# How to Develop a Statewide System to Link Families with Community Resources: A Manual Based on *Help Me Grow*

## The Facts

- Children with developmental/behavioral problems are eluding early detection.
- While programs exist to provide services to young children and their families, child health care providers face challenges in connecting at-risk children with needed services.
- Children and their families benefit from a coordinated, statewide system of early detection and intervention for children at risk.

This online manual offers guidance for exploring, creating, and/or enhancing a single-point-of-access system to connect children at risk for developmental or behavioral problems with community resources.

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The material in this manual is based on Connecticut's *Help Me Grow* initiative, a program of the State of Connecticut's Children's Trust Fund. *Help Me Grow* is a collaborative among the Children's Trust Fund; The United Way of Connecticut/Infoline; the Connecticut Birth to Three System; the Children and Youth with Special Health Care Needs section of the Connecticut Department of Public Health; and Connecticut's State Department of Education's Preschool Special Education Program.

*Help Me Grow* is a unique program that assists families and providers in identifying developmental concerns in children up to age 8, establishes an inventory of appropriate resources, and helps families connect with these programs and services. Program components developed through this collaboration include: a statewide toll-free telephone number that providers and families can use to access care ([Child Development Infoline](#)); partnerships with community-based agencies throughout the state; and child development community liaisons who serve as conduits between the community-based services and the telephone access point.

## Section I - Framing the Issue: Detecting Developmental Problems

### The Facts:

- An estimated 15 percent of children nationwide experience developmental, behavioral, and/or emotional disorders.
- Less than half of these children are identified prior to school entry.
- Undetected childhood behavioral health and developmental problems have a significant impact not only on the children who experience them, but also on their families and communities and the medical, mental health, and educational systems they use.

### Developmental Surveillance

[Developmental surveillance](), unlike developmental screening, is a flexible, continuous process in which knowledgeable professionals perform observations of children while providing care. Development is continuously monitored within the context of overall well-being, rather than viewed in isolation during a testing session. Specific screening tests, such as parent-completed questionnaires and professionally administered tools, may be used to enhance early detection. Pioneered in Great Britain, developmental surveillance is broader in scope than screening and other traditional techniques and encompasses all activities relating to the detection of developmental problems.

Components of developmental surveillance include eliciting and attending to parental concerns about a child's behavior, learning, or development; obtaining a developmental history; observation of a child's development; and communicating with others in the child's life (such as childcare providers or preschool teachers). Because research has shown that parental concerns are important indicators of problems, soliciting parents' input is critical to the developmental surveillance approach. Properly employed, developmental surveillance is family-focused, accurate, and efficient and can guide clinical decision-making.

The *Help Me Grow* program includes outreach to child health providers on developmental surveillance as well as referral of at-risk children. *Help Me Grow* seeks to educate child health providers on developmental surveillance and referral of at-risk children. Outreach and training are provided through the [Educating Practices in Communities Program (EPIC)](). Through the support of The Commonwealth Fund, *Help Me Grow* visited and trained more than 50 percent of the community-based practices in Connecticut—300 practices in all.

## Connecting with Community Resources

Even when developmental surveillance is done, however, the challenge of linking children with developmental problems to needed services remains. The *Help Me Grow* experience has shown that, on average, it takes approximately 12 phone calls to connect a family with concerns about a child's behavior to the needed service. That kind of burdensome, often confusing process can be an impediment to getting children the help they need—an impediment that *Help Me Grow* was designed to eliminate through the Child Development Infoline. By using this toll-free number, child health providers or parents can access professional assistance and a database of statewide support services.

The following are "snapshots" of the program in practice:

- *Snapshot:* A grandmother called because her granddaughter's behavior was out of control. She was the primary caregiver. She was connected to grandparent support groups. She didn't realize how many grandparents were dealing with similar challenges.
- *Snapshot:* A child health provider called because a family refused to connect to much-needed early intervention services. *Help Me Grow* found a support center in the family's neighborhood that could help educate them about developmental delays.
- *Snapshot:* A Spanish-speaking parent who had recently moved from Puerto Rico called about a five-year-old child with developmental delays. *Help Me Grow* was able to identify the child's school district and initiate the intake process. The child began attending school a week later.
- *Snapshot:* A child health provider called with concerns that a father was "very dictator-like" in his approach to a mother and child. The child was exhibiting aggressive behaviors and bed-wetting. The provider was concerned about domestic violence,

but was not able to engage the mother in a conversation on this subject. The *Help Me Grow* staff talked with the mother. She disclosed that her husband "yelled a lot" and wondered if that was why her son was having problems. After three phone calls, the mother asked to be connected to a domestic violence support group.

