

See the related paper “Examining Parents’ Experiences and Information Needs Regarding Early Identification of Developmental Delays: Qualitative Research to Inform a Public Health Campaign” by Melissa Raspa et al., on page 575.

## Towards a Critical Reframing of Early Detection and Intervention for Developmental Concerns

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In 2002, in response to research from the Centers for Disease Control and Prevention (CDC) suggesting that autism rates were at least 10 times higher than found in previous studies, Congress mandated the establishment of a national awareness and education program to disseminate information regarding autism identification and diagnosis to families and health care providers. The CDC responded to the mandate by developing the “Learn the Signs. Act Early” campaign (L TSAE) ([www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)). The developers of L TSAE wisely recognized the need to involve health care professionals, parents, and early educators in formative research, message and material testing, and a baseline survey before dissemination. This communication research, which consumed more than 1 year, profoundly informed the content of the campaign by yielding 2 key recommendations: that the campaign’s primary focus be expanded from the early detection of autism to that of children with a broad range of developmental concerns; and that the campaign should explicitly focus on the importance of monitoring children’s development. Furthermore, the results also directly informed the campaign’s strategic approach, objectives, messages, and materials. For example, the priority audience of the campaign shifted to low-income parents whose children are particularly vulnerable to adverse developmental outcomes as a consequence of economic disadvantage, rather than families of children identified with a disability at birth or soon thereafter.<sup>1</sup>

Since its inception, research and evaluation has continued to be a critical component of this health communication campaign. In this issue of the journal, Raspa et al<sup>2</sup> report on the most recent assessment of L TSAE’s approach and materials. Their evaluation is worthy of readers’ careful attention for several reasons. Perhaps most obvious is the

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extent to which findings reinforce key principles of successful early detection. For example, findings emphasize the critical importance of parent engagement and eliciting parents’ opinions and concerns. Parents were typically the first to express a concern about their child’s development and often compared their children’s development with other children of the same age to determine whether their child was developing differently. Past research has demonstrated the validity of parents’ appraisals of their children’s development, including such concerns and estimations.<sup>3</sup> The finding that most participants discussed their concerns with their child’s health care provider reinforces the critical role of the pediatrician in both eliciting and responding to parents’ concerns and opinions—key tenets of the American Academy of Pediatrics’ (AAP) policy statement on identifying children with developmental disorders in the medical home.<sup>4</sup> As noted by the authors, findings also support the belief that parents and health care providers should routinely discuss children’s development, review milestones, and address parents’ questions and concerns. Furthermore, the authors’ acknowledgment of the utility of screening tools in guiding conversations with parents and enabling parents to raise concerns more frequently confirms the value of monitoring children’s progress through the AAP-recommended integrated process of developmental surveillance and screening.

Other findings reinforce the importance of addressing barriers to successful early detection and intervention. In particular, although parents’ appreciated and understood the importance of the “early” aspect of the L TSAE message, they did not equally understand the “action” component, and study participants felt that materials were less clear on *how* to act early. For example, many participants wanted more specific contact information about whom to call with their developmental concerns. Parents’ seeking of help was further compromised when a cohort of child health providers assumed a “wait and see” approach. These findings are consistent with research demonstrating significant gaps between the identification of concerns and the receipt of developmental services by children and families. This gap has encouraged researchers to call for increasing awareness of the need for better care coordination across systems involved in meeting the developmental needs of children. For example, Kavanagh et al<sup>5</sup> have proposed a coordinated approach to meeting children’s developmental needs through the adoption of the SERIES paradigm of

developmental screening in which each step—Screening, Early Identification, Referral, Intake, Evaluation, and Services—is seen not as an isolated activity, but rather an integral component of a single process.

Our own experience with the design, implementation, evaluation, and national dissemination of *Help Me Grow* is consistent with these research findings. *Help Me Grow* focuses on the early detection of vulnerable children at risk for adverse developmental and behavioral problems and the linkage of such children and their families to community-based programs and services.<sup>6</sup> Core components include the training of child health providers in parent engagement and the process of developmental surveillance and screening, parent and community outreach, the creation of a central portal of entry to care coordinators to access developmental programs and services, and data collection to identify gaps and capacity issues to inform advocacy and system building. Facilitating access through such care coordination enables more than 80% of children for whom parents share concerns to be effectively linked to assessment and/or intervention services. The *Help Me Grow* National Center ([www.helpmeginational.org](http://www.helpmeginational.org)), currently providing technical assistance to more than 20 states, has a strong partnership with LTSAE. In several affiliates, LTSAE ambassadors are leading *Help Me Grow* replication efforts.

Perhaps the most inspiring reason for readers' attention to this study is the extent to which LTSAE is evolving in a manner consistent with remarkably synergistic efforts across federal agencies in response to the need for a comprehensive approach to early detection and intervention for developmental concerns. For example, the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau's (MCHB) Home Visiting Collaborative for Improvement and Innovation Network, using the Breakthrough Series Collaborative framework and the Model for Improvement, sequentially evolved from an initial focus on developmental screening to a broader emphasis on parent engagement, surveillance and screening to, currently, a comprehensive and continuous algorithm for developmental and behavioral promotion, early detection, and intervention.<sup>7</sup>

Similarly, the Administration for Children and Families' (ACF) Birth to Five, Watch Me Thrive is a coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them. Key components are consistent with LTSAE themes and include celebrating milestones, promoting universal screening, identifying early possible delays and concerns, and enhancing developmental supports.<sup>8</sup> HRSA/MCHB Early Childhood Comprehensive Systems grants enable states to focus on early detection and developmental screening of young children to identify and treat problems early in the context of a broad and comprehensive approach to system building.<sup>9</sup> Further synergistic efforts are evident in the Substance Abuse and Mental Health Services Administration's (SAMHSA) Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) grants, which improve co-

ordination across child-serving systems, build infrastructure, and increase access to high-quality prevention and wellness promotion services for children and their families.<sup>10</sup> Project LAUNCH is guided by a federal-level partnership among SAMHSA, ACF, HRSA, and, not surprisingly, the CDC.

In summary, this important report demonstrates the value of ongoing program evaluation to inform the evolution of developmental interventions. Indeed, the capacity and flexibility of the LTSAE campaign to invoke a new and strategic framing illustrates the importance of continually reconsidering beliefs and key drivers. At present, the CDC has engaged external evaluators who are planning a randomized control study to assess the impact of LTSAE in pediatric settings (Simani Price, personal communication, June 29, 2015). The extent to which the CDC is continuing to evolve its paradigm for early detection in a manner synergistic with other federal agencies is particularly impressive and encouraging. As we disseminate *Help Me Grow* across the nation, we, too, are increasingly reframing activities in the context of system building, viewing early detection as but one critical step in a comprehensive process of developmental promotion, early detection, and referral and linkage. The LTSAE experience informs and inspires our collective efforts.

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