

**Enhancing Impact of Early Childhood Systems:
Embedding Goal Concordant Care within Help Me Grow**

con·cord·ant

/kən'kôrdnt/

An adjective meaning in agreement; consistent.

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Introduction

The earliest years of life present a unique opportunity to support lifelong well-being, self-sufficiency, and quality of life, given the rapid brain development that occurs. In fact, by the time a child enters kindergarten, brain development is 90% complete, suggesting that relationships, experiences, and events, both positive and negative, can significantly impact a child's lifelong trajectory.¹

In order to optimally support child development, *we need to ensure that families and providers are aware of, connected to, and engaged with a comprehensive and interconnected system of resources and supports designed to help children thrive.* When the system functions well, families can access an organized inventory of resources and leverage those resources that best align with their unique strengths, priorities, needs, and personal preferences. However, when the system does not function well, it can be difficult for families to access vital services, and in turn, negatively impact child health, development, and well-being.

Help Me Grow (HMG) is an evidence-based system model that leverages existing services, resources, and infrastructure to build integrated and comprehensive approaches to early childhood in collaboration with communities across the nation. HMG began as a pilot project in Hartford, Connecticut in 1997 as a strategy to explore how child health services could best promote children's healthy development and well-being, recognizing 1) the gap between pediatric health care settings and community-based services and resources; 2) the significant influence of social, environmental, and behavioral factors on healthy development, such as food insecurity, quality housing free from environmental hazards, and financial stability of families; and 3) the value of comprehensive, integrated, and coordinated system of care to support young children and their families.

Early feasibility studies demonstrated HMG's ability to: 1) strengthen community capacity for developmental promotion, early detection, referral, and linkage; 2) strengthen families' protective factors; and in turn, and 3) improve child- and family-level outcomes. Inquiries and requests for support from other communities lead to the establishment of the HMG National Center (National Center) in 2010. The National Center now supports a National Affiliate Network of states and communities seeking to strengthen early childhood systems for all children, with a targeted focus on children who are at risk for adverse outcomes, including developmental delays.

The National Center partners with communities to strengthen their early childhood systems by implementing four Core Components:

1. **A Centralized Access Point (CAP)** that helps families and professionals connect with services and resources to support identified needs.
2. **Family & Community Outreach (FCO)** strategies to build: 1) parent and organizational understanding of healthy child development; 2) awareness of the services and resources

¹ Center on the Developing Child (2007). The Science of Early Childhood Development (InBrief). Retrieved from www.developingchild.harvard.edu.

available to children and families; and 3) how both are important to improving child outcomes.

3. **Child Health Care Provider Outreach (CHPO)** to enhance early detection and intervention efforts and connect child health care providers to the system of services and resources that support children and families.
4. **Data Collection & Analysis (DCA)** to support ongoing evaluation and quality improvement efforts as well as the identification of systemic gaps negatively impacting children and families.

In January of 2017, the U.S. Departments of Education and Health and Human Services issued a joint statement indicating the position of both Departments, “that all infants and toddlers and their families should have access to coordinated, comprehensive services that support overall health, development, and wellness.” Additionally, the joint statement endorsed HMG as a comprehensive system that “... provides centralized intake, screening, and referral systems at state, regional, or local levels which has proven to be an effective way to ensure that families have timely access to appropriate services that meet their needs.”

HMG is a solution for aligning fragmented initiatives that are the result of disparate efforts and investments in early childhood. This fragmentation is due to initiatives operating in isolation, inconsistent and transient funding, and insufficient and/or ineffective strategies to embed family priorities within the system of care supporting young children and their families. While HMG developed, refined, and disseminated effective strategies to address the first two opportunity areas, it has not systematically cultivated and advanced efficacious strategies to center early childhood systems on family priorities and goals.

Project Overview

Effective communication plays a critical role when caring for and supporting the development of young children. Too often, conversations with parents about goals, personal values, and what might happen in the future happen too late in the course of a young child’s development, impacting short-, moderate-, and long-term health, development, and well-being outcomes.

To foster optimal healthy development and enhance outcomes for young children and their families, we must build trust with parents; elicit and document family priorities, needs, and goals, and make measurable progress on parent- and family-identified priorities.

