 months of age a child should be pointing, demonstrating aspects of joint attention, and
using language skills to communicate wants and needs. A lack of these skills, as determined through surveillance and screening, may warrant a referral for a developmental or medical diagnostic evaluation to rule out autism. Developmental and medical diagnostic evaluations involve the expertise of physicians and frequently involve other early childhood specialists. Developmental evaluations are conducted to identify a specific diagnosis, whereas a medical diagnostic evaluation is completed to understand the etiology or cause of a disorder (AAP, 2006). For example, a medical diagnostic evaluation may include genetic testing to determine whether the disorder is caused by a genetic anomaly. In contrast, surveillance and screening methods identify risk for a diagnosis and can be performed by providers from multiple backgrounds including early childhood providers, public health professionals, or early intervention providers. To conduct surveillance and screening, providers need proper training in systematic collection of developmental risk and protective factors, administration of screening instruments, communication of results to the parents, and suitable information about referral for diagnostic evaluation.

When a screening result is cause for concern, providers need to communicate the results to the family in a way that is supportive but direct. Fant, Clark, and Kemper (2005) outline 7 recommendations for parental education in relation to communicating newborn screening results. Although newborn screening is different from developmental and behavioral screening, the recommendations for newborn screening may be helpful for early intervention providers. Therefore, the AAP (2005) recommendations have been modified to better meet the needs of providers who are screening children for a developmental or behavioral problem and are outlined herein.

First, the provider should explain the benefits of screening to the parents. Parents should be informed that a positive screening result does not confirm that a child has a diagnosis. Parents should be informed, however, that if a delay is confirmed following diagnostic evaluation, they may pursue early intervention services that can help their child develop to his or her fullest potential. Second, the provider should explain the potential risks associated with screening. That is, even though the screening may suggest a delay, the subsequent diagnostic evaluation could indicate that an actual delay is not present. Scheduling and waiting for the results of a diagnostic evaluation may cause stress for the family. The provider should reassure the family that they are available to support the family during this time and to answer any questions regarding the screening. Third, the provider should describe the methods by which parents will be informed of the results. In this instance, parents need to know whether they will be notified regardless of the screening results. Fourth, the provider should explain the importance of seeking diagnostic evaluation following a positive screen and subsequently link the family to the appropriate medical providers. Finally, parents should be informed if there is a fee associated with the screening.

While the benefits of detection of developmental and behavioral problems through early identification methods are recognized as best practice, little is known about the developmental screening practices of community health care providers. We utilized web-based survey methodology to better understand community health care professionals’ maternal and child screening practices. The child developmental screening practices are reported herein.

SUMMARY OF DEVELOPMENTAL SCREENING SURVEY

A web-based survey was used to elicit responses regarding the type of screening instruments most frequently used to detect developmental delays in children. Web-based surveys are an effective and efficient method of conducting survey research (Sills & Song, 2002; Zhang, 1999). All study procedures were approved by the institutional
Participants

The invitation to participate was sent to a nonprobability sample of approximately 600 providers in a Midwestern state. One hundred twenty-nine providers entered the web-based survey system and 78 (60%) completed the entire survey. The sampling frame (Draugalis, Coons, & Plaza, 2008) consisted of respondents who serve families and children aged birth to 5. Professionals were specifically recruited if they provided services in the following programs: early intervention, Women, Infants and Children, Headstart, public health, and childcare. Participants were recruited to take the survey through electronic list serves, via professional newsletters, and at professional meetings.

Screening survey

The survey was developed from focus group feedback \(n = 15\) and interviews \(n = 2\) conducted with community health care providers. The focus group and interviews were audio recorded and the recordings were transcribed. Content analysis was used to draft the survey questions. A paper draft of the survey was administered to 20 community health care providers, and they were asked to provide comments after each question regarding the question’s clarity and usefulness. Cognitive interviews about question clarity and usefulness were conducted with 3 of the 20 community health care providers. A team of experts reviewed the comments provided by the 20 participants and the final survey was created. The survey consisted of 72 questions and took approximately 30 minutes to complete.

Procedures

The web-based survey system was supported by a state agency in the Midwest. Participants whose e-mail addresses appeared on electronic list serves were sent an e-mail invitation that contained a link to access the survey. Invitations to take the survey were also published in statewide newsletters and announced at a statewide professional meeting for maternal and child health providers. The survey was available on the web-based system for a period of 4 months. Three e-mail reminders to take the survey were sent during the first week of each month. When the online survey was closed, responses were downloaded into an Excel spreadsheet. Narrative responses from the open-ended categories were reviewed, categorized, and coded. All coded data were exported into SPSS version 17 for descriptive analysis.

