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Authors

Maitre, Nathalie
Burton, Vera
Duncan, Andrea
et al.

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Network Implementation of Guideline for Early Detection Decreases Age at Cerebral Palsy Diagnosis

Nathalie L. Maitre, MD, PhD,[a,h] Vera J. Burton, MD, PhD,[c,d] Andrea F. Duncan, MD, MSClinRes,[e] Sai Iyer, MD,[f] Betsy Ostrander, MD,[g] Sarah Winter, MD,[g] Lauren Ayala, DPT,[g] Stephanie Burkhardt, MPH,[a] Gwendolyn Gerner, PsyD,[c,d] Ruth Getachew, BS,[c] Kelsey Jiang, BS,[f] Laurie Lesher, RN, MBA,[g] Carrie M. Perez, MA, LPA,[e] Melissa Moore-Clingenpeel, MA, MAS,[b] Rebecca Lam, BA,[i] Dennis J. Lewandowski, PhD,[a] Rachel Byrne, PT[i]

abstract

BACKGROUND AND OBJECTIVES: Early diagnosis of cerebral palsy (CP) is critical in obtaining evidence-based interventions when plasticity is greatest. In 2017, international guidelines for early detection of CP were published on the basis of a systematic review of evidence. Our study aim was to reduce the age at CP diagnosis throughout a network of 5 diverse US high-risk infant follow-up programs through consistent implementation of these guidelines.

METHODS: The study leveraged plan-do-study-act and Lean methodologies. The primary outcome was age at CP diagnosis. Data were acquired during the corresponding 9-month baseline and quarterly throughout study. Balancing measures were clinic no-show rates and parent perception of the diagnosis visit. Clinic teams conducted strengths, weaknesses, opportunities, and threats analyses, process flow evaluations, standardized assessments training, and parent questionnaires. Performance of a 3- to 4-month clinic visit was a critical process step because it included a Hammersmith Infant Neurologic Examination, a General Movements Assessment, and standardized assessments of motor function.

RESULTS: The age at CP diagnosis decreased from a weighted average of 19.5 (95% confidence interval 16.2 to 22.8) to 9.5 months (95% confidence interval 4.5 to 14.6), with $P = .008$; 3- to 4-month visits per site increased from the median (interquartile range) 14 (5.2–73.7) to 54 (34.5–152.0), with $P < .001$; and no-show rates were not different. Parent questionnaires revealed positive provider perception with improvement opportunities for information content and understandability.

CONCLUSIONS: Large-scale implementation of international guidelines for early detection of CP is feasible in diverse high-risk infant follow-up clinics. The initiative was received positively by families and without adversely affecting clinic operational flow. Additional parent support and education are necessary.

Worldwide, cerebral palsy (CP) is the most common childhood physical disability, with an incidence in the United States of 2 to 3 per 1000 live births.[1] In the past decade, evidence for neuroplasticity in the first years of life has grown, as has the body of evidence for early targeted interventions to restore function. In the United States alone, there are 8 National Institutes of Health (NIH)–funded studies (as of June 2019) aimed at improving the

[a]Center for Perinatal Research and [b]Biostatistics Core, The Abigail Wexner Research Institute, and [h]Department of Pediatrics, Nationwide Children's Hospital, Columbus, Ohio; [c]Division of Neurology and Developmental Medicine, Kennedy Krieger Institute, Baltimore, Maryland; [d]Department of Pediatrics and Neurosciences Intensive Care Nursery, School of Medicine, Johns Hopkins University, Baltimore, Maryland; [e]Department of Pediatrics, The University of Texas Health Science Center at Houston, Houston, Texas; [f]Program of Developmental Behavioral Pediatrics, Department of Pediatrics, Mattel Children's Hospital, and University of California, Los Angeles, Los Angeles, California; [g]Department of Pediatrics, School of Medicine, University of Utah, Salt Lake City, Utah; and [i]Cerebral Palsy Foundation, New York, New York

