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Richard C. Adams, Carl Tapia and THE COUNCIL ON CHILDREN WITH DISABILITIES

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## CLINICAL REPORT

# Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes

Richard C. Adams, MD, Carl Tapia, MD, and THE COUNCIL ON CHILDREN WITH DISABILITIES

**KEY WORDS**

Part C, IDEA, medical home, children with special health care needs, CSHCN, collaboration, comanagement, coaching, learning in the natural environment

**ABBREVIATIONS**

AAP—American Academy of Pediatrics

El—early intervention

IDEA—Individuals With Disabilities Education Act

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## abstract

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The medical home and the Individuals With Disabilities Education Act Part C Early Intervention Program share many common purposes for infants and children ages 0 to 3 years, not the least of which is a family-centered focus. Professionals in pediatric medical home practices see substantial numbers of infants and toddlers with developmental delays and/or complex chronic conditions. Economic, health, and family-focused data each underscore the critical role of timely referral for relationship-based, individualized, accessible early intervention services and the need for collaborative partnerships in care. The medical home process and Individuals With Disabilities Education Act Part C policy both support nurturing relationships and family-centered care; both offer clear value in terms of economic and health outcomes. Best practice models for early intervention services incorporate learning in the natural environment and coaching models. Proactive medical homes provide strategies for effective developmental surveillance, family-centered resources, and tools to support high-risk groups, and comanagement of infants with special health care needs, including the monitoring of services provided and outcomes achieved. *Pediatrics* 2013;132:e1073–e1088

In decades past, debate centered on the question: “does early childhood intervention work?” Time and extensive research clearly reveal an affirmative answer.<sup>1</sup> In the new millennium, the focus of discussion has turned to distinct conceptual matters and specific questions:

- What roles and actions are best assumed by collaborative professionals in providing a system of early intervention (EI) shared by pediatricians in the medical home and EI programs?
- What models of intervention are optimal when considering infants/toddlers, families, agencies, pediatricians, and best use of resources for optimal outcomes?
- What systematic barriers to optimal intervention are present and what supports are available to overcome them?

Given the ever-growing body of evidence demonstrating the value of EI services for infants with special needs and their families, there remains a necessity for close collaboration between the infants’

medical home and their respective Individuals With Disabilities Education Act (IDEA) Part C state programs. This clinical report, reflecting the work of diverse stakeholders (clinicians, policy makers, academicians, family members, and governmental staffs), will:

1. Review the common core components of IDEA Part C and the medical home;
2. Review evidence of the value of medical home and EI programs for infants/toddlers with special needs;
3. Provide pediatricians with information on evidence-based best-practice models for effective EI;
4. Highlight systematic barriers to identification/integration of infants in EI services; and
5. Offer resources for medical home personnel and families to support this collaboration.

## **CORE COMPONENTS OF IDEA PART C AND THE MEDICAL HOME**

### **IDEA Part C Programs**

For more than half a century, the field of early childhood intervention has emphasized factors impacting an infant's overall function. These encompass both biologic (epigenetic, infectious, etc) and experiential variables (quality of relationships; exposure to, or lack of, opportunities for exploration and learning).<sup>2</sup> The importance of these early experiences was a compelling concept in the 1975 creation of the Education for All Handicapped Children Act (Pub L No. 94-142), which provided "special education" services for children 5 to 21 years of age. Eleven years later, the law was extended and broadened to incorporate the concept of support to infants 0 to 3 years old and their families. This 0 to 3 component, now called Part C of IDEA, addressed "an

urgent and substantial need" in several areas: (1) enhancing the development of infants and toddlers with special needs; (2) reducing downstream governmental costs of special education and/or institutionalization by intervening earlier; and (3) supporting the ability of families to interact with and meet the needs of the infant/toddler.<sup>3-6</sup>

The long-standing charge to each state's Part C program is to create and sustain a statewide, comprehensive, coordinated, family-centered, multidisciplinary, and interagency system of EI services for delivery in the local or regional area. In doing so, each state is required to establish eligibility criteria for serving, at a minimum, 2 cohorts of children: (1) those with a diagnosed physical or mental condition with a high likelihood of developmental delays; or (2) a developmental delay in 1 or more of 5 domains (cognitive, motor, communication, social/emotional, adaptive).<sup>3,5</sup> States may also elect to serve infants at risk for delay because of biological or environment risk factors and/or children who have been in Part C but are now eligible for preschool education (if the family desires to stay in the Part C system).

Because each state is charged with developing these eligibility criteria and is subject to legislative and budgetary constraints, notable variations in eligibility and services occur from state to state. Historically, federal monies for Part C are relatively small. Thus, states rely on systems of coordination with state, local, other public, and private funding sources, serving as payers of last resort rather than as primary payers for intervention services.

This model has demonstrated success on several levels. By 1992, 143 000 children and their families were receiving services via Part C. In 2009, that number had risen to 349 000, or

2.67% of the US population 3 years or younger. With variables related to eligibility criteria and budgets, the percentage of the 0- to 3-year-old population being served in 2009 ranged from 1.24% (Georgia) to 6.5% (Massachusetts). Despite fiscal challenges at the federal and state level, at the time of this publication, all 50 states continue to participate in the Part C program.<sup>3,7</sup>

The most recent reauthorization of IDEA Part C in 2004 placed increasing importance on quality measures of outcome, provision of services in the child's natural environment, and identification efforts for eligible infants ("child find"). There was also a strengthening of the relationship between EI and services being rendered in each state according to the Child Abuse Prevention and Treatment Act Reauthorization Act of 2010 (Pub L No. 111-320).<sup>8</sup>

Because of state-to-state variations regarding eligibility criteria, definitions of "developmental delay," and state budgetary priorities, the nature of EI services can seem heterogeneous when viewed through a national lens. Nonetheless, 2 core concepts remain stable across Part C programs across the country:

- Nurturing relationships are the fundamental elements for optimal early development; and
- IDEA Part C is dedicated to helping families better understand their infants and to coordinating the various regional systems and services available to the family and child.

