# Modifying the Parent Evaluation of Developmental Status to Target 4-month-old Infants Who Would Benefit From the Meade Movement Checklist During Community Screening

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To evaluate infant development using a modified Parent Evaluation of Development Status (PEDS) of 6 questions and the Meade Movement Checklist (MMCL). Parents of 4 to 6 month old infants attended community screening clinics, listed concerns on 6 questions (modified PEDS) and were then screened using the MMCL (n=55). Individual PEDS questions were evaluated and MMCL results were compared to a gold standard, the Bayley Scales of Infant Development II. Significant correlation was found between infant risk-positive status, eligibility for special educational or medical services and parent concerns (RR = 1.7; P=.003). A second screen using the MMCL demonstrated 66.6% sensitivity, 94.1% specificity, 85.7% positive predictive value and 84.2% negative predictive value. Four of 6 questions on a "Modified" parent concerns test accurately targeted infants for a second screen (MMCL). Evaluating parent concerns and risk-positive status, increased PPV from 70% to 85.7% at the expense of decreased sensitivity. An algorithm is recommended to increase infant screening effectiveness.

Keywords: Developmental screening; Infant identification; Community health

Early intervention services provide critical early experiences to improve functional developmental skills and the quality of life in infants with developmental delay or disability. <sup>1,2</sup> The United States federal government recognized the importance of early and accurate identification of children with developmental delay or disability through the IDEA mandate to identify 1% of infants, and requires states to set up methods to find those eligible for services (child-find activities). <sup>3</sup>

Eligible infants are not always identified in a timely manner. <sup>4</sup> Current researchers suggest that 12.8% of children from birth through age 17 have a health care need <sup>5</sup> and current prevalence rate of all disabilities may be as high as 18% <sup>2</sup>; however, between 30% and 50% of these children reach kindergarten without identification. <sup>4</sup> An even higher rate is estimated for children with autism (approximately 60%). <sup>6</sup>

Developmental screening is now considered an important component of child health care. The 2006 American Academy of Pediatrics recommendation reaffirmed the 2001 policy statement <sup>7</sup> that all children should be screened at each well child visit. A current survey of American Academy of Pediatrics members suggests that more children are being screened using standardized tests than in the previous survey (23% in 2002 vs. 47.7% in 2009)<sup>8</sup>; however, most children were identified at 2 to 3 years of age and not in early infancy. <sup>8,9</sup>

Many pediatric and community practices use parent information as a strategy for monitoring the development of young children. <sup>9–11</sup> A recent report of the implementation of developmental screening indicated that 15 of 17 pediatric practices, representing both community and large, urban pediatric practice settings, chose to use parent report measures to assist with work flow. <sup>9</sup> King and colleagues <sup>10</sup> evaluated the use of parent information tests and found that twice as many children had a concerning result on the Parent Evaluation of

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Development Status (PEDS) than on the Ages and Stages Questionnaires (ASQ) (22% vs 11%; P = .001) although referral rates for concerns listed on the PEDS were far lower than those for a failed ASQ (43% vs 72%; P = .001). Rhdz et al<sup>11</sup> evaluated 317 parents (90%) who agreed to complete the Ages and Stages Questionnaire (81%) and the Child Development Inventory (CDI) (75%). Predictive values were calculated for the ASQ and the CDI (sensitivity: 0.67 and 0.50; specificity: 0.39 and 0.86; positive predictive value: 34% and 50%). The authors reported concerns that using parent information alone for screening did not meet current recommended screening standards for sensitivity and specificity of between 80 and 90%. 11 Schoenwald et al<sup>9</sup> studied the efficacy of using parent concerns in a busy practice and reported that while screening of children increased by 61%, referrals only increased for those over the age of 3 years. This study contributes to current knowledge by determining which parent information assists earlier identification and referral, particularly of infants younger than 1 year.

### Identifying Very Young Infants

Prediction of developmental delay in individual infants is a challenge faced by primary care providers and requires flexibility and creativity in the implementation of screening programs. 12,13 The purpose of screening is to identify infants who may be delayed or "at risk" in one or more areas of development. 14,15 Professionals determining the primary goal of a screening program decide upon acceptable levels of sensitivity and specificity based upon the consequences of false negatives and false positives. 16 Sensitivity, ruling in those with the condition, is important when the risk of missing a diagnosis is high, as in the case of disease or debilitating deformity. Specificity, ruling out the condition, is more important than sensitivity if the costs associated with intervention are high. 16 The positive predictive value (PPV) reflects the accuracy of correct referrals and therefore, the efficacy of the screening program. 16 Targeting a population and increasing the specificity of a test are the 2 methods recommended by Portney and Watkins 16 and used in this study to increase positive predictive values.