Dr Maitre conceptualized, designed, and executed the study, conducted the initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript; Drs Winter, Ostrander, Iyer, Burton, Duncan, Gerner, and Ayala, and Ms Lesher designed individual processes, coordinated and supervised data collection, and critically reviewed the manuscript for important intellectual content; Ms Burkhardt, Ms Jiang, Ms Getachew, Ms Perez, and Ms Lam designed individual processes, coordinated and collected data, and critically reviewed the manuscript for important intellectual content; Ms Moore-Clingenpeel designed, conducted, and drafted the final analyses and reviewed and revised the manuscript; Dr Lewandowski designed the SQUIRE (Standards for Quality Improvement Reporting Excellence) 2.0 framework for the work, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Byrne funded, conceptualized, and executed the study and reviewed the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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QUALITY REPORT

development of infants with CP.[2] However, the design and testing of early interventions for CP is challenging because the age at which diagnosis is ascertained throughout the United States is ~2 years.[3] Authors of a recent large study of parent perceptions in the United States suggested the possibility and preference for receiving an earlier diagnosis.[4] Previous studies implicated delayed diagnosis, with parents experiencing more dissatisfaction with the health care system, mistrust of providers, and subsequently higher rates of anxiety and depression.[5]

In 2017, international guidelines for early diagnosis of CP recommended an algorithm for detection by using assessments determined through a series of systematic reviews.[6] Experts from all disciplines and parent stakeholders stated that diagnosis should occur as early as possible and proposed 2 different pathways to establish an accurate, early diagnosis before 12 months. Tools for detection included neuroimaging and Prechtl's General Movements Assessment (GMA)[7] before 5 months and use of the Hammersmith Infant Neurologic Examination (HINE)[8] in a longitudinal fashion between 3 and 12 months. These tools, combined with various motor function assessments, including the Test of Infant Motor Performance (TIMP),[9] assist in establishing a comprehensive picture that includes neurologic examinations, clinical history, motor function evaluation, imaging of perinatal brain insults, and biomarkers, thus making early diagnosis both feasible and accurate.[6]

There is, however, a gap in practice between the expert endorsement of evidence in the guidelines for early detection of CP and the current clinical approach in many US high-risk infant follow-up (HRIF) programs. Implementation science can help address this gap, not only at a local and/or programmatic level[10] but also in a scaled-up approach throughout a network. Therefore, our goal was to successfully implement the guidelines for early detection of CP throughout 5 US institutions serving a diverse mix of rural and urban populations (combined catchment area equivalent to 14% of the contiguous United States). Approximately 50% of infants diagnosed with CP at any time have identifiable perinatal events that result in NICU care; these infants are routinely managed in an HRIF program.[11–14]

Using standard implementation science methodology combining plan-do-study-act (PDSA) cycles and leveraging Lean Six Sigma principles, we aimed to decrease the age at CP diagnosis throughout our network of HRIF programs to 12-months corrected age (CA) over the course of 1 year. Secondary aims included demonstration of process improvement through increase in 3- to 4-month CA visits with recommended standardized assessments and examination of balancing measures of clinic flow indexed as patient no-show rates.

METHODS

Context

HRIF clinics were recruited through leadership attendance at the American Academy of Cerebral Palsy and Developmental Medicine annual meeting and with assistance from the Cerebral Palsy Foundation. Site characteristics are listed in Table 1. A requirement for site inclusion during the 3-month planning phase was demonstration of leadership vision support and institutional commitment to change through personnel and time allocation. All sites' HRIF referral criteria represented standard clinical practice including prematurity, very low birth weight, birth depression, extracorporeal membrane oxygenation, neonatal encephalopathy, and primary provider concerns for birth insult.

Intervention

During the planning phase, organizational infrastructure was developed, with a lead site that had previously implemented the guidelines. Local coordinators and a central project manager were identified, and a commitment to the project from teams and leadership at all institutions was demonstrated. A targeted framework for a strengths, weaknesses, opportunities, and threats (SWOT) analysis (Supplemental Fig 4) allowed critical examination of basic resource needs. A general suppliers, inputs, process, outputs, and customers (SIPOC) chart (Fig 1) with key intervention elements (Supplemental Table 5) was developed at the lead site, where close examination of process flow waste and value added to patients and teams was conducted. An education bundle and strategic infrastructure plan were agreed on between the foundation and the lead site, where a central institutional review board (IRB) was approved. A Research Electronic Data Capture (REDCap) database was designed to allow Web-based input of a basic data set and questionnaires, including a repository for deidentified GMA videos for clinical reading purposes only.