### **The Medical Home**

By definition, a "medical home" for children is a process of care. The American Academy of Pediatrics (AAP) has described the medical home as

the provision of primary care to children that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. Historically, the medical home was commonly discussed in the context of children with special health care needs, but increasingly, its value has been seen across the full spectrum of infants, children, and adolescents.<sup>9–11</sup>

Clearly, the core components of care that define a medical home match closely those specified legislatively in IDEA Part C. As child find is mandated in Part C, there is recognition that the pediatric medical home is an integral part of that process.<sup>11</sup> Emerging evidence supports the medical home process regarding its value to children's ultimate development and well-being.<sup>12–18</sup> The Healthy People 2020 goals and those of the Patient Protection and Affordable Care Act cite the promotion of the patient-centered medical home.<sup>19,20</sup> When considering the intersection of EI and the medical home, a key component of the medical home process is that of identifying infants and toddlers with developmental disorders.<sup>21–25</sup> A natural next step is timely and appropriate referral to EI services for coordinated, culturally effective, and family-centered developmental intervention.

Over the past decade, the medical home concept has extended beyond pediatric practices into those of family/community physicians and internal medicine. A recent workforce study by the AAP described a robust pediatric workforce for the population of US children but noted a significant problem of distribution (regional shortages and oversupplies).<sup>26</sup> Family physicians provide a medical home opportunity for approximately one-third of the US pediatric population. Historically, these services have been in rural communities; estimates

suggest up to 5 million children/adolescents live in counties with no pediatrician. Supporting both family physician medical homes and Part C agencies serving rural and/or frontier areas of the country should be a focus at both the preservice and in-service levels.<sup>27</sup>

As the model of the pediatric medical home has gained support over recent years, the number of recommended or expected tasks/screening procedures for the primary pediatrician has also increased.<sup>14</sup> Acknowledging potential time and budgetary constraints within pediatric practices, methods to streamline identification of infant developmental delays have been developed and are critical to meeting family needs and successful referral to EI services for the child.<sup>4,28</sup>

### EVIDENCE-BASED OUTCOMES AND BEST PRACTICE CONSIDERATIONS

Over the past half century, research in the neurosciences and in child development have placed an increasing priority on the support needed in the first few years of life as brain growth and function are being shaped for future “scaffolding” of skills and knowledge. Program development and methods of program evaluation have since been generated and demonstrated to assist in this neurodevelopmental process. From this body of work have emerged several global principles related to early childhood development and intervention for optimal development.<sup>29</sup> Brains are built over time and are modulated by the interactive influences of genes and experience that literally affect the architecture of the developing brain.

- Access to basic medical care (prenatal and during early childhood) prevents threats to healthy development through early diagnosis/identification of problems with

subsequent EI and ongoing care management.

- When parents, community programs, and professionals who provide early childhood services (including the pediatrician in the medical home) promote supportive relationships and rich learning experiences for infants and young children, a stronger foundation is created for higher achievement in school and, eventually, the community.
- The economic cost of creating and applying supportive conditions for early childhood development is less than the alternative “down the road” costs of addressing problems later in childhood or adolescence.
- From a legislative and policy perspective, a strong investment in early childhood intervention is foundational for community and economic development on multiple levels.

Although these global incentives derive from studies across various medical and nonmedical fields, it is instructive to consider, more specifically, the benefits stemming from the 2 entities being considered: the medical home and EI services for infants and toddlers.

### Benefits From Participation in a Medical Home

The primary care medical home, with core attributes including being family centered; community based; and accessible, coordinated, and continuous in support, has increasingly been endorsed by the AAP and other child-oriented agencies as highly valuable.<sup>30</sup> The core concepts of these processes of care seem intuitive for physicians charged with providing preventive and timely care to infants/toddlers.

The benefits of a medical home in providing efficient, high-quality, comprehensive primary care are well documented. For example, the medical home has been linked to improved health status, more timely care, increased family-centeredness, improved family functioning, and more appropriate health-care utilization.<sup>9,10,13,17,31,32</sup> The National Survey of Early Childhood Health reports that nearly half of parents have concerns about their child's development,<sup>33</sup> yet few parents report that their concerns are elicited during outpatient clinic visits.<sup>34</sup> In addition, children at high-risk of developmental delay have been associated with lower odds of having a medical home compared with children at low or no developmental risk.<sup>35</sup> Thus, a growing consensus recognizes the ability of a medical home process to provide developmental health services and promote a comprehensive system of community services for early childhood development,<sup>33,36,37</sup> a process altogether consistent with and supportive of the core elements of EI services under IDEA Part C.