Current research reported on a previously undetected group of infants. Older preterm infants were shown to be at very high risk of developmental problems; this group is often not targeted for screening programs. <sup>17,18</sup> In one recent study, late preterm infants, between 33 and 37 weeks, accounted for 74% of the lifetime disabilities of all infants born preterm. <sup>18</sup> This study will highlight the value of inviting parents to specify their concerns during community screening, create a risk group which included late preterm infants, and increase screening efficacy for young infants.

### Gathering Parent Information

Researchers have focused on gathering information from parents to decrease professional time and costs. <sup>9,19</sup> Parent information consisted of 2 broad categories: parent descriptions and parent appraisals. <sup>19</sup> Parent descriptions may use recall of

past events, which is not a valid strategy, or descriptions of current skills, which becomes valid when questions are specifically worded. 19

Parent appraisals or opinions on the quality of a child's development includes 3 areas: parent estimations of their child's development, predictions (not a valid measure), and concerns. <sup>19</sup> Table 1 reflects relevant research <sup>19–29</sup> on the 3 valid methods (parent descriptions, parent estimates and parent concerns), used to create the 6 questions for gathering parent information in this study.

### Parents' Identification of Disabilities

Parents have many concerns and questions about their young infants, which could be tapped into by inviting parents to attend screening clinics. In a follow-up study of infants with very low birth weight, the parents who chose to attend follow-up clinics had infants with more delays in their development compared to infants and their parents who did not attend. <sup>28</sup> This finding supported the assumption that parents who attended clinics were appropriately concerned about their infants. <sup>29</sup> The parents not attending clinics had infants who scored higher on developmental testing and may have been more confident that their infants were developing normally. It is possible that a parent's choice of whether to attend a clinic may increase the specificity of the program. <sup>29</sup>

Parents of very young infants may have concerns without being sensitive to the presence of a disability. Bailey and colleagues <sup>30</sup> found that parents were not concerned about the presence of a 'problem' in development until the average age of 7 months. Parent concerns may not lead to identification of a disability (increased sensitivity) but may identify a target group of infants for a second screen. In a PEDS study of infants (aged birth through 18 months), 19 of the 86 parents had significant concerns about their children, while only 3 of these 19 children had a disability. <sup>19</sup> For this young age group, the PPV was only 16% but reportedly increased in older age groups of children. <sup>19</sup>

In the PEDS validation studies, 7 children with cerebral palsy were identified. <sup>19</sup> These parents estimated their child's development as lower for their age or had concerns with feeding skills. <sup>19</sup> When infant nutritive sucking skills at 6 months of age were compared to outcomes on the BSID-II, researchers found that sucking was 78% specific and 80% sensitive, supporting the need to add a question concerning feeding for very young infants. <sup>31</sup>

This target group, similar to Glascoe's group of over-referrals using the PEDS, could benefit from further evaluation, education, and anticipatory guidance. <sup>29</sup> In this study, a community-based screening program used parent information as a first step to screen very young infants. Parents were invited to attend the screening clinics and answered 6 questions, modified from the Parent Evaluation of Development Status (PEDS), <sup>26</sup> [which included 4 significant predictor questions on the PEDS for early infancy], and added one question estimating the infant's development <sup>26</sup> and one "feeding" question. <sup>31</sup>

Infants were screened with a second test, the Meade Movement Checklist  $(MMCL)^{32}$  and followed with a full developmental evaluation  $^{33}$ 

Specific Aims

This study analyzed concerns of parents (modified PEDS) and infant responses (MMCL) and compared scores to a gold standard, the Bayley Scales of Infant Development II (BSID-II)<sup>33</sup> to:

- 1. Determine which parent responses assisted earlier identification of those children who qualified for special educational or medical services.
- 2. Determine validity by comparing MMCL scores to a gold standard, the BSID-II.
- 3. Create an algorithm to increase the specificity and PPV of the screening process.

### Methods

### Subject Recruitment

Parents of all infants, 4 to 6 months old, adjusted for prematurity (n = 213), residing in Houston County, Minnesota, were eligible to participate in a program to screen their infants for all areas of development. Multiple, singleton, and preterm infants were included.