Each team included a site principal investigator and/or coinvestigator (neonatologist, neurologist, or developmental pediatrician), process coordinator, and partner specializing in psychometric assessments (physical therapist or neuropsychologist). Funding was provided for education and data collection efforts but not for providers to perform assessments; GMA, HINE, and motor tests were to be implemented as standard clinical care. Foundation partners coordinated site communication

TABLE 1 Site Characteristics of Participating Hospitals

	UCLA	NCH	Utah	KKI	UT-Houston
Setting	Urban predominant	Urban-rural mix	Rural predominant	Urban predominant	Urban-rural mix
NICU catchment area, square miles	~5000	~60 000	>300 000	~12 000	~30 000
Beds in referring NICU(s)	45	260	108	80	120
Level of the NICU(s)	4 and 3	4 and 3	4 and 3	4 and 3	4
Annual NICU admissions	623	3251	1250	1080	1500
Annual admissions <1000 g	48	187	95	85	100
Annual HIE admissions	17	58	27	20	20
Annual HRIF visits	385	5400	567	1072	0
HRIF clinic team	Neonatologist, DBPeds, NP, PT, OT, fellow, RD, coordinator	Neonatologist, neurologist, NPs, RN, RD, LSW, OT, PT, coordinator, SLP, psychologist	DBPeds, neurologist, NPs, PT, OT, RN MBA	Neurologist, neonatologist, PT, OT, RN, coordinator, psychologist, NPs	Neonatologists, PMR, PT, LPA, RN

DBPed, developmental and behavioral pediatrician; HIE, hypoxic ischemic encephalopathy; NCH, Nationwide Children's Hospital; KKI, Kennedy Krieger Institute; LPA, licensed psychological associate; LSW, licensed social worker; MBA, master of business administration; OT, occupational therapist; PMR, physical medicine and rehabilitation; PT, physical therapist; RD, registered dietician; RN, registered nurse; SLP, speech language pathologist; UCLA, University of California, Los Angeles; UT-Houston, The University of Texas Health Science Center at Houston.

efforts through telehealth, created tool repositories, and kept records of process troubleshooting solutions.

The preparation phase included site-specific IRB approvals, baseline data acquisition, and training of clinical personnel involved in early detection with the HINE and GMA. During site visits, preplanned SWOT analyses had identified the most common challenges as lack of formal training in neuromotor tools, variability of visit schedules and components, and variability of process flow efficiency (waste and value) in clinic settings. At site visits, Lean Six Sigma methodology allowed current process flow analysis and redesign to incorporate standardized schedules and assessments plus communication and care pathways.

Planning and preparation phases were collectively allocated 3 months; the implementation phase was initiated over the course of 1 week with subsequent data collection on a continuous basis for 9 months. Key steps of implementation (Supplemental Table 5) included critical adjustment to all HRIF clinic schedules to include a 3- to 4-month visit with an HINE, GMA, and motor assessment; this scheduling change replaced the existing 2- to 6-month visits. Return visits for infants with high risk for CP classification were scheduled 3 months later for a repeat HINE and review of neuroimaging if applicable. The implementation phase included data collection, monthly site-specific calls with the lead site and foundation, and monthly all-site calls to address process issues, obstacles, and education needs and to jointly troubleshoot common issues. To facilitate implementation of the GMA, sites uploaded deidentified videos to REDCap for advanced readers to review and discuss. Additional videoconferences addressed difficult GMA cases, HINE consistency, and TIMP.[9]

Study of the Intervention

To assess the impact of the intervention, we compared postintervention data over 3 consecutive trimesters to a 9-month baseline (same calendar months in the previous year, with intervening 3-month washout; Supplemental Fig 5). This allowed us to establish whether outcomes resulted from the intervention and measure how rapidly changes occurred.

Measures

The primary outcome measure was CA at CP diagnosis. The primary process measure was the number of visits at 3 to 4 months' CA because this was the critical entry point in pathways to receiving the diagnosis in the SIPOC chart and published implementation efforts.[10] We also examined the number of new CP diagnoses and number of infants classified as high risk for CP to further assess the impact on interventions. Additional secondary measures were the number of GMAs performed in the NICU as an ancillary pathway entry point, number of these infants with abnormal GMA, including those who would not typically qualify for HRIF clinics, as well as the number of infants in the pathway with abnormal GMA at 3 months and age at high risk for CP diagnosis. Quarterly reviews monitored data completeness and accuracy; aggregate data were shared quarterly during all-site calls. Balancing measures were parental perception of diagnosis visits and monthly no-show