## Benefits From EI

When evaluating benefits derived from early identification and intervention, there are 2 major streams for measuring outcomes: (1) benefits to the child and the family; and (2) economic advantages derived from EI programs.<sup>38</sup>

An increasing number of well-constructed longitudinal studies have emerged over the past decade. The indicators measured reflect positive and sustainable outcomes. The Infant Health and Development Program tracked outcomes in low birth weight and preterm infants who received EI services. At 8 years of age, improvements were noted in verbal abilities, receptive language scores, and overall cognitive performance.<sup>39</sup> At the 18-year

follow-up, there were notable improvements in academic performance and endorsement of less risky behaviors, fewer arrests, and a lower dropout rate.<sup>40</sup> Other studies have generated similar positive data as long as 15 to 40 years beyond early childhood.<sup>41,42</sup>

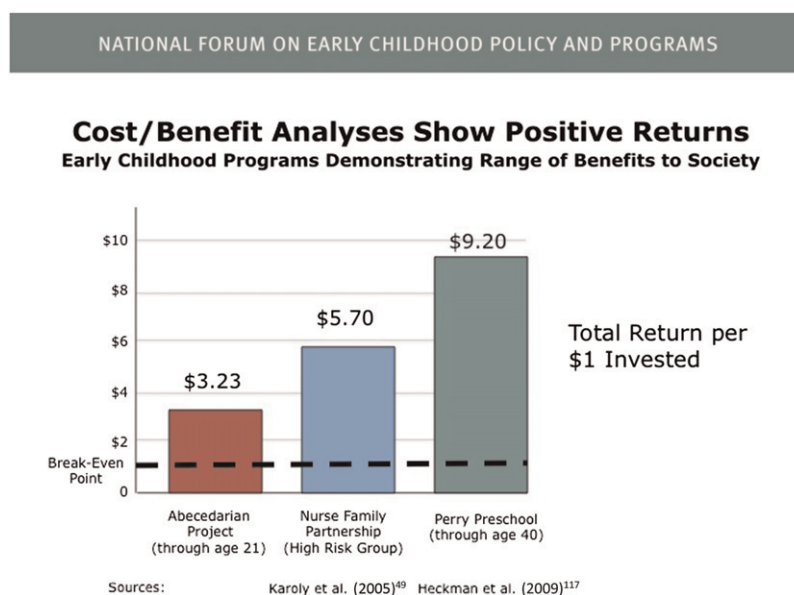
Equally important to communities and agencies are the studies demonstrating the fiscal advantages of providing quality EI services. A 2003 report from the Federal Reserve Bank of Minneapolis reveals EI programs as "economic development initiatives" that should be at the top of economic lists for local and state governments. The authors found that 1 program demonstrated an \$8 return for every dollar invested in EI and estimated that 80% of the benefits were directly applicable to society in general (because of more efficient use of school services and less use of criminal justice and other public systems).<sup>43–46</sup> In the 2008 study, *The Economics of Early Childhood Policy*,<sup>47–49</sup> Kilburn and Karoly provide the foundation for support of EI from strictly an economic

perspective and conclude: "The costs savings for government could be large enough to not only repay the initial costs of the program but also to possibly generate savings to government or society as a whole multiple times greater than the costs."

The benefits reflected in these studies and other studies expand the concept of EI from one of solely a social-service/educational policy to one of critical economic-development and conservative fiscal responsibility.<sup>50</sup> Availability of these data should support advocacy efforts of the medical home on behalf of infants (Fig 1).

## MEDICAL HOMES, EI PROGRAMS, AND BEST PRACTICE MODELS

Given the evidence-based data regarding the value of medical homes and EI services, the continuing challenge is to identify which models of intervention are consistent with best practice consensus, and which demonstrate greatest outcomes with best stewardship of professional and fiscal resources. The medical home can be essential in helping families and



**FIGURE 1**

Cost/benefit analysis of benefits to society of early childhood programs. (Reprinted with permission from the Center on the Developing Child at Harvard University, [www.developingchild.harvard.edu](http://www.developingchild.harvard.edu)).



diverse providers better understand the roles played by professionals involved in the infant's overall intervention program.

Two concepts are increasingly prioritized when translating evidence-based neuroscience into functional application for "best practice" provision of EI services:

1. Creating frequent opportunities that allow for "learning in the natural environment" rather than in simulated "treatment" situations; and
2. Utilizing methods of "coaching" as a model for families, medical homes, and EI programs providing services to infants.

The concept of providing intervention services within the context of a natural learning environment has been a legal and conceptual component of IDEA Part C intervention since its inception. Part C considers "natural environments" as meaning settings that are natural or typical for similarly aged and nondisabled peers. The broader concept of learning in the natural environment encompasses several key elements:

- There is base acknowledgment that learning takes place in the context of relationships, and as such, intervention strategies should enhance rather than disrupt typical activities unique to a family.
- There is endorsement of parents, siblings, extended family, and others as key agents for the infant's developmental learning.
- Thus, emphasis is on supporting those change agents and their abilities during everyday activities, rather than attempting to teach new skills outside of natural contexts.
- Focus is on function and development of personal-social skills in the infant while promoting awareness and confidence in parents to

guide their infant with special needs.

Rather than a "medical model" wherein a specific treatment is applied directly to the child for a specific malady, the paradigm is shifted to a contextual and consultation-based delivery of supports and services to the family and the infant.<sup>51,52</sup> Similar to the concept of the medical home being a process, rather than an address, the concept of natural environment describes process rather than a physical address.<sup>53</sup> These concepts have been endorsed by national stakeholder organizations, including those of speech, physical, and occupational therapies.<sup>54–56</sup>

Increasingly, a best practice method, endorsed across diverse disciplines, provides coaching strategies to families for use in the child's natural learning environments. This method has been shown to build the capacities of a parent or other caretaker as new skills (both in the family member and the child) are acquired.<sup>57,58</sup> Coaching techniques to support parents are used by therapists in the natural learning environment and can be modified and applied by the pediatrician in

the medical home process.<sup>59–62</sup> Key elements in the coaching process are shown in Table 1.