All eligible parents were sent an invitation (Appendix I) to participate in one of 5 screening clinics in each town over a one year time period. A follow-up letter by Houston County Public Health staff was sent to each eligible child's parent to schedule a time to attend. Interested parents signed up for one of the scheduled sessions.

The eligible infants were further divided into 2 groups, based on screening attendance. Group one included those parents who chose to attend, and group 2 included a random selection of parents who did not respond to the invitation to attend a screening clinic.

Group one included the infants (n = 55) attending the screening clinics. Of these, 43 infants were evaluated in their homes, at age 6 months adjusted for prematurity, by the principal investigator (PI) (blinded to all subject information). This study focused on the concerns of parents in this subgroup of infants who attended the screening clinics. In this study, any environmental, biologic, or established factor placing an infant "at risk" in any area was termed *risk-positive*. <sup>14,34</sup>

Group 2 consisted of randomly selected parents (n=65) from the total group of parents (n=158) who did not attend a screening clinic. The parents in group 2 received a follow-up letter, and the Modified PEDS was sent to their homes. Surveys were returned on 11 infants (see Meade, et al 2009  $^{35}$  for details of group 2).

The institutional review board of Rocky Mountain University of Health Professions gave consent to use human subjects for this study. Letters of agreement were obtained from the Director

of Houston County Public Health, and parents also completed a consent form for the Public Health Department in Houston County, Minnesota.

### Instrumentation and Measurement

The following 3 tests were used to gather the information on the infants in this study of parent concerns.

- 1. Modified PEDS. 26 This modified version was adapted from the original PEDS 10 questions, an instrument which measures parent concerns about child development from birth through age 8. It was created using 4 questions, which were reported by Glascoe to be "predictive" for young infants aged from birth to age 18 months. 19 These 4 questions included one for global concerns, one for receptive language, one for behavioral, and a 4th question which tapped into "any other concern" which the parents might specify. Items were scored as 1 (any concern listed) and 0 (no concern) for questions 1 to 4. For the 2 additional questions, estimates of the child's developmental status was scored as 1 point if younger, and feeding concerns scored as 1 point, for a range of scores for the 6 questions of 0 to 6. The PI scored the PEDS according to criteria in the manual to ensure reliability and this study addresses content validity. Reliability for the PEDS questions is between 88% and 95% agreement. 19 Additional reliability and validity studies were not completed on the questions prior to this study (See Appendix II for questions and examples).
- 2. The MMCL<sup>32,34,35</sup> is a motor-based, observational screening test which is quick and easy to administer. The 27 items allow screeners to structure observations of infants, with adjusted ages (for prematurity) between 4 and 6 months, as parents actively interact and play with the child in 6 positions. Each item is scored as 1 if the item matches a set criteria, and 0 if it does not, for a total score between 0 and 27 risk points. Previous researchers evaluated 998 infants between 16 and 24 weeks of age, reporting no significant difference in scores at any week (16 through 24 weeks) or if the infant was full term or premature. 35 In one component, the reported inter-rater reliability correlation  $[ICC_{(3,1)}]$  was = .82; overall validity, 88%. 35 The reliability of the screeners in this current study was measured twice: once after an initial day long training session and a second time midway through the data collection period using both a video film protocol and live infant models. The inter-rater reliability correlation  $[ICC_{(3,1)}]$  was .98.<sup>34</sup>
- 3. The BSID- $11^{33}$  is a tool that measures mental and motor development of children from 1 to 42 months of age and is considered the gold standard for identification of developmental delays for children 0 to 3 years of age. Individuals are scored in SDs from a mean of 100; one SD is 16 points above and below the mean (range of 1 SD is 84-116). Reliability of the BSID-II has been reported at r =