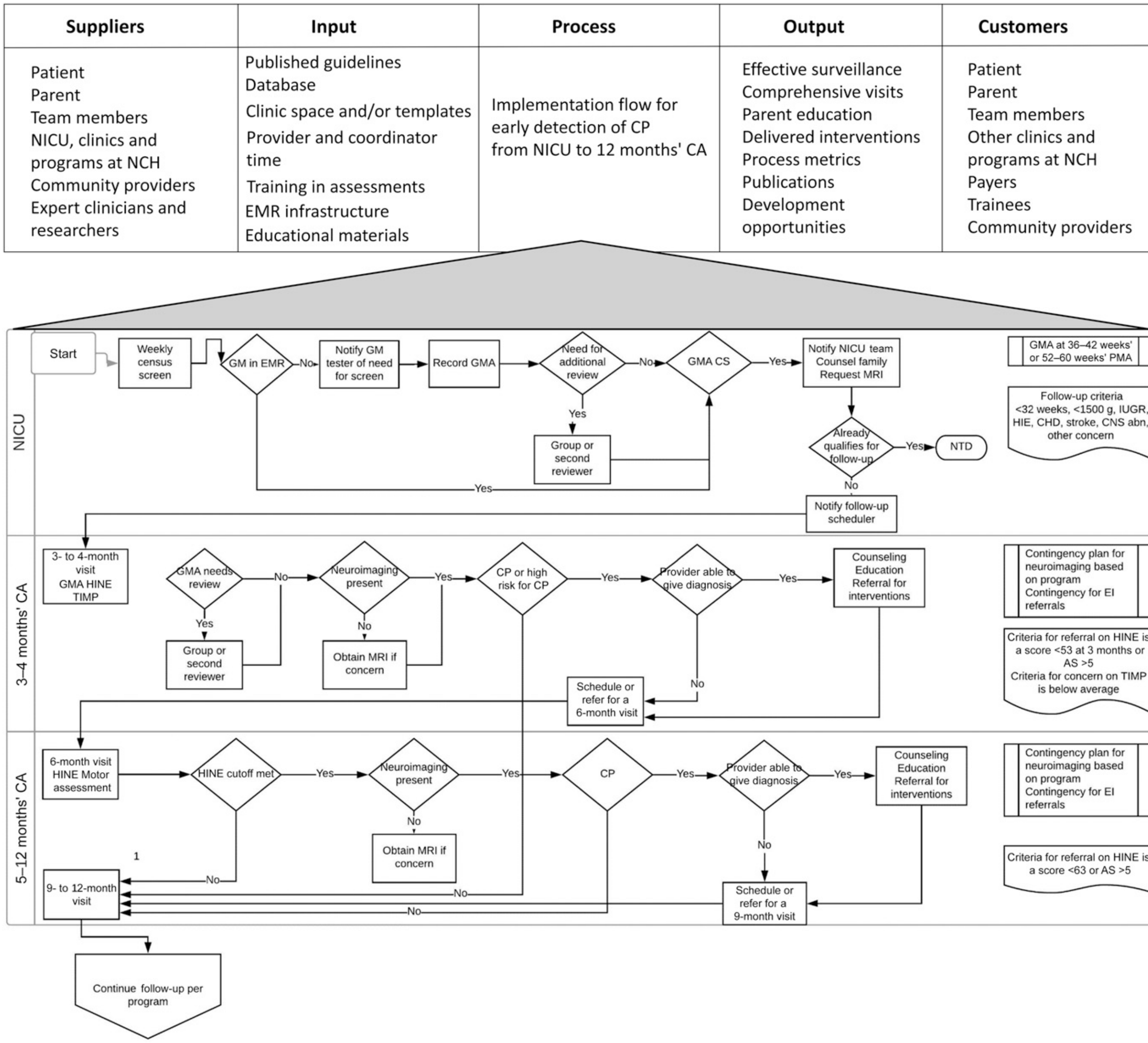

FIGURE 1
Initial SIPOC chart with process flow developed at lead site. Entry into process happens in the NICU or the clinic. In the NICU, a coordinator (social worker, nurse, therapists, etc) screens the census weekly for infants meeting GMA age criteria. If there is no EMR GMA, the coordinator notifies the inpatient GMA team (therapists or physicians) of needed GMAs. The team can request additional review by an advanced GMA reader or entire team if uncertain. If the read is cramped synchronized (CS), the primary clinical team for the infant is notified and counseling is provided to the parents and/or team with request for an MRI. An HRIF visit at 3 to 4 months' CA is scheduled if the patient does not already qualify per clinic criteria. If the infant is already at 3 to 4 months and the GMA is abnormal, the HRIF team can perform the HINE and make recommendations in the NICU. At 3 to 4 months, infants receive the TIMP, GMA, and HINE in addition to standard HRIF visit components. TIMP is performed by therapists, HINE by medical providers, and both can perform the GMA. If assessments indicate a high-risk for CP on the basis of published evidence and neuroimaging cannot confirm a perinatal brain insult, a classification of high risk for CP is given with counseling. MRI is ordered, and a return visit is scheduled to discuss MRI results and repeat the HINE. If assessments, history, imaging, and examination all indicate CP and no progressive disorder is suspected, a diagnosis of CP is given. Counseling and educational materials are provided, a follow-up phone call to discuss further questions is offered, any therapy or clinical trial referrals are made as applicable, and the next visit is scheduled 3 months later for goal setting and adjustments to the plan. abn, abnormality; AS, asymmetry score; CHD, chronic heart disease; CNS, central nervous system; EI, early intervention; GM, general movements; HIE, hypoxic ischemic encephalopathy; IUGR, intrauterine growth restriction; NCH, Nationwide Children's Hospital; NTD, nothing to do; PMA, postmenstrual age.

rates. Parental perceptions were obtained by a questionnaire derived from Baird et al[5] conducted 3 to 4 months after diagnosis in person, through e-mail or text links, or by phone; no-show rates were extracted from each site's electronic medical record (EMR).

Analysis