There is a more complex subset of infants who might benefit periodically from adjunctive traditional "hands-on" (direct) medical therapy. This is generally for specific goals and often for limited periods of time. These complex health care needs may include severe visual or hearing impairments, tracheotomies, and congenital malformations with inherent limitations to daily activities or needs, etc. Referrals for supportive direct services should be based on specific and measurable outcome goals. Preferably, such goals should be written in concert with the global goals of the family (also reflected in the individualized family service plan as a component of "care coordination").

Unfortunately, confusion is too often experienced by families when the infant is dually served by therapists applying direct medical therapy and professionals in the medical home and/or EI program by using transdisciplinary coaching within the natural learning environment. Unless these services are explained and

**TABLE 1** Elements in the Coaching Process

Element	Examples for Application
Joint planning	Agreement by coach and parent on actions assumed by coach and subsequent opportunities for the parent to practice between coaching visits.
Observations	Consider the family's actions/practices/routines to better develop new skill sets, strategies, and ideas for use in the natural learning environment.
Action	Spontaneous or scheduled events, occurring in real-life situations, that allow the family member to practice, refine, or analyze new skills.
Reflections	The coach revisits the existing strategies to ensure they are in keeping with evidence-based practices and consider if/when modifications are needed.
Feedback	After the family member is allowed to reflect on strategies employed, actions being applied, and opportunities to practice new skills in the natural learning environment, the coach provides information affirming the parent's understanding or adds information to deepen the parent's understanding.

Modified from Rush DD, Shelden ML. *Evidence-Based Definition of Coaching Practices*. Morganton, NC: Center for the Advanced Study of Excellence in Early Childhood; 2005.<sup>114</sup>

closely coordinated, a mistrust of one professional or the other can develop.<sup>57</sup>

**FOUR DEVELOPMENTALLY  
HIGH-RISK GROUPS COMMON TO  
MEDICAL HOMES AND EI  
PROGRAMS**

Among all the children seen in the medical home, several subgroups involve particularly high risks, specific opportunities for EI services, and ongoing collaboration with the pediatrician:

**Infants and Toddlers From  
Environments of Abuse or Neglect**

Data from the US Department of Health and Human Services (2011) revealed ~825 000 substantiated cases of abuse/neglect resulting in 1770 child deaths.<sup>65</sup> Infants younger than 1 year remained the highest risk group for fatalities. Among children 0 to 3 years of age who are maltreated but survive, negative effects (social/emotional, cognitive, and/or physical) have been described in up to 47%.<sup>64</sup> Given the astounding cost of child protective services (provision of educational, judicial, and health-related services are estimated at \$94 to \$103 billion per year), the ability to identify and prevent conditions leading to maltreatment warrant serious consideration and action.<sup>15</sup>

A gap exists in the provision of EI services to maltreated infants and toddlers. Of the ~35% with a need, only 12.7% actually receive services.<sup>65</sup> The Child Abuse and Prevention Treatment Act of 2010 acknowledged this and sought to advance “effective practices and programs to improve activities that promote collaboration between the child protective services system and the medical community, including providers of mental health and developmental disability services,

and providers of early childhood intervention services.”

Social and emotional development is most vulnerable to previous maltreatment, with attachment issues, severe feeding differences, and sleep disorders being especially prominent among infants.<sup>66</sup> Given research evidence that (1) early brain development affects lifelong capacity to regulate emotions and learn; (2) the “active ingredient” for brain development is the quality of relationships between the infant and those providing care and nurturing; and (3) infants/toddlers exposed to persistent multiple risk factors are in need of EI as early as possible, the close, collaborative interaction of the medical home and the regional Part C program is vital to infant outcome and community cost containment.<sup>67,68</sup>

**Infants and Toddlers With Mental  
Health Issues**

Closely related to the issues of maltreatment, but by no means limited to this group, are infants and toddlers experiencing mental health issues (either primary to the child or among their caregivers).<sup>69</sup> Coexisting conditions can act as “red flags” for developing infant mental health concerns (Table 2).<sup>70,71</sup> Likewise, mental health issues affecting the infant/toddler can result in additional developmental delay

or dysfunction.<sup>15</sup> As awareness of infant mental health issues increases and as more focus is placed on providing needed services for this group, the medical home and the Part C programs together remain at the forefront of identification, intervention, and surveillance over time.<sup>72–75</sup>

Elements of support for infant mental health include: (1) easy accessibility for diverse families; (2) a system for early identification of concerns and timely application of screening/referral; (3) provision of full access to an array of supportive resources; (4) promotion of family knowledge of conditions and of service delivery systems; and (5) ensuring family-centered care with family satisfaction as an outcome of interventions.<sup>76,77</sup> These elements are provided when the medical home process and the regional Part C program perform collaboratively. The focus of intervention to support infant mental health remains on the infant-caregiver relationship rather than on solely the child or adult.<sup>78</sup> Instruments such as the Ages and Stages, Third Edition,<sup>79,80</sup> the Ages and Stages: Social/Emotional screener,<sup>81</sup> Mental Health Screening Tool Zero to 5 Years,<sup>82</sup> and the AAP “Addressing Mental Health Concerns in Primary Care: A Clinician’s Toolkit,”<sup>83</sup> among others, offer functional options for use with families.