	Further Information and Key References	Behavior Science Systems, Box 580274, Minneapolis, MN 55458; phone: 612-929-6220 Ireton <sup>20</sup>	http://www.pbrookes.com Hix-Small et al <sup>21</sup> Bricker <sup>22</sup> Squires et al <sup>23</sup> Skillem et al <sup>24</sup> Woodward et al <sup>25</sup>	http://www.pedstest.com/ Glascoe <sup>19</sup>
Parent Information Tests: 3 Valid Methods of Gathering Parent Information 19	Sensitivity/Specificity and Research	Sensitivity greater than 75% across studies Specificity is 70% across studies in correctly detecting normally developing children.  Main limitation has been excessive length. <sup>20</sup>	Sensitivity 75-90/specificity 77%-85% <sup>21</sup> Reliability 88%-94% between parents and professionals Test-restest, interobservor reliability 97% <sup>22</sup> Excellent for surveillance of 'at risk' children over time due to the large range of covered ages (from 4 mo to 60 mo). <sup>22</sup> Major limitation: small completion rate (54%) <sup>21</sup> low sensitivity in early infancy. <sup>23</sup> Limited validity reported for identifying delays at 4 mo of age. <sup>23</sup> The ASQ is valuable for excluding children developing normally, as demonstrated by the high negative predictive value (98%) reported for the ASQ in a study of 216 premature infants and should be combined with other screening tests for a comprehensive screening program. <sup>24</sup> Serial nature of the ASQ, available every 2 mo, useful in improving follow-up rates for infants born prematurely. <sup>25</sup>	Sensitivity 74%-79%/Specificity 70%-80% <sup>26</sup> Reliability between examiners reported at 88% to 95% agreement; test-retest 88%. <sup>19</sup> Validated against a battery of 14 tests for 771 children. <sup>19</sup> Through factor analysis, 4 of 10 questions on the PEDS (global, receptive language, any other concerns, and behavior) were determined to be predictors of subsequent disabilities in infants age birth to 18 mo. <sup>19</sup>
	Age/Administration/Scoring	Age: 3-72 mo Administered by: paraprofessionals Time to administer: 30-50 min Time to score: Standard scores provided	Age: 4-6 mo Administered by: parent report Time to administer: 10-15 min Time to score: 5 min Standard scores provided	Age: 0-8 years Administered by: parents, paraprofessionals Time to administer: 2-10 min Time to score: 5 min Standard scores provided
Parent Information T	Category of Test/ Description	Parent descriptions 1. Communication 2. Gross and fine motor 3. Problem solving 4. Personal-social	Parent descriptions 1. Communication 2. Gross and fine motor 3. Problem solving 4. personal-social areas	Parent concerns 10 questions cover global concerns plus specific areas
Table 1.	Test	CDI	ASQ	PEDS

Harris <sup>28</sup>	Glascoe and Sandler <sup>29</sup>
Evaluated parent estimates in a sample of 31 infants, 16 preterm and 15 full-term, aged 3-9 mo. <sup>28</sup> Compared parents' answers with the BSID scores: sensitivity was 60% for the mental scale and 80% for the motor scale; however, the specificity was higher at 85.7% for the mental scale and 90.9% for motor scale results. The negative predictive values were even higher at 90% for the mental scale and 95% for the motor scale. Parents were particularly accurate if their infant, even at such a young age, was developing normally. <sup>28</sup>	Glascoe evaluated parents' ability to estimate their child's developmental age combining 2 studies of 234 parent-child dyads (infant average age: 31 mo; age range: birth to 77 mo). Parents were 90% specific in estimating their infant's developmental age if the infant was developing normally, but only 75% accurate if their infant had developmental delays <sup>29</sup>
Ask "compared with other babies the same age, my baby is a) ahead of schedule; b) right on schedule; c) slightly delayed d) very delayed". The parents' answers were dichotomized as 'normal' (a/b) or 'delayed' (c/d) and based on scores of within one standard deviation from the mean (normal) and greater than one standard deviation below the mean (delayed).	
Parent estimation	Parent compares
Estimation question	

.96 for the mental scale and r = .75 for the motor scale; validity was reported as acceptable using subgroups of children with disabilities. 33 The psychomotor development index and mental development index of the second edition was specifically selected for this study due to clinical concerns, which have since documented the reduced sensitivity of the BSID-III. 36 A cutoff of 1 SD below the mean (<85) was selected instead of 2.0 SD used in Minnesota in 2005 because researchers have shown that children who scored as having only a mild delay may benefit from further evaluation and access to intervention services. 19,37 The PI was examined for reliability using video correlations with an experienced examiner during the data collection period. Every fifth child was chosen for videotaped reliability testing until 5 infants were videotaped to check accuracy of the measurement instruments. The reliability was calculated at: ICC = .84 for the mental development index and ICC = .91 for the psychomotor development index.34

### Qualification for Services

Infants qualified for services if staff-completed standardized developmental assessment met Houston County criteria for entrance into special educational services. Infants were also identified if, in the staff's clinical judgment, the infant would benefit from referrals for medical services (regardless of test scores).