Weighted, linear mixed-effects regression evaluated whether the age at CP diagnosis changed significantly over time by comparing weighted-average ages during each intervention period to the baseline. The average age for each site-era was used as the outcome measure; weights were applied on the basis of the proportion of total observations that were represented in the site-era average, such that resulting weighted-average ages accounted for varying numbers of patients contributed per site. Poisson mixed-effects models were used to determine at which intervention periods the cumulative average numbers of 3- to 4-month visits and new CP diagnoses differed from the baseline period; weighted averages (least-squares means) and 95% confidence intervals (CIs) were reported for each study era. Analyses were conducted by using SAS 9.4 (SAS Institute, Inc, Cary, NC).

Ethical Considerations

Ethical aspects of implementing the intervention included reviewing parent questionnaires for signs of concern within 24 hours of question entry. Coordinators were instructed to access local social work resources should concerns arise for mental and/or behavioral health during process implementation. IRB approval for the initiative was obtained at Kennedy Krieger Institute and the University of Utah; the initiative was deemed exempt after IRB review as quality improvement at Nationwide Children's Hospital, The University of Texas Health Science Center at Houston, and University of California, Los Angeles.

RESULTS

Weighted-average age at CP diagnosis declined by 3.5 months (95% CI −5.3 to −1.7) per intervention era ($P <$ .001), from 19.5 months during the baseline period to 9.5 months by trimester 3 (Fig 2A, Table 2). By trimester 2, the age at diagnosis was already younger than the age during the baseline period. During the 9-month baseline era, there were on average 24 visits per site per trimester at 3 to 4 months' CA (Table 3). The number of 3- to 4-month visits per site and per trimester was not different from the baseline at trimester 1 but was significantly greater than the baseline for trimesters 2 and 3 (Fig 2B, Table 3). There was a significant increasing trend for 3- to 4-month visits over time from trimester 1 to trimester 3 ($P <$ .001). The total number of visits at 3 to 4 months' CA was 515 in the 9-month baseline period and 893 in the 9-month intervention period (Supplemental Fig 5). There were significantly fewer CP diagnoses per site per trimester in trimester 1 compared to the baseline, whereas there was no significant difference among the baseline and trimesters 2 and 3 (Table 3, Fig 2C). There was, however, a significant increasing trend over time for new diagnoses from trimester 1 to trimester 3 (P = .002). Total new diagnoses (133 cumulative at trimester 3 vs 111 at baseline) may not accurately reflect the number of diagnoses given that 144 infants had a new "high risk for CP" classification during the intervention phase (Supplemental Fig 6) and might convert to CP diagnosis after the 9-month intervention period.