**TABLE 2** Risk Factors Potentially Impacting Infant Mental Health

Family and Associated Environmental Factors	Child Factors
Low socioeconomic status/poverty	Premature birth
Low maternal education	Low birth weight
History of domestic violence	“Difficult” temperament and/or poor “goodness of fit” with primary caregivers
Maternal/paternal depression	Exposure to “toxic stressors” (alcohol, illicit drugs, traumatic events, environmental exposures, such as lead, etc)
History of parental criminality	Cognitive dysfunction
Parental health problems	Genetic conditions with associated behavioral disorders
Parental mental health disorders	
Family history of mental health disorders	

Modified from Brauner CB, Stephens BC. Estimating the prevalence of early childhood serious emotional/behavioral disorders: challenges and recommendations. *Public Health Rep.* 2006;121(3):303–310.<sup>70</sup>

### Infants and Toddlers From Culturally Diverse Backgrounds

Linguistic and/or cultural differences between families and professionals in the medical home or EI program create barriers to both appropriate screening and, potentially, to enrollment and provision of services. Families' beliefs and understanding of child development and differences in developmental progression reflect cultural perspectives. Their views of "community" and the child may differ from a professional's "deficit-oriented" interpretation of the child's functioning capacity.<sup>84</sup>

Numerous factors and variables affect the process of screening, referral, and service provision, including: socioeconomic status, religious differences, regional demographics, English proficiency or literacy, immigration status, family support systems, and access to services. When 1 or more of these potential barriers exist, the results may include families' feelings of being insulted or treated rudely, fear of the medical community in general, confusion about appointments/referrals, or being discounted in the decision process.<sup>85–89</sup>

The disparities noted previously can negatively affect the processes of care in the medical home and the regional Part C program.<sup>90</sup> Feinberg et al<sup>91</sup> discussed the effect of race on effective participation in EI programs. African American children with developmental delay(s) were 5 times less likely than were white children to receive EI services. Garcia and Ortiz<sup>84</sup> have described similar differences in the Latino population and have offered suggestions for prereferral interventions to support culturally and linguistically different populations. As medical home personnel consider quality improvement efforts, areas for consideration might include lack of awareness of racial privilege,

assumptions of the value of science over spirituality (in reference to developmental differences), importance of individual over the family group, and logistics required for higher frequency interactions with the developmental or medical community<sup>91,92</sup> (Table 3).

### Infants and Toddlers From Economically Deprived Backgrounds

Robust data from economically at-risk populations describe (1) disparities in referral and provision of services for EI and developmental support; and (2) variations in policy commitment to low-income young children and families. Some of these disparities remain at the institutional/policy level within each state (eligibility criteria, coordination efforts, etc). For example, among states with narrow EI eligibility criteria, poor children are 18% less likely to receive EI services.<sup>93</sup> Some are the result of barriers discussed above relative to cultural differences and to mental health issues.<sup>94–98</sup>

The effects of poverty and comorbid conditions, such as food insecurity, have been linked not only to health and ultimate educational performance but also to mental health and behavior in

young children and their mothers.<sup>99,100</sup> It is critical for professionals in both medical homes and Part C programs to integrate quick and effective methods of surveillance for poverty-related issues, such as food insecurity, as a component of early childhood intervention<sup>101</sup> (Table 4).

### TOOLS FOR THE MEDICAL HOME: MEETING THE CHALLENGES OF COLLABORATION

The medical home process is highly valued by families as they perceive "added value" benefits of more predictable care and less unplanned emergent care, especially among families of children with special needs.<sup>12</sup> As the value placed on the medical home continues to rise, so too are the seemingly unending expectations. But as screening procedures and protocols are encouraged, time and reimbursements remain significant limiting factors.<sup>102,103</sup> Thus, it is imperative that the professionals in the medical home have ready access to tools to provide efficient screening, surveillance, referral, and ongoing collaboration in support of infants/toddlers and EI services.<sup>104</sup> In 2006, the AAP published a policy statement, "Identifying infants and

**TABLE 3** Cultural Barriers to Medical Home Screening and Referral for EI Services

Families	
	Limited proficiency in English (parent and/or child); differences in speech or dialect
	Limited reading skills
	Acculturation level and knowledge of/comfort with agencies
	Attitudes toward child development and disabilities
	Conflicts: work, child care, transportation, or financial
	Extended family expectations different from parents/professionals
Medical homes	
	Sensitivity to cultural diversity within medical home staff
	Sensitivity to religious preferences and differing family traditions
	Paternalistic approaches to parents of infants from different cultures
	Use of medical jargon
EI programs	
	Lack of language-appropriate information materials
	Shortage of available bilingual personnel
	Inflexible scheduling practices
	Sensitivity to cultural diversity among families served

Modified from Zhang C, Bennett T. Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. *Focus Autism Other Dev Disabil*. 2003;18(1):51–59.<sup>115</sup>



**TABLE 4** Potential Questions for Social History in Families of Infants/Toddlers by Using the *IHELLP* Mnemonic

Area of Interest	Example Questions
<b>Income</b>	
General	Do you have fear of running short of money by the end of the month?
Food security	Do you or anyone in the family ever skip meals because there is not enough money for food? Do you receive assistance (food stamps, etc)?
<b>Housing</b>	
Associated utilities	Is housing or payment for housing a problem for you? Do you have trouble or concern about paying electric/gas/water bills?
<b>Education and development</b>	
Early childhood programs	Do you have concerns about how your infant is developing? Is your child in a program to assist you in supporting her development? Do you feel the need for such a program?
<b>Legal status</b>	Do you have questions about your immigration status or about benefits/services for you and your infant/toddler?
<b>Literacy</b>	Do you have trouble reading forms given from our office or agencies? Do have difficulty in reading generally? Do you read to your child each day? (Based on above answers)
<b>Personal safety</b>	Do you feel that you and your infant/toddler are safe in your present situation/relationship? Have you or your spouse ever been the subject of domestic violence?