### Data Analysis

Descriptive analysis was used for demographic information and to evaluate the 6 questions on the modified PEDS. To further evaluate the results,  $2\times 2$  contingency tables were used to calculate relative risks between parents with and without concerns, risk-positive status, the MMCL result and if infants qualified for special education or medical services.

The MMCL data (independent variables) was also evaluated using 2 × 2 contingency tables for sensitivity, specificity, positive and negative predictive values compared to BSID-II mental and motor index scores (dependent variables) for the parents listing any concerns on the Modified PEDS.

### Results

### Demographics

Two hundred thirteen families of eligible infants were invited to attend a clinic, and 55 (25.8%) infants attended over the year. More male (n = 32/55; 58%) than female infants attended the clinics, and the majority of infants (n = 52/55; 92%) were white. Thirty-four (68%) infants who attended the clinics were risk positive, defined for this study as any adverse factor in the pregnancy or birth history, subsequent illness, or established medical diagnosis. The sample included 2 sets of twins; both

Question no.	N	%	In Services	Not in Services	Correlation	Significance
1. Global	17	51%	5	12	r = .243	P = .622
1. Globai 2. Understands	0	0	NA	NA	NA	NA
3. Behavior	0	0	NA	NA	NA	NA
4. Other (any other concern)	9	27%	4	5	r = .144	P = .426
5. Feeding	20	61%	7	13	r = .044	P = .80
6. Estimate: younger	7	21%	3	4	r = .105	P = .565

sets born prematurely at 33 weeks of gestation. (See Meade et al for tables on demographics.)<sup>34</sup>

Aim 1: Determine Which Parent Responses Assisted Earlier Identification of Those Children Who Qualified For Special Educational or Medical Services Parent concerns were measured using 2 methods in this study, parent choice to attend clinics and parent documentation of their concerns on the Modified PEDS. Parents' choice to attend clinics effectively reduced the percentage of children who did not need to be screened by almost 75%, as reported in the original research, resulting in a group of targeted infants whose parents had concerns, for the second screen, the MMCL.<sup>34</sup>

Of the 55 infants and their parents choosing to attend screening clinics, 22 (40%) listed no concerns on the Modified PEDS and 33 (60%) listed one or more concerns (out of 6 possible questions). The frequency of number of concerns of the parents on the Modified PEDS is as follows: 22 indicated no concerns (40%), 18 had 1 concern (32.7%), 11 noted 2 concerns (20%), and 4 had as many as 3 concerns (7.3%).

The 6 Questions on the Modified PEDS Comparing percentages of concerns by individual question revealed the greatest concern (61%) was on question 5, feeding. The next highest was question 1, global concerns (51%). Question 3, parents reporting any other concern ranked third at (27%). For question 6, estimate how your child compared to others the same age, the majority of parents estimated their infants to be performing at age level (60%). Of the other choices (estimate as older or younger), 7 (21%) of the parents estimated their infants at younger than age level. Three of the 15 parents with children who eventually qualified for special services (20%) estimated that their child was performing younger than others of the same age; compared to 2 parents (7.1%) who estimated that their child performed similar to younger children and did not qualify for services.

No parent listed a concern for the second and third questions regarding understanding and behavior, which supports other research indicating these questions may not be as relevant for infants between 4 and 6 months of age and have been removed from the analysis. <sup>38</sup> Individual questions did not correlate with any of the outcome measures or identify which children would qualify for services (Table 2).

Aim 2: Determine Validity By Comparing Screening Scores To A Gold Standard, the BSID-II From the 213 infants eligible to attend clinics, 55 infants attended a clinic and of these, 43 (78.2%) received detailed evaluations using the BSID-II, completed by the PI, which represented 20.2% of the total number of infants originally invited to attend clinics. Of these 43 evaluations, 15 infants (34.8%) met referral criteria for evaluation. Eight infants met criteria for Early Childhood Special Education (ECSE), 4 for specialty medical services, and 3 for monitoring (rechecked at regular intervals until 3 years of age). These 15 infants represented 27.3% of the 55 infants who attended clinics and 7.04% of the total (n = 213) population invited. (See Meade<sup>34</sup> for subject flow Table 1.)

Parent Concerns for Those Who Qualified for Services For the 15 children who qualified for additional medical or special education services, parents' voiced concerns for 12 out the 15 infants who qualified (80%) versus 21 parents voicing concerns out of the 40 who did not qualify for services (52%). Evaluating each question individually revealed no significant differences between parents who reported concerns and their infant's qualification for specialized services. However, parents who expressed any concern on the modified PEDS, and agreed to follow-up evaluation (n = 26), had infants who were significantly more likely to end up qualifying for additional services (31% versus 69%;  $\chi^2 = 4.42$ , P = .035).