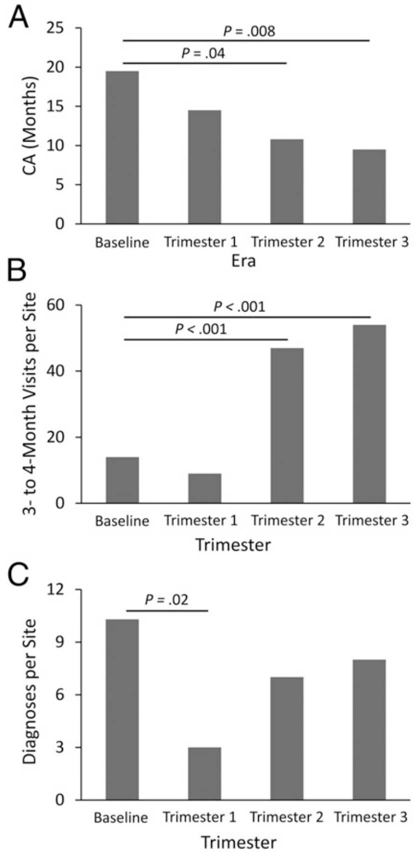

FIGURE 2
Primary outcome measure and process metrics. A, Weighted-average age at CP diagnosis (primary outcome). Model-adjusted estimates account for variability across sites; P values are based on Dunnett's correction for multiplicity. B, Visits at 3 to 4 months' CA per site and per trimester (primary process measure). C, New CP diagnoses per site per trimester. Median number of visits and diagnoses per site per 3-month period; P values are based on model-adjusted values for within-site and within-study era variability.

Additional process metrics included new assessments performed (NICU GMAs, cramped synchronized GMAs, infants who would not have met criteria for HRIF without NICU GMA, absent fidgety GMA, and the number and timing of classifications of high risk for CP). New assessments demonstrated adherence to the process and are being used in the next PDSA cycles, although no comparisons could be made to the era before implementation (Table 4).

TABLE 2 Primary Outcome Measure

Era	Weighted Average Age at Diagnosis, mo[a] (95% CI)	P[b]
Baseline	19.5 (16.2 to 22.8)	Reference
Trimester 1	14.5 (5.9 to 23.0)	.57
Trimester 2	10.8 (5.1 to 16.6)	.04
Trimester 3	9.5 (4.5 to 14.6)	.008

[a] Model-adjusted estimates account for variability across sites.
[b] Based on Dunnett's correction for multiplicity.

TABLE 3 Process Metrics: 3- to 4-Month Visits and New CP Diagnoses

	Actual Values		Model Adjusted		*P*
	Median	IQR	Mean[a]	95% CI	
No. 3–4 mo visits per site per trimester					
Baseline (per trimester)	14	(5.2–73.7)	24.0	(9.8 to 59.0)	Reference
Trimester 1	9	(5.5–60.5)	19.7	(8.0 to 48.6)	.23
Trimester 2	47	(24.0–115.0)	45.5	(18.6 to 110.8)	<.001
Trimester 3	54	(34.5–152.0)	59.8	(24.6 to 145.4)	<.001
No. new diagnoses per site per trimester					
Baseline (per trimester)	10.3	(1.7–17.7)	6.6	(2.3 to 19.0)	Reference
Trimester 1	3	(1.0–8.5)	3.0	(1.0 to 9.0)	.02
Trimester 2	7	(4.0–16.5)	6.4	(2.2 to 18.6)	>.99
Trimester 3	8	(2.5–25.0)	7.4	(2.6 to 21.1)	.89

IQR, interquartile range.

a Model-adjusted values are not actual values. They are numbers modified for within-site and within-study era variability and allow statistical comparisons.

With regard to balancing measures, no-show rates across the network remained constant during the intervention period (15% vs 16%; *P* = .90). Balancing measures also included parent metrics of those receiving a CP diagnosis. Although 76% were married, only one parent was present to receive the diagnosis approximately half of the time. Providers (98% physician, 2% nurse practitioner [NP]) sat 65% of the time while giving the diagnosis and stood 31% of the time. A large majority of parents felt providers showed empathy and support, but 10% did not. Information about the diagnosis was sufficient in content 55% of the time and in words understandable to parents 72% of the time. All providers asked parents if they had questions before the end of the session (Fig 3).

DISCUSSION

This is the first successful implementation of international guidelines for early diagnosis of CP across a clinical network of US institutions. We implemented a process that lowered the age of diagnosis below 12 months' CA and achieved this goal in 12 months through careful adherence to CP diagnosis criteria.[15] Applying all elements of the guidelines allowed clinicians to have available much earlier clinical history, neurologic examination, motor function assessments, neuroimaging, and biomarkers after they ruled out progressive disorders or other diagnoses. The implementation phase finished in 2018, 15 months after publication of the guidelines.