Modified from Kenyon C, Sandel M, Silverstein M, Shakir A, Zuckerman B. Revisiting the social history for child health. *Pediatrics*. 2007;120(3). Available at: [www.pediatrics.org/cgi/content/full/120/3/e734](http://www.pediatrics.org/cgi/content/full/120/3/e734).<sup>101</sup>

young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening”<sup>105</sup> (<http://pediatrics.aappublications.org/content/118/1/405.full.html>), which offers a roadmap and valuable resources to the pediatrician seeking to identify and refer eligible infants for EI services. Since its publication, Earls et al<sup>23</sup> reported a longitudinal study of developmental and behavioral screening in a North Carolina project containing insightful ideas and suggestions for practical applications in practice.

King et al<sup>24</sup> conducted a quality improvement follow-up study on developmental screening and surveillance. Attempting to apply the algorithm suggested in the 2006 AAP policy statement, clear gains were made in identifying and referring young children to EI programs. But many practices described struggles in implementing the pro-

cesses in particularly busy seasons, with staff turnover, and regarding certain time-sensitive screens. Tracking of referrals made was difficult. King et al’s<sup>24</sup> review (<http://pediatrics.aappublications.org/content/125/2/350.full.html>) offers insights for other medical homes attempting to optimize identification and referrals for EI.

Marks et al<sup>106</sup> in 2011 published suggestions for enhancing the algorithm for developmental and behavioral surveillance in children ages 0 to 5 years (<http://cpj.sagepub.com/content/50/9/853>). In addition to further data supporting the use of specific screening tools, the review offers practitioners specific guidance in the following components of care:

- Eliciting and addressing parents’ concerns;
- Milestone and behavioral skill monitoring;

- Identifying developmental/behavioral risk and protective factors;
- Making accurate and informed observations about child-parent interactions; and
- Child referral resources.

Three other resources available to the medical home offer guidance and efficiency in approaching at-risk infants/toddler who have potential need for EI services. The 2006 clinical report from the AAP,<sup>107</sup> “Clinical genetic evaluation of the child with mental retardation or developmental delays,” remains a useful tool for the practitioner in which decision trees, clinical guidelines, and resources for clinical application are outlined (<http://pediatrics.aappublications.org/content/117/6/2304.full.html>). Michaud’s<sup>108</sup> overview of prescribing therapy services for children with motor disabilities (<http://pediatrics.aappublications.org/content/113/6/1836.full.html>) and Sneed et al’s<sup>109</sup> review of the differences in prescribing therapies and medical equipment in medical versus educational settings (<http://pediatrics.aappublications.org/content/114/5/e612.full.html>) are both practical and insightful guides for the busy medical home.

Once the practitioner has identified an eligible infant/toddler in need of services, the family benefits from open and effective lines of collaboration between the medical home and the Part C program. A summary of suggestions for better communication between medical homes and EI programs is provided in Table 5.<sup>110,111</sup> A representative sample of the numerous resources available to the medical home and to families is outlined in Table 6.

Despite the barriers and challenges inherent to practitioners and programs, there remains strong potential for collaboration between medical homes and EI programs at the policy

and programmatic levels.<sup>89,112</sup> Kozlowski et al<sup>113</sup> described an investigation comparing parents of toddlers with autism to those of children with other developmental disorders. The data, generated through the Louisiana Part C Program, described time delays between when parents first perceived differences in their children's communication styles and when referrals from physicians were made to the EI program. Collaborative model ventures such as this will continue to inform families, medical home professionals, EI service programs, and state agencies.

### SUGGESTIONS FOR COLLABORATION BETWEEN THE MEDICAL HOME AND EI PROGRAMS

- Improving child-find and optimizing the referral process

Practitioners should incorporate the AAP recommendations for developmental surveillance, which allows for enhanced identification and timely referral for EI services.

The referral should set the stage for collaboration with EI programs. The AAP referral form is available ([http://www.medicalhomeinfo.org/downloads/pdfs/EIReferralForm\\_1.pdf](http://www.medicalhomeinfo.org/downloads/pdfs/EIReferralForm_1.pdf)) and can help streamline the process, and individual states may have referral forms that are specific for the individual state Part C program. Such forms can be used in referrals to adjunctive service programs.

The referral provides an opportunity for education about appropriate developmental milestones, as well as eliciting family goals and expectations, which should inform supervision of the individualized family service plan and clinical approval for EI and other developmental services.

The medical home should incorporate a system for referral tracking. An example referral form (Appendix) provides a template to obtain family permission at the time of the referral so that EI programs can communicate the results of the initial evaluation with the medical home. Modifications for individual states/programs may be needed (Appendix).