Infants were more likely to be eligible for special services if parents listed any concerns and failed the second screen (P = .006) (Table 3). Infants were also more likely to be in services if

Table 3. Parents with Concerns, Infants Failed the MMCL and Qualified for Services (N = 55)

Parent Concerns		Qua	Qualify for Service			
on Modified PEDS	MMCL	No	Yes	Total		
None	Pass	17	1	18		
TVOIC	Fail	1	3	4		
	Total	18	4	22		
One or More	Pass	21	3	24		
0100	Fail	1	8	9		
	Total	22	11	33		

Table 4. Children Who Are Risk Positive, in Service, and Have Concerned Parents (N = 55) Parent Concerns Children Risk-Positive Children Not in Service Children in Service Total No concerns No 14 14 Yes 4 4 8 Totals 18 4 22 Concerns No 7 0 7 Yes 15 11 26 Totals 11 11 33 Based on Kendall's  $\tau$ -b value = .367; P = .003.

parents were concerned and deemed to be "risk-positive" (P = .003) (Table 4).

**Relative Risks** For concerned parents, if their status was risk positive and the child also failed the MMCL, infants were significantly (RR = 1.73; 95% CI: 1.24-2.40; P = .003) more likely to qualify for services. If infants passed the screen, parents reported no concerns and infants were not risk positive, infants were significantly (RR = 2.00; 95% CI: 1.00-3.99; P = .007) less likely to be in services (Table 5).

*Validity of Parent Concerns* Of the 43 evaluations completed by the PI, 26 infants had parents who listed concerns on the modified PEDS test. Comparing the MMCL to the BSID-II, for these infants with parent concerns (n=26), resulted in high rates of specificity (94.1%); positive predictive value PPV (85.7%) and negative predictive value (84.2%) but a low rate of sensitivity (66.6%) (Table 6). The first 3 values were higher than the previous review of the 43 infants whose parents consented to follow-up since 17 of these parents listed no concerns in the original study. <sup>34</sup>

AIM 3: Targeting parents with concerns and creating an algorithm Targeting infants for a second screen (using the MMCL) based on parent concerns, increased specificity from 91.4% in a previous study 34 to 94.1% in this current study. The positive predictive value increased from 70% using the modified PEDS in the first study 34 to 85.7% in this study. Reviewing all variables and comparing to infants eligible for services allows development of an algorithm to increase efficacy of screening programs (Fig. 1). For those parents accepting an invitation to attend screening clinics, infants were more likely to qualify for special educational or medical services if parents listed any concern and had infants with a risk-positive status, and then the infant failed the MMCL.

### Discussion

Three positive findings from this study may refine the early identification process for infants who could benefit from early interventions services. These include: (1) focusing parent concern on the young infant may increase

Table 5. Relative Rrisks for Children With Risk-Positive Status, Who Failed the MMCL, Were in Service, and Had Parents With Concerns. Total N=55

Parent Concerns on Modified PEDS	Risk Positive	MMCL	Not in Service	In Service	Total
No	No	Pass	13	0	13*
No	Yes	Pass	4	1	5
		Total	18	4	22
Yes	No	Pass	7	0	7
Yes	Yes	Pass	14	3	17
		Total	21	3	24
No	No	Fail	1	0	1
No	Yes	Fail	0	3	3
		Total	1	3	4
Yes	No	Fail	0	0	0
Yes	Yes	Fail	1	8	9**
		Total	1	8	9

<sup>\*</sup>Parent not concerned, no risk-positive, passes MMCL RR = 2.00 (95% CI:1.00-3.99).

<sup>\*\*</sup>Parents concerned, risk-positive, fail MMCL RR = 1.73 (95% CI;1.24-2.40).

Table 6. Sensitivity<sup>a</sup>, Specificity<sup>b</sup> of MMCL Compared to BSID-II for Those Parents Attending Clinics and Listing Concerns (total N = 26)

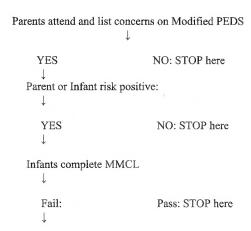
MMCL >0	BSID-II >1.0 SD below mean	BSID-II within 1 SD of mean	Total
MMCL >6 risk points	6	1	7
MMCL 6 or less risk points	3	16	19
Total	9	17	26

Sensitivity = 6/9 = 66.6%; specificity = 16/17 = 94.1%; positive predictive value = 6/7 = 85.7%; negative predictive value 16/19 = 84.2%

identification for those under one year of age needing specialized services; (2) outreach encouraging parents to bring questions to community screening clinics, where parents can be educated about further screening and evaluation, increased successful referral rates; and (3) an algorithm could increase specificity and positive predictive values of the screening program by targeting infants and parents listed as risk positive.