This online tool provides practical information and guidance on creating a system to help families and providers like those described above connect at-risk children with community resources. (See diagram on the next page.)

**1** Anyone with concerns about a child's behavior or development calls Help Me Grow.

**2** Telephone Care Coordinators triage the call to identify the questions or concerns.

**3** Child Development Liaisons identify and build relationships with existing community resources to create a comprehensive resource inventory.

**4** Care Coordinator provides family with resources. Follow up occurs in 2 weeks.

**5** Statewide, providers are trained in developmental surveillance and receive tools and resources that aid them in using the Help Me Grow program.

**6** Data is collected to measure effectiveness and identify gaps and barriers. Policymakers are informed of progress, results.

# Help Me Grow

## Section II - Building Collaboration: The Recruitment, Retention, and Recognition of Partners

Genuine collaboration may require changes in policies, governance, and operating procedures at both administrative and direct service levels. Such changes do not come easily. Whether creating a new program from the bottom up or modifying existing programs, collaboration and system coordination are essential to a successful single-point-of-access system.

A number of barriers to collaboration have been identified in the literature and by practitioners in the field. One of the most challenging is the issue of control—who "owns" the program. Additional barriers include: competitiveness; lack of compelling mutual interest; parochial interests; lack of skill in coordinating; difficulty communicating across disciplines; preoccupation with administrative rather than functional structures; concerns about client confidentiality; resistance to change; external pressures; lack of accountability; lack of monitoring and evaluation procedures; inadequate knowledge of other agencies; negative attitudes; and little consideration of political bases.

However, research indicates that most of these barriers can be addressed, at least in part, through attention to the process of collaboration. Our suggestions for such a process are outlined below.

### A. Identifying Your Partners
Develop a short list of potential partners; having too long of a list risks encountering detours and time constraints. Remember: you are providing enhancements and support to existing programs.

The following list includes broad categories for possible partners:

- A parent group and/or individual parents
- Advocacy organizations
- A physicians' group (such as the American Academy of Pediatrics) and/or individual doctor(s)
- Legislators
- Potential funding sources, such as Children's Trust Funds; federal funding sources (for example, Title V—MCH Block Grant Funds or Title XIX—Medicaid); state funds, and community foundations.
- Information and referrals (I&Rs) services and specialized call centers already operating in the area. (See the establishing a call center section for more information.)

## A. Recruiting and Maintaining Partnerships

Once you identify potential partners, ask yourself "What's in it for them?" How would they benefit from having one or more of the following in their community: a single-point-of-access system; a program that connects children "at-risk" to services; and providers trained in developmental screening? Strategies for approaching partners will vary depending on who is being approached and their potential roles.

The following guidance is offered in recruiting, retaining and recognizing partners.

1. Is there a strong advocate who is well connected and respected who could become your champion? If so, that person should be recruited first as that support will add leverage and credibility.
2. Document current gaps/barriers in the systems that serve at-risk children from the perspective of families, health care providers, child care programs, other direct service providers, policymakers, funders, and other stakeholders. Be able to discuss these barriers from all perspectives.
3. Develop a draft of core principles to share with potential partners. Be open to reviewing and revising them; new partners will want their issues and needs reflected in the document.</li><li>Clarify the roles and responsibilities of each partner and how they will be supported.
4. Know what is needed from a systems and fiscal perspective and how your proposal will:
    1. *be cost-effective,*
    2. *coordinate systems,*
    3. *offer "one-stop shopping," and*
    4. *be family focused.*
5. Obtain consensus on the design and implementation of a formal system for communication among all partners. Once implemented, be prepared to revise it, if needed. (See section on continuous quality improvement for more information.)
6. Build in a method for ongoing tracking and monitoring of the system and share this information regularly with all partners.
7. Address issues/concerns as they occur in an environment that is open, direct, and non-threatening.</li><li>Remember to celebrate successes and acknowledge those involved with them.

(To see the image go to the next page.)