The starting average-weighted age at CP diagnosis across all institutions was 19.5 months, consistent with international registries and publications.[13,16,17] The American Academy of Pediatrics recommends screening for neuromotor problems in general pediatric settings as early as 9 months,[18] although currently there are no formal statements regarding early CP diagnosis. Similarly, although guidelines for early diagnosis exist and experts agree on their value, many providers still hesitate to use tools at or below 3 to 4 months to diagnose CP.[10,19,20] The discomfort with early diagnosis (at least in US settings) may relate to lack of knowledge.[21] GMA training is time and resource intensive, and reliability of the assessment increases only with repeated practice and self-assessment.[22,23] Therefore, GMA training was part of a comprehensive package that included regular review of videos with the network sites, advanced training for superusers, and a secure deidentified repository that allowed newer practitioners to obtain advice from more experienced ones, while respecting the Health Insurance Portability and Accountability Act.

TABLE 4 Secondary Process Metrics

9-mo Data	Before[a] Implementation	9 mo After Implementation
GMAs performed in the NICU,[b] *n*	95	965
Infants with cramped synchronized GMA in the NICU, *n*	5	63
Infants with cramped synchronized GMA not typically referred to HRIF, *n*	3	23
Infants with absent fidgety GMA at 3–4 mo CA, *n*	c	66
High risk for CP classifications, *n*	c	144
Weighted CA at high risk for CP, mo	c	5.1

a Only 1 site had processes in place before implementation; data from 4 other sites were 0.

b Only GMAs performed clinically are included.

c No previous data were collected on this metric.

Another educational gap prevalent in HRIF clinics with multidisciplinary providers was lack of a common standardized neurologic examination, which may contribute to uncertainty in diagnosis and difficulties in communication, especially with more specialized providers. Although the HINE is not the only standardized neurologic examination in infancy and is by no means comprehensive, it is the only one with published

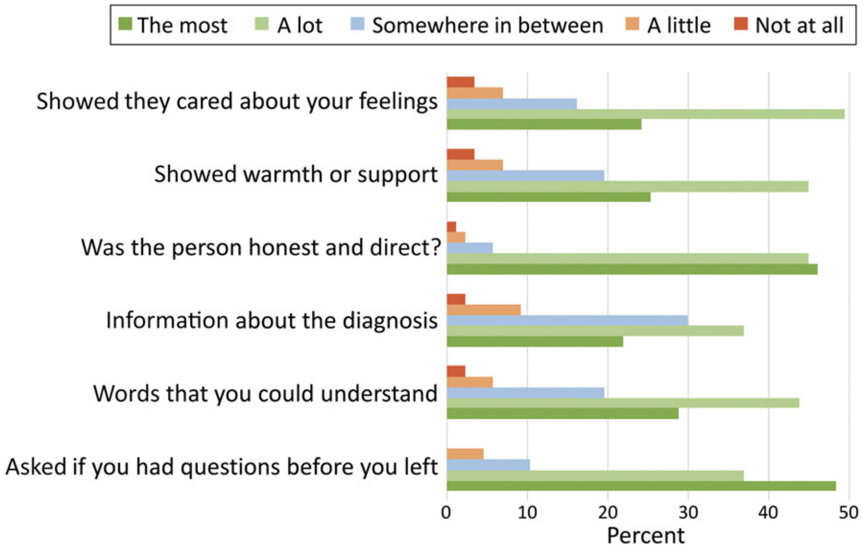

FIGURE 3
Parent metrics: perception of provider. Percentages of parents' responses to questions regarding the diagnosis visit are shown. Questionnaires were conducted 3 to 4 months after the diagnosis visit either in person, through e-mail or text links, or over the telephone.

optimality and cutoff scores.[24] Broad and manualized training in the HINE[25] and insistence on reliability and regular self-assessment enhanced the comfort level of practitioners in our network and contributed to the success of our initiative. The HINE allows early detection of typology of CP and additionally provides a longitudinal evaluation of impairment severity in infants (before the Gross Motor Function Classification System can be reliably ascertained).[26]

Reliance on rigorous examination and reevaluation of organizational processes in HRIF settings contributed to the success of the project and trust from institutional supports. Process metrics revealed increased frequency of 3- to 4-month visits, allowing for more consistent use of the GMA at fidgety age, when sensitivity and specificity for CP are highest.[27,28] Although a reliable pathway to this initial visit from the NICU or the community often proved challenging, all sites were able to implement it without adverse effects on other clinic processes. In particular, template use remained consistent with stable no-show rates. The restructuring of process flows to include a 3- to 4-month visit replaced early visits or shifted an existing schedule but did not cause undue disruptions to the patients' clinical journeys or overburden the system.