### Focusing Parent Concerns

Modifying the PEDS to use only 6 questions appropriate for young infants assisted efficacy. Two of the 4 estimated predictor questions 1 (global concerns) and 4 (any other concerns) used in the modified PEDS had high response rates in this study, while the 2 questions (2 and 3) regarding how an infant understands the parent or how the infant behaves, received no responses. These response rates were similar to a recent study of implementation recording high rates of concerns for PEDS question 1, global concerns (75%) and for PEDS questions 4, any other concern (59%). <sup>38</sup> This study also indicates that the 2 PEDS questions on understanding and behavior, consistent with other research, are more sensitive when the infants demonstrate expanded variations in behavior with increasing age. <sup>19,38</sup>



INFANT REFERRED For Full Developmental Evaluation

1. Recommended algorithm based on risk a

**Fig. 1.** Recommended algorithm based on risk and a second screen.

### Outreach For Parent Concerns

Glascoe confirmed that children of concerned parents represented a subgroup with lower developmental test scores. 30 Inviting parents to attend clinics was shown to be the most effective first step. 34 Parents were enticed to attend screening clinics, using an attractive brochure, thank you gift bags and an opportunity to be part of a drawing (Appendix 1). More parents with concerns responded to the opportunity to detail their questions and therefore become available for the second screen. Sixty percent of parents listed one or more concerns at the beginning of the screening clinic, and 85% said they were happy with their infant's progress by the end of the session, suggesting that targeting parents who had questions and concerns resulted in more knowledgeable parents who were also open to further screening and evaluation. Parental willingness to follow through with referral to services would address one of the major difficulties with current screening programs.<sup>20</sup>

Parents of young infants were concerned about current developing skills such as feeding (question #5), similar to a recent study of comments added to PEDS forms, which cited that 4% of concerns added to the form were about feeding.<sup>38</sup> In this study, of the 33 surveys which identified concerns, 20 (61%) listed feeding issues. Feeding concerns were identified by parents of the 5 children who performed poorly on the MMCL and the BSID-II and the 3 children with medical conditions who were all eligible for early intervention services. These concerns included completion of feeding in a practical time frame, confusion on how and when to introduce solids, and questions about gastrointestinal issues such as regurgitation and constipation. The high number of feeding concerns is consistent with work correlating feeding skill to 6 month developmental performance. 31 Medoff-Cooper and Gennaro's study of coordinated nutritive sucking in very low-birthweight infants<sup>31</sup> was positively correlated (r = .59, P < .05) with the infants' BSID psychomotor development index at 6 months adjusted age.

Parents were asked to estimate how their child compared to others of the same age in the 6th question on the modified PEDS in this study. Parents without concerns consistently rated their infants as developing similar to or more advanced than other infants the same age on the estimate question. Similar to Cox and collegues', <sup>38</sup> parents also added comments concerning how well their child was doing, indicating that the estimate question is also a valuable addition to the Modified PEDS test for infants.

Only 3 parents listed concerns about future development, consistent with research by Bailey. <sup>30</sup> Parents of the 3 infants with developmental delays listed a total of 3 concerns each on the survey, supporting Glascoe's findings that 75% of infants were accurately referred when parents reported 2 or more significant concerns using the PEDS 10 questions. <sup>19</sup> The only parents concerned about future development also had high-risk infants with medical vulnerability as illustrated in the following examples.

Example 1: Infant with suspected neurofibromatosis. Because her eldest child had a diagnosis of neurofibromatosis, a mother was concerned her infant would also receive this diagnosis. The diagnosis of neurofibromatosis was confirmed immediately after the screening clinic. The mother stated she was pleased with her infant's progress. Example 2: Twins born prematurely at 33 weeks of gestation. One twin was already being followed medically for torticollis and severe plagiocephaly, but the parents felt concerned that the second twin, who was not receiving any follow-up services, was more "behind" developmentally. Twin 2 qualified based on the results of this community screening program.