# Connecticut's
# Child Development Infoline

The Gateway to Help and Referrals for
Pediatric Professionals ● Parents ● Providers

## 1-800-505-7000

## Connecticut Birth to Three System
*Birth to 36 months of age*

**For children birth-36 months of age with developmental delays or disabilities.**

- Evaluation
- Services to eligible children and families:
  - o Service Coordination
  - o Individualized Family Service Plan (IFSP)
  - o Services such as PT, OT, speech, special instruction, family training and others identified in IFSP

## Help Me Grow
*Birth through Age 5*

**For children birth through age 5 considered 'at-risk' for developmental or behavioral problems**

- Connects families to community based resources
- Provides Ages and Stages child monitoring program
- Trains child health providers in developmental screening
- Facilitates regional community networking

## Preschool Special Education Program
*Ages 3 through 5*

**For children ages 3 through 5 who need special education services**

- Evaluation
- Services to eligible children:
  - o Individualized Education Program (IEP)
  - o Special education and related services

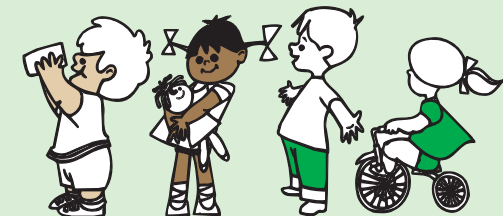## Regional Medical Home Support Centers
*Birth to Age 21*

**For children and youth birth to age 21 with chronic physical, developmental, behavioral, or emotional conditions who require more health and related services than other children the same age.**

- Service Needs Assessment
- Care Coordination
- Benefits Coordination
- Family/Caregiver Support
- Respite Planning
- Links to health care services
- Referrals to community based resources
- Transition Planning

## Participating Agencies

Children's Trust Fund ▌ Department of Mental Retardation ▌ Department of Public Health ▌ Department of Education ▌ United Way of Connecticut

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## Section III - The Call Center: The Single-Point-of-Access Partner

### Step 1: Establishing a Call Center

Even the best services are not helpful unless they can be easily accessed when needed. Telephone services have proven to be an effective single point of access to community resources. They are cost-effective, easy to promote, efficient in identifying needs, and effective in supporting callers and triaging to appropriate services. They also can be used to collect data on both resources and callers. If call centers in your area are already serving families and children, partnering with those centers is the most efficient way to create access to services.

The first step in establishing a call center is researching those that may already be operating in your service area. Resources to assist in locating local services include:

- The Alliance of Information and Referral Systems (AIRS) has information on information and referral (I&R) services throughout the country.
- The National Association of Child Care Resource and Referrals Agencies (NACCRRA) has information on local child care resource and referral agencies throughout the country.
- Local United Ways often fund I&Rs. Information available through the United Way of America Web site.
- The Child Find provision of the Individual with Disabilities Act requires all states to have a "comprehensive Child Find system" to ensure that all children in need of early intervention or special education services are located, identified, and referred.
- The Birth to Three system in your state. This is an entitlement program for families whose children under age 3 have significant developmental delays or disabilities.
- The State Health Department, which is responsible for administering maternal and child health (MCH) programs, including the Children and Youth with Special Health Care Needs (CYSHCN) program and a MCH (Maternal & Child Health) hotline. CYSHCN is the state's Title V Maternal and Child Health Block Grant program. Federal legislation (1989) mandated the operation of an MCH hotline in every state.
- Local hospitals and universities.
- Community/local foundations. Many fund call centers in their communities.

Arrange meetings with call centers that are potential collaborators. Before a meeting, learn as much as you can about the service. The more you know, the more prepared you will be to promote service expansion. Make sure you know answers to the following:

- What is their current target population(s)?
- Who funds them and how is the funding provided?
- What is the call volume and staffing level?

This information can be gathered through Web sites, either those of the call centers and/or their funding sources, and through annual reports or other publications. You can also make contact with the call center to experience firsthand how the staff members handle calls. Prior to the first meeting, begin to develop a proposal on why this expansion is appropriate for the call center and what added resources and value you bring to their service. Existing call centers are likely to anticipate additional funds to support marketing, new staff, staff training, and data collection.

The initial meeting and your research should provide enough information to develop a budget and identify potential funding sources. Having your single point of access housed in a call center that is already in operation is both cost-effective and promotes "one-stop shopping" for families—benefits that appeal to funders. Many resources and Web sites offer guidance in researching, concept planning, and proposal writing, including the Foundation Center's [Web site](), which includes a short course on proposal writing and project planning.

Your research will likely identify additional potential collaborators and champions, such as other call centers, direct service providers, advocates, parents, and legislators. Develop strategies for inclusion as soon as possible.