Opportunities for improvement were evident in the initial process steps in most settings, where use of the GMA in the NICU uncovered differences in the ability of various sites to obtain neuroimaging. MRI was not always performed in the NICU or in the clinic because of cost considerations, general anesthesia risk, or other provider considerations.[29] Additional opportunities for process optimization included better integration into the EMR and streamlining of communication when abnormal findings were detected and became goals of the ongoing development phase. The most pressing opportunity for improvement was better support of parents around the diagnosis visit. Easy changes included emphasizing current research on the topic and ensuring physicians sat during counseling (eg, providing additional seating). Patients perceive physicians as better listeners and more empathetic when they sit for important conversations, rather than stand.[30] To improve physicians' projection of caring, we included feedback from the parents of patients, self-assessments, and support from more experienced practitioners. Such a "buddy system" was already implemented at the lead site[10] and became a priority throughout the network.

Importantly, balancing measures (eg, stable clinic no-show rates, parent questionnaire responses that supported overall positive impression of the initiative) were consistent with previous single-site implementation efforts.[10] Because processes at all sites carefully considered waste and value added during preparation and implementation, this result was not unexpected. Generally, parents of infants who received a CP diagnosis during this implementation initiative were satisfied with the providers and the information received. Overall, satisfaction rates were no different from those reported for other types of disorders including autism or developmental disabilities.[31–33] However, parent responses revealed numerous opportunities for improvements, as did review of secondary metrics.

With regard to information giving, the network sites decided to pool their existing resources and learn from parent feedback about which resources were most useful and accessible. For example, whereas some parents liked *The Cerebral Palsy Tool Kit*,[34] sites in the areas that were more rural (Table 1) preferred Web-based resources that included capsules of videotaped information.[35] This may be due in part to varying literacy rates across the United States. In our network, estimates of the proportion of the population ≥16 lacking basic prose literacy skills are 23% (CA), 19% (TX), 11% (MD), and 9% (UT and OH).[36] In addition, in central Appalachian counties of Ohio, low literacy rates are 20.6%.[37]

Limitations of this study included its primary focus on HRIF programs. These programs were chosen for feasibility purposes; however, some of the processes described and measures implemented may not be relevant or feasible in primary care practice. We focused on large academic centers with regional referral NICUs to have the broadest catchment areas. Therefore, modifications of the approach would be necessary for settings in which lower-risk populations of infants or low-resource settings are considered. Elements that could remedy distance or training issues include remote reads of videotaped GMA (as in the current project) and ongoing peer-to-peer support for medical providers through telehealth. Finally, although the weighted average of new CP diagnoses across sites did not reach statistical significance, the total number increased and will continue to increase as those with high-risk classifications convert to CP, with the next improvement cycles addressing this conversion.

CONCLUSIONS

Implementation of guidelines for early detection of CP by using quality improvement and implementation science tools is both feasible and effective. Children diagnosed before the age of one year were immediately referred to available services or NIH-funded research programs. Parents were able to offer their opinions on communication improvements and voice their needs for future improvements. The resulting next steps include the development of wraparound models of parent-targeted education, evidence-based research integration, and parent support through behavioral health resources. Each site continues through PDSA cycles to improve the structure and content of implementation with continued dialog across institutions. Transparency between sites allows for the rapid selection and adoption of optimal interventions. Finally, the success of the implementation process encouraged state collaboratives and other large state institutions to join the network or learn from its challenges.

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ABBREVIATIONS

CA: corrected age
CI: confidence interval
CP: cerebral palsy
EMR: electronic medical record
GMA: General Movements Assessment
HINE: Hammersmith Infant Neurologic Examination
HRIF: high-risk infant follow-up
IRB: institutional review board
NIH: National Institutes of Health
NP: nurse practitioner
PDSA: plan-do-study-act
REDCap: Research Electronic Data Capture
SWOT: strengths, weaknesses, opportunities, and threats
SIPOC: suppliers, inputs, process, outputs, and customers
TIMP: Test of Infant Motor Performance

Address correspondence to Nathalie L. Maitre, MD, PhD, Department of Pediatrics, Nationwide Children's Hospital, 700 Children's Way, Columbus, OH 43205. E-mail: nathalie.maitre@nationwidechildrens.org

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