- Efficient evaluation and coordination of services

Practitioners should not wait for a specific diagnosis before initiating an appropriate referral to EI. Early referral should request:

- assistance with multidisciplinary assessment;
- provision of support to parents in addition to the child;
- provision of knowledge about and integration with community resources; and
- a preferred mechanism for information return from the intervention program.

Various protocols are available to guide a stepwise developmental evaluation of infants and young children (see above). Included among

these resources is the AAP "Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians."

As practices enhance their capacity for care coordination, consideration should be given to develop mechanisms for identifying families who need assistance with the referral process or who have complex psychosocial or medical issues. These strategies might include:

- closer follow-up;
- linkage to a care coordinator; and
- incorporation of health information technology to assist in identification, clinical decision support, and tracking.

Families should be encouraged to partner with the professionals in the medical home to recognize and monitor appropriate consultation and service options. These may include:

- monitoring of the child's progress being made related to services being purchased;
- informing families of appropriate treatment models;
- being available to programs and school systems for clarification of medical issues that affect development and learning; and
- proactively planning the transition from Part C (birth to 3 years) to Part B of IDEA, and the 3- to 5-year-old programs in their local school system.
- Advocacy roles for physicians in the medical home

**TABLE 5** Ideas for Communication/Collaboration Between Medical Homes and Part C

Channels for concise bidirectional, "minimum effort" communication needs to be in place and familiar to both the medical home and the regional Part C Program.

Tools such as the AAP Referral Form for Early Intervention should be deemed acceptable (with modifications as needed) and readily available ([http://www.medicalhomeinfo.org/downloads/pdfs/EIReferralForm\\_1.pdf](http://www.medicalhomeinfo.org/downloads/pdfs/EIReferralForm_1.pdf)).<sup>113</sup>

Professionals at both the medical home and the Part C program need continual update in medical records as the child is seen and changes are noted.

To best sustain the process of information sharing, the individuals at each program should know who one another are and how to contact directly when needed. Information from the medical home should be available to the Part C assessment team before its evaluation and information, and recommendations on intervention should be forwarded to the medical home as the individualized family service plan is developed and modified.

When the child is seen by subspecialists, their input to both the medical home and the Part C program is valuable.

Timely and ongoing flow of information between the medical home and the Part C program reassures the family of coordinated, family-centered care; it relieves the family of the burden of having to interpret and transport the information.

Modified from Stille CJ. Communication, comanagement, and collaborative care for children and youth with special healthcare needs. *Pediatr Ann.* 2009;38(9):498–504.<sup>110</sup>

**TABLE 6** Resources for Medical Homes and Families

Resource	Comments
American Academy of Pediatrics <a href="http://www.HealthyChildren.org">www.HealthyChildren.org</a>	At the American Academy of Pediatrics Web site. Includes developmental milestones for infants/toddlers 0–5 y of age. Information about infants born preterm and about early childhood delays in all areas, including language and social skills, is available.
Zero To Three <a href="http://www.zerotothree.org">www.zerotothree.org</a>	Includes information and resources on a number of topics, including early development, language, and behavior.
Learn the Sign, Act Early Center for Disease Control and Prevention, The National Center on Birth Defects and Developmental Disabilities <a href="http://www.cdc.gov/actearly">www.cdc.gov/actearly</a>	Provides an array of checklists, fact sheets, positive parenting tip sheets, and links to useful sites for specific issues.
National Dissemination Center for Children With Disabilities <a href="http://nichcy.org/babies">http://nichcy.org/babies</a> 1-800-695-0285	Funded by the US Office of Special Education and Rehabilitative Services. This site provides information about services in one's state and local region. Information is guided for families, medical professionals, and school personnel.
Family Voices <a href="http://www.familyvoices.org">www.familyvoices.org</a>	Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. The site provides families with tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a partner in the child's health care. National and state sites and organizations are available.
Child and Family WebGuide: Expert Reviewed Sites on Children and Families <a href="http://www.cfw.tufts.edu">www.cfw.tufts.edu</a>	The WebGuide is a directory that evaluates, describes, and provides links to hundreds of sites containing information about child development research and practical advice for professionals and families.
Your Child: Development and Behavior Resources: A Guide to Information and Support for Parents <a href="http://www.med.umich.edu/yourchild/index.htm">www.med.umich.edu/yourchild/index.htm</a>	The site provides: evidence-based information for families and professionals; links to support groups, agencies, and organizations; recommended books and other tools; links to sites for "timely topics"; and a guide for families on using the Internet to find reliable parenting information.
National Association for the Education of Young Children (NAEYC) <a href="http://www.naeyc.org/">http://www.naeyc.org/</a>	Founded in 1926, NAEYC is the world's largest organization (80 000 members) working on behalf of young children. Resources and publications for medical homes, families, and agency programs for infants and toddlers are available.

Realize state-to-state differences in eligibility criteria, assessment policies, and services provided under Part C; be aware of updated changes in aspects of service for your state.

Be aware of potential costs to the family (public funding, private insurance, private pay).

Be cognizant of resources (fiscal and professional) available within the state and their local Part C

programs and support efforts to optimize services to infants/toddlers. Maintain an updated resource list of local and regional services/resources, including both subspecialty consultants and supportive programs.

Assign time to meet with staff from local and regional programs (in office, over telephone, or through local continuing education or hospital staff meetings).

Work within AAP Chapter structures to monitor and encourage state governmental services to infants and children; interaction at the legislative and the agency levels is critical to support fiscal, policy, and quality assurances of outcomes. Fiscal considerations include both monies to operate quality programs and a system of proper reimbursements for primary physicians and specialists caring for children with special needs. Policy considerations include ensuring that families have timely access to primary and subspecialty services.