**Step 2: Staffing a Call Center**
The staff who answer the phones are crucial to a successful system. Callers must feel safe, respected, and heard. The center must be adequately staffed with individuals who are trained in telephone casework and cultural sensitivity and who have backgrounds in child development.

In phone interviews there is no eye contact or observation of body language and no opportunity to provide feedback or encouragement by nodding or smiling. However, seasoned and well-trained telephone caseworkers have honed their listening skills—How does the caller sound? Are there background noises, such as a baby crying?—as well as their telephone interviewing techniques, which are based on guidance developed for I&R telephone interviews. According to the guidelines, "Listening is done with attentiveness, questions are asked with sensitivity, confidence is treated with respect, restraint is exercised in imposing personal views on callers, and care is taken to avoid disappointments and uneasiness based on glib and ill-founded statements and promises."

Collaborating with a call center that is already operating helps to ensure you are working with a staff experienced in telephone casework. However, depending on the call center's target population, additional staff training in child development and early childhood behavior problems may be needed. The following Web sites have information on these topics: DBPeds.org, the Centers for Disease Control's Learn the Signs, Act Early, Zero to Three, and The Child Development Institute.

**Step 3: Maintaining Resource Information**
In order for call center staff to make appropriate referrals, resource information must be maintained and updated. Ideally, the inventory of resources should be supplemented with up-to-date information prior to making a referral to ensure that there is no waiting list and that service criteria have not changed. Community-based program staff are an excellent source for keeping information current. Other options include: developing reciprocal referral agreements in which agencies immediately respond to referrals from the call center and contracting with community-based agencies available for home visits.

The Alliance of Information and Referral Systems (AIRS) and Info Line of Los Angeles offer support and guidance on developing a "human service taxonomy," defined on the AIRS/Info Line Taxonomy of Human Services Web site as: "a classification system that allows you to index and access community resources based on the services they provide and the target populations they serve, if any. It provides a structure for your information and it tells people what is in your information system and how to find it."

As you research and meet with call centers within your area, keep the following in mind:

- How is resource information collected, maintained, and made available to staff?
- How and how often and by whom are updates made to the system?
- What types of information would you like made available to call center staff and ultimately to families?
- Be aware of possible legal issues related to referring to for-profit services or practices. If those are important resources for families in your area, think about how that information can be shared.

## Step 4: Collecting Data
Call centers are in a unique position to collect data that reflect system-level issues—information not only on who calls and why, but on what happens to families seeking help. All call centers should collect:
- information on how callers heard about the service;
- caller demographics;
- facts about the person in need;
- information on what assistance is being requested;
- records of actions taken to assist callers; and
- outcomes of the contacts with the call center

Many call centers also have the ability to track barriers experienced by families referred for services. Think about what information you would like collected, how the data should be generated, and with whom you would share the data.

## Section IV - Community-Based Liaisons

In the bestselling book *The Tipping Point*, journalist Malcolm Gladwell writes about the critical role that certain persons, known as connectors and mavens, play in spreading messages that result in the development of trends.

- *Connectors* know many people and have a gift of bringing people together. They are comfortable in many different words and subcultures and can act as the social glue and help spread a message.
- *Mavens* gather and create databanks of important information. Furthermore, mavens pass along this information, encouraging problem solving.

Community-based staff are both connectors and mavens and are an essential component of the system infrastructure. They are hired to build the system by developing relationships with existing community resources and creating a comprehensive resource inventory for the call center.

Community liaisons interact with a wide variety of people, including family support workers, supervisors, directors, parents, teachers, researchers, consultants, and health care professionals. Interactions might include visiting agencies, conducting trainings, attending meetings, or bringing people together at networking events. As a result of their work, community-based staff are always in the process of gathering and disseminating information about people, services, trainings, knowledge, and resources, so that this information is available to those who need it.

The following provides an overview of the role of the *Help Me Grow* community liaisons:

- Child Development Community Liaisons (CDLs) are located within the community in regional offices.
- CDLs work together with the Child Development Infoline Care Coordinators to assess what resources are available to meet the family's needs and wants.
- CDLs provide outreach to providers, physicians, and parents to increase awareness of the *Help Me Grow* program.
- CDLs create community networking efforts that maximize access to services and lead to optimal use of existing resources.