Data analysis

Descriptive statistics were used to analyze survey data. At each stage of the survey, descriptive characteristics were calculated on the basis of the number of respondents completing that section. Descriptive analyses included the assessment of frequency and percentage data for the type of screening instruments used, barriers to developmental screening, and interventions viewed as important to increase developmental screening. In addition, preliminary results were presented for review by a policy and advocacy committee responsible for implementing policy changes in the state. Members of the committee included state employees, academicians, and professionals involved in the provision of services to children and their families. The purpose of this review was to receive feedback regarding the nature of the findings and to evaluate how the data may be used to influence policy decisions.

SUMMARY OF SURVEY RESULTS

Of the 129 respondents who began the survey, 78 completed it in its entirety. Forty-three of the 72 counties in the state had respondents who entered the survey. Of the 129 respondents, most identified their professional role as a public health provider (17.8%) followed by dietician or nutritionist (13.2%), childcare/or early care provider (12.4%), and
birth to three provider (11.6%). A majority of the respondents (58%) held a bachelor's degree and 29% of the respondents held a master's degree. The greatest number of respondents (21.7%) indicated that they had more than 26 years of experience and there was representation of respondents from across the state. Almost half of the respondents (41%), who completed the background information section, indicated that at least three-fourths of the population they served were low-income.

INSTRUMENTS USED BY COMMUNITY HEALTH CARE PROVIDERS TO SCREEN CHILDREN

Frequency and percentage data summarizing the types of instruments used to screen children are presented in Table 1. A majority of the respondents (85 of 115, or 74%) perform developmental screening. Twelve surveys were terminated after the question that asked whether the respondents screened for developmental delays. As such, 59 of the 73 (81%) providers who conduct developmental screening report using the ASQ independently or with other instruments to determine whether further evaluation is warranted. The ASQ was the most frequently used instrument to screen children for developmental delays.

Table 1. Reported Use of Developmental Screening Instruments

<table>
<thead>
<tr>
<th>Screening Instrument</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASQ</td>
<td>34</td>
<td>46.6</td>
</tr>
<tr>
<td>Denver II</td>
<td>2</td>
<td>2.7</td>
</tr>
<tr>
<td>HELP</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Dev checklist</td>
<td>2</td>
<td>2.7</td>
</tr>
<tr>
<td>(not specified)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other/MultiOther</td>
<td>6</td>
<td>8.2</td>
</tr>
<tr>
<td>ASQ+Denver</td>
<td>12</td>
<td>16.4</td>
</tr>
<tr>
<td>ASQ+Other</td>
<td>8</td>
<td>11.0</td>
</tr>
<tr>
<td>ASQ+Denver+Other</td>
<td>5</td>
<td>6.8</td>
</tr>
<tr>
<td>No Answer</td>
<td>3</td>
<td>4.1</td>
</tr>
</tbody>
</table>

Abbreviation: ASQ, Ages and Stages Questionnaire.

BARRIERS TO DEVELOPMENTAL SCREENING

Frequency and percentage data summarizing respondents' reports of barriers to developmental screening are reported. Using a 4-point scale with responses ranging from never to very often/usually, respondents identified the frequency that the following barriers interfered with developmental screening: (1) time, (2) funding, (3) family instability, (4) physician values, (5) parent-physician communication, (6) parent values, (7) staff or professional values, and (8) parent-provider communication. Twenty of 91 (22%) respondents indicated that funding was the most frequently reported barrier to developmental screening. After funding, family instability was also rated as a frequent barrier (20%; 18 of 91).

INTERVENTIONS TO IMPROVE DEVELOPMENTAL SCREENING

Frequency and percentage data indicating respondents' perceptions of interventions that would improve developmental screening are reported. Providers were asked to rate the level of importance for the following interventions: (1) providing education on community resources, (2) peer on-site mentoring, (3) trained health advisors, (4) free on-site seminars, (5) staff meetings to modify service delivery models, and (6) staff or family meetings to modify service delivery models. The intervention rated as most important to improve developmental screening was providing education on community resources to providers.