Explore opportunities to participate on statewide or regional boards tasked with oversight of the early childhood programs.

## CONCLUSIONS

The positive economic effect of front-end EI services has been clearly demonstrated. Short-term and longitudinal data (even into young adulthood) demonstrate the value of early childhood intervention focusing on family-centered, coordinated services that support parent-child relationships as the core element of intervention. Likewise, the economic and health-related values (long-term) derived from being a child supported by the medical home process continue to emerge.

Seeking to enhance collaboration between the sister systems and to minimize systematic barriers is clearly in the best interest of infants, toddlers, their families, and the larger community. Such collaboration serves families in their critical roles as coaches to their children (living, playing, and growing in the infant's natural learning environment).

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## APPENDIX: EI REFERRAL FORM TEMPLATE (FROM TEXAS DEPARTMENT OF ASSISTIVE AND REHABILITATIVE SERVICES AND TEXAS PEDIATRIC SOCIETY [NOT FOR USE OUTSIDE OF TEXAS]).

Pediatricians can customize for use in their own communities (but should ensure that the form meets requirements of the Health Insurance Portability and Accountability Act as well as the Family Educational Rights and Privacy Act). ASQ, Ages & Stages Questionnaire; ICD-9, *International Classification of Diseases, Ninth Revision*. ECI, Early Childhood Intervention; M-CHAT, Modified Checklist for Autism in Children; PEDS, Parents' Evaluation of Developmental Status.

### Physician Referral and Feedback

#### Child Information

Child's Name \_\_\_\_\_ DOB \_\_\_\_\_ Parent's Name(s) \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Language \_\_\_\_\_

Race: ☐ American Indian or Alaskan Native ☐ Asian ☐ Black or African American ☐ Native Hawaiian or Other Pacific Islander ☐ White Ethnicity: ☐ Hispanic/Latino/Spanish

#### Physician Information

Physician's Name \_\_\_\_\_ Phone \_\_\_\_\_ Fax \_\_\_\_\_

Address \_\_\_\_\_ Contact Name/Title \_\_\_\_\_

#### Reason for Referral

1. Suspected developmental delay in the following area(s): ☐ Cognitive ☐ Motor ☐

Communication

☐ Adaptive/Self-Help ☐ Social-Emotional ☐ other (specify) \_\_\_\_\_

2. Medically diagnosed condition(s), if applicable, including ICD-9 code(s) – list all: \_\_\_\_\_

\_\_\_\_\_

3. Sensory Impairment: ☐ Auditory ☐ Visual

4. Screening results, if applicable: ☐ ASQ \_\_\_\_\_ ☐ PEDS \_\_\_\_\_ ☐ M-CHAT \_\_\_\_\_

☐ other (specify) \_\_\_\_\_

► Physician's Signature \_\_\_\_\_ Date \_\_\_\_\_

#### Authorization to Release Pertinent Medical Information to ECI

I authorize the physician named above to send to the ECI program any of my child's pertinent medical information that the physician determines would assist ECI in evaluation of, and determining service needs of my child.

► Parent or Legal Guardian's Signature \_\_\_\_\_ Date \_\_\_\_\_

**For Physician:** Prior to sending referral to ECI, indicate the information you want to receive from the ECI program by checking the appropriate boxes in **Sections 1, 2, and 3 (below and on page 2)** AND obtain written parental consent for Section 1. ECI will send information only for those sections that are marked and after parental consent is obtained.

☐ **Section 1: Referral Status** – If Section 1 is checked the ECI program will complete and return page one to physician.

ECI must confirm with parent their consent to send this information.

#### Authorization to Release Referral Status to Physician

- ☐ Parent declined evaluation
- ☐ Eligible for ECI services – parent accepted services
- ☐ Eligible for ECI services – parent declined services
- ☐ Not eligible for ECI services



☐ Unable to establish contact with the parent (consent not required to release this information)

I authorize the ECI program that receives this referral to provide to the physician identified on this form the applicable information about the referral indicated in Section 1. I understand that before sending this information to the physician that ECI will reconfirm my consent and give me the opportunity to withdraw my consent to provide this information to the physician.

► **Parent or Legal Guardian's Signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**For Physician:** Indicate the information you want to receive from the ECI program by checking the appropriate boxes

☐ **Section 2: Eligibility Determination**

Please send me a copy of the completed Eligibility Statement forms that show the basis for the determination of eligibility or any other information used to establish eligibility.

☐ **Section 3: Request for Additional Information**

After development of the child's Individualized Family Service Plan (IFSP), please send me the following information:

☐ Initial IFSP Service Pages showing services the child and family will receive from ECI

☐ Other \_\_\_\_\_  
\_\_\_\_\_

I authorize the ECI program that receives this referral to provide the physician the information requested in Sections 2 and 3 above. I understand that before sending this information to the physician ECI will reconfirm my consent and give me the opportunity to revoke my consent to provide any or all of this information to the physician.

► **Parent or Legal Guardian's Signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**For ECI Program:** To be completed by ECI provider

**Confirmation to Release Information to Physician**

ECI has fully informed the parent or legal guardian of the information to be sent to the child's physician as requested in Sections 2 and 3 above and explained their right to revoke their consent.

► **Initials of the ECI staff member confirming consent** \_\_\_\_\_ **Date** \_\_\_\_\_

## Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes

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