- CDLs conduct [office-based training on developmental surveillance](#) and on the use of *Help Me Grow* program. The trainings also provide on how to administer and utilize the [Ages & Stages Questionnaire (ASQ)](#) and the [Parents' Evaluations of Developmental Status (PEDS)](#), thus supporting the widespread use of these family-driven tools.

## Section V - Data Collection, Evaluation, and Continuous Quality Improvement (CQI)

### Step 1: Maintaining a Computerized Data System

The importance of gathering, reviewing, and reporting program data cannot be overemphasized. Policymakers, program administers, advocates, families, and funders will want data such as how many families are using information and referral resources; how many families are consequently receiving services; and what types of services are being received. A single-point-of-entry system should therefore collect the following:

- demographic information;
- how callers heard about the system;
- what concerns callers presented;
- what action(s) were taken;
- where referrals were made; and
- outcomes of the cases.

[The demographic information](#) collected on *Help Me Grow* provides examples of data that are available through a single-point-of-entry client-tracking system.

### Step 2: Evaluating Impact

In addition to program tracking data, states should use other strategies for monitoring the extent of developmental surveillance and referral by health care providers, families, child care centers, and agencies. One strategy is to perform a periodic analysis of who is calling the access point and why they are calling. This analysis can help determine needs for ongoing community education and outreach efforts. Another strategy is to review State Children's Health Insurance Program (SCHIP) and Early Periodic, Screening and Diagnosis and Treatment (EPSDT) data to see the extent to which children are receiving well-child services that can serve as the starting point to their connection to community-based developmental support services. Child health care practices and other sites should be encouraged to review their own performance in monitoring development and referring children. Discussion of these strategies can be part of the training.

The ideal data set for evaluating the impact of a *Help Me Grow*—type of program would include long-term outcomes for children connected to services through the system. One goal of early intervention is to decrease the number of children requiring—and the intensity of—special education services in schools, and to improve school

performance overall. To measure long-term success, states are also encouraged to monitor the number of individuals in need of social services that address emotional and behavioral well-being throughout the lifecycle.

In addition to gathering information on program processes and outcomes, states should collect data on training and outreach. Doing so helps to determine the extent of contacts with providers throughout the state and the development of a distribution list for program materials and updates. This database is essential for implementing a coordinated outreach effort to the state's child health care providers.

Prior to developing a training program, child health care providers and other target audiences should be surveyed to determine perceived barriers to monitoring development and making referrals to early intervention services. National data exist for pediatricians, but barriers reported by family physicians and mid-level providers should also be considered. State data also inform the development of training content by targeting issues specific to each state.

Survey data also should be collected at or shortly after each training session. Participants should be asked to complete questionnaires about their satisfaction with the training and the extent to which they found it useful in their practices. These data give the training staff real-time feedback, allowing them to refine the presentation and materials to meet the needs of target audiences.

The ongoing monitoring of data from these surveys provides an important framework for continuous quality improvement and general training evaluation. In Connecticut, the training program was pilot-tested in a few practices. Data about its impact and information gleaned from follow-up phone calls were used to revise the program prior to the statewide rollout.

## Step 3: Using Data for Advocacy and Planning: Legislative Support

State agencies and other governmental bodies will want information on the use of the *Help Me Grow* system. Denise Merrill, co-chair of the Connecticut legislature's Appropriations Committee, explains: "Appropriations Committees deal primarily in numbers. The best testimonies are those that employ accurate and meaningful data....Statistics spell out an argument in black and white. Make sure that statistics used are...applicable [and] to check where the studies were done, when they were completed, and by whom. The most

accurate and admissible information comes from non-partisan organizations. Government publications, academic journals, and university-sponsored research are good sources to cite. I cannot stress enough the power of numbers."

**Step 4: Continuous Quality Improvement (CQI)**
A mechanism and supporting data are needed to ensure that the system remains responsive to families, service providers, and program staff. CQI is an approach to quality management that builds upon traditional quality assurance methods by emphasizing the organization and systems. It focuses on "process" rather than the individual, recognizes both internal and external "customers," and promotes the need for objective data to analyze and improve processes.

The following links offer additional information on CQI: elements of CQI, a model for improvement, and commonly used CQI tools and methods.

**Section VI - Closing Comments**

The Connecticut Children's Trust Fund and The Commonwealth Fund hope the information in this online tool, which is based on <em>*Help Me Grow's* experience of moving theory into practice, helps others address the potentially serious consequences of undetected developmental problems by offering practical guidance for creating an effective system of early intervention, referral, and support.

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