# Follow-up of Children Referred For Specialized Educational or Medical Services

Eight of the 15 infants referred from the screening program were eligible for services; 5 met the more stringent criteria of either 2 SD below the mean in one area or 1.5 SD or more below the mean in 2 areas; criteria used in Minnesota in 2005 during data collection (since 2007, Minnesota IDEA referral status is moderate, referring infants at -1.5 SD below the mean in any area of their development). The other 3 infants met criteria in the diagnostic category, with an established condition known to adversely impact development.

Four additional infants were referred to medical services; one infant was referred to a specialist for pulmonary problems and received a diagnosis of tracheomalacia, and one was referred for "failure to thrive." Two infants were receiving physical therapy services for torticollis. Three other infants received scores on the Bayley Scales of Infant development II in the borderline range (and would have met current Minnesota IDEA referral criteria); 2 were monitored by Early Childhood Special Education ECSE, and one by public health. As reported by ECSE service providers, all 8 eligible infants continued to require intervention services, and one child who had been monitored became eligible for ECSE services at 18 months of age based on speech delays. This infant failed the MMCL but passed the BSID-II at 6 months of age. In Minnesota, only 450 infants under one year of age were served in 2005 and 2007 (.6% of the infant population). 37 During 2005, Houston County identified 15% or 7% of the infant population using this outreach clinic model and focused parent questions reported in this study.

## Limitations and Clinical Relevance

Although the final numbers for analysis appear to be small, 75% of this study population (213 families) invited to the screening clinics ruled themselves out and could be considered normal based on the evidence provided in this study, leaving only 55 infants to screen. This limitation in numbers could be considered a positive benefit for large urban populations and large follow-up clinics, particularly those interested in focusing on the late preterm infants who are currently not targeted for screening.

Secondly, evaluating only infants whose parents had concerns, increased specificity and positive predictive values at the expense of decreasing sensitivity (from 87.5% <sup>11</sup> to 66.6%). Recently researchers <sup>39</sup> have criticized targeting for missing too many cases (decreased sensitivity) and referring too many typically developing children. Consistent with this criticism, a few cases were missed by targeting parents with concerns in this study, but the resulting high specificity and PPV meant that the children who were evaluated needed services. These findings might increase the willingness of large, rural areas and large urban centers to be involved in otherwise expensive use of resources to screen every child, encourage inclusion of the late preterm infant and finally, assist referral sources to confidently encourage parents to follow through with referrals to services.

### Conclusions

This study evaluated the responses of parents who chose to attend community screening clinics on 6 questions of a "modified" PEDS screening test. Four of 6 questions on the "Modified" test of parent concerns targeted infants who would benefit from a MMCL during community screening clinics. Using parent concerns and "risk-positive" status to target infants resulted in an increased PPV from 70% to 94.1% at the expense of decreased sensitivity. The purpose of the screening program must be clear in order to selectively target infants. An algorithm based on parent concerns, risk status and results of the MMCL is recommended to increase infant screening program effectiveness.

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# · You and your baby

### What happens at this event?

You will receive a thank you bag.

### When & Where is it offered?

#### How can I get this screening?



The screening is FREE and one component of a doctoral research project. Even if you are not interested in beingpart of

the research, you are still invited to attend and enjoy the screening!

Int to you by the Houston County Early Childhood Initiative, Houston County Interagency Early Intervention Committee (IEIC), Early ood Family Education in Caledonia, Houston, La Crescent Hokah and Spring Grove, Houston County Public Health, Hiawatha Valley

Education District & Vickie Meade Therapy Services.

Countact: Houston County Public Health

304 South Marshall Street © Caledonia, MN 55921Phone 507-725-5810 © FAX: 507-725-2150

### Appendix II. Example Answers

Modified PEDS Baby #.....Baby Age...... Date.....

1. Please list any concerns about your child's learning, development and behavior.

"I will be concerned this first year due to low Apgar scores to see if she is on track"

"Not rolling, not waving arms and legs as much"

2. Do you have any concerns about how your child understands what you say?

"No"

3. Do you have any concerns about how your child behaves? "No - he is very happy"

4. Please list any other concerns.

"Fluid on kidneys"

"Breathing issue"

#### Feeding question

5. Do you have any concerns about how your child is feeding?

"He is a big eater and spits a lot- how can this be prevented." "He's slow"

### **Estimation question**

Compared to other children, do you think your child is performing at?

- 1. a more advanced age,
- 2. at a similar age, or
- 3, younger than other children at this same age?

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