CONCLUSION

Much of the literature about early identification procedures during early childhood emphasizes the significance of developmental and behavioral screening using a standardized screening instrument (AAP, 2006; Fant et al., 2005; Hix-Small et al., 2007; Rydz et al., 2005). A combination of surveillance and screening is the best approach to
ensure appropriate referral for diagnostic evaluation (Rydz et al., 2005) and referral to early intervention services. Recommendations for periodicity of screening, appropriate screening instruments, and methods of communicating the purpose of screening to parents were reviewed. In addition, findings from a web-based survey conducted to better understand the developmental screening practices of community health care providers in a Midwestern state were summarized. The purpose of the survey was to better understand the screening practices of community health care providers, the screening instruments most commonly used, barriers to screening, and potential interventions that would improve screening rates.

Interestingly, the ASQ is recommended by the AAP (2006) and was the most commonly reported instrument used to screen for developmental delay. While many providers reported conducting screening, they also identified 2 primary barriers to developmental screening. Not surprisingly, providers identified funding as a major barrier to developmental screening. None of the community providers responding to the survey qualify for reimbursement of developmental screening through public or private insurance companies. In the state where the survey was administered, reimbursement for conducting a developmental screening through the Early Periodic Screening, Diagnosis, and Treatment Program offered through Medicaid is limited to pediatricians, neurologists, and psychiatrists. Although some of the HMOs that serve the state’s Medicaid population have adapted and encouraged the use of a validated and standardized screening instrument by its participating physicians, most have incorporated this practice into well child visits with no additional reimbursement. In states where the Early Periodic Screening, Diagnosis, and Treatment reimbursement for developmental screenings was changed to include nonphysician providers, developmental screening rates increased dramatically (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2009).

Providers also identified family instability as another barrier to developmental screening. Unstable home environments are associated with poor developmental outcomes (Harden, 2004). The findings from the survey suggest that poor developmental outcomes may be partially due to a lack of early identification services and the barriers that providers encounter when a child lives in an erratic or unstable home environment. An expansion of screening services to community-based nutritional programs may increase the likelihood of identifying children who are frequently uprooted or living in chaotic homes. Even when a family is experiencing an erratic period or housing insecurity, they still are able to receive nutritional services through Women, Infants, and Children.

Providers clearly identified that interventions to educate them about community resources would improve the rate of developmental screening. Iowa’s First Five program is an example of an innovative community-based approach designed to increase screening and the referral of children with the developmental and behavioral problems. This program has staff members whose sole role is to link providers and families to appropriate resources (Silow-Carroll, 2008). Other innovative programs that involve collaboration across multiple service delivery systems such as early intervention, primary pediatric care, and public health may be best suited to meet the developmental needs of young children. The disadvantage of having an overabundance of professionals involved in developmental screening is that children may be overscreened. To avoid duplication of screening, statewide database systems that maintain screening records, similar to those utilized to maintain records of immunizations, may be helpful in decreasing duplication of services.

**IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE**

Future research could examine screening practices of mothers and children in other states by using the aforementioned survey. To
improve the information obtained from the survey, we could include clarification questions to better understand how to implement an intervention that would promote screening. For example, the respondents identified that education about community resources would improve screening rates. While this strategy may be helpful, each community has access to different resources and consequently may have different educational needs. Therefore, education about community resources may vary across communities and the information that serves one community may not benefit a different community. This level of detail would be needed to develop an effective intervention to increase screening. Additional research could evaluate the costs and benefits of screening. While there is evidence indicating that parental completed screening instruments are more cost-effective than provider-administered instruments (Dobrez et al., 2001), there is a paucity of evidence indicating that screening provides significant cost savings over time. In addition, research could examine the influence of maternal and child health policies regarding screening practices to determine the effect of such policies. Do policies that support maternal and child screening result in increased screening practices? Does it matter if a policy is mandated, but unfunded? Finally, further research could examine whether training and technical assistance increases screening practices and referral.

LIMITATIONS OF THE SURVEY

Although web-based survey methodology is a rapidly growing and powerful method used in survey research, there are inherent limitations (Sills & Song, 2002). The potential for sampling error due to biased sampling, responses from unintended individuals, multiple submissions, and incomplete surveys may influence interpretation of the data. In the current study, the use of non-probability sampling and the lack of a formal response rate pose challenges to generalization of the findings to all community health care providers who serve families with young children. Nonetheless, the findings provide an overall description of developmental screening practices in a Midwestern state and these findings may inform policy development and the development of interventions to increase developmental screening.

REFERENCES


Frankenburg, W. K., Camp, B. W., & van Natta, P. A.