With support from The JPB Foundation, the National Center is developing and pilot testing a goal concordant care framework for HMG that focuses on eliciting and responding to parent priorities for their child’s health, development, and well-being. Goal concordant care describes, “clinical care that helps reach a patient-identified goal and respects any treatment limitations the patient has placed on clinical care.”² In doing this, the National Center hopes to advance early childhood systems towards leveraging a shared agenda, shared practices, and shared outcomes

² Turnbull AE, Hartog CS. Goal-concordant care in the ICU: a conceptual framework for future research. *Intensive Care Med.* 2017 Dec;43(12):1847-1849. doi: 10.1007/s00134-017-4873-2. Epub 2017 Jun 27. PMID: 28656453; PMCID: PMC5717114.

within and across systems and sectors serving children and families. Outcomes of interest include:

- Advancing HMG Model implementation;
- Provider and parent satisfaction with interventions;
- Permeation and traction of HMG within communities, including utilization rates of the HMG Centralized Access Point;
- Enhancing the HMG Centralized Access Point's ability to meet family priorities and needs (i.e. what the family needs to achieve their priorities);
- Enhancing family and community outreach strategies by creating the conditions necessary for parents to co-produce and co-lead HMG activities; and
- Sharing of family goals between two or more child-serving sectors.

The project is currently divided into four phases:

- Phase 1: Convene and facilitate a national work group to develop a goal concordant care framework for HMG.
- Phase 2: Design a Learning Community to pilot test implementation of the HMG goal concordant care framework.
- Phase 3: Implement the Learning Community and pilot test the HMG goal concordant care framework.
- Phase 4: Assess and understand if and how the HMG goal concordant care framework enhances implementation and evaluation of HMG using a pre-determined set of process and outcome measures.

This report introduces the HMG goal concordant care framework and summarizes phase 1 of the project.

Convening a National Work Group to Develop a Help Me Grow Goal Concordant Care Framework

The National Center leveraged Childhood Prosperity Lab, an initiative of Connecticut Children's Office for Community Child Health, to convene and facilitate the national work group to create a HMG goal concordant care framework. Childhood Prosperity Lab is committed to elevating *social innovations*, which are creative strategies and opportunities that address the social, behavioral, and environmental challenges that children and families too often face. The Lab guides the development of social innovations that support children, families, and communities so that they will thrive in the environments and systems in which they live, learn, work, play, and pray. Unlike innovations that focus on treatment, social innovations focus on promotion and prevention efforts.

The Lab is committed to supporting the equitable distribution of health, development, and well-being outcomes by leveraging a systems approach to drive community and population health. The National Center and Childhood Prosperity Lab have a history of collaboratively advancing innovative system enhancements that strengthen implementation and evaluation of the HMG Model, as demonstrated through projects like the HMG Innovation Challenge; the Women,

Infants, and Children (WIC) Community of Practice; and Early Care and Education Community of Practice; and the Centralized Access Point Work Group.

Work Group Composition

The work group was composed of early childhood professionals identified by the HMG National Center. Professionals invited to participate in the work group had an in-depth understanding of and significant experience implementing and/or supporting implementation of the HMG Model or a specific facet of the Model. Table 1 is an alphabetized list of those who participated in the work group.

Table 1: Work Group Participants (alphabetized)

| Participant | Affiliation |
|--------------------------|---------------------------------------|
| Noshin Ahmed | HMG National Center |
| Kimberly Martini-Carvell | HMG National Center |
| Paul Dworkin | HMG National Center |
| Rebecca Hernandez | HMG Implementation Expert |
| Aedra Jones | HMG National Center |
| Heather Little | HMG Implementation Expert |
| Cabrini Merclean | Quality Improvement Advisor and Coach |
| Wally Patawaran | HMG Funder |
| Lynn Pullano | HMG Implementation Expert |
| Jill Sells | HMG Implementation Expert |
| Sara Sibley | HMG National Center |
| Cassandra Therriault | HMG National Center |
| Jane Witowski | HMG Implementation Expert |
| Sarah Zucker | HMG National Center |

Work Group Activities

The goal of the national work group was to create a HMG goal concordant care framework. Work group participants engaged in a number of interconnected activities to develop the framework, including:

- Four 2-hour semi-structured discussions to explore goal concordant care in the context of HMG. Discussion questions were provided to participants in advance of the discussion via email.
- Three surveys were administered to document perspectives, reflections, and feedback on goal concordant care within HMG. The first survey was administered preceding the first semi-structured discussion; the second survey was administered preceding the second session; and the third survey was administered preceding the fourth session.
- Five small group discussions were leveraged to review and solicit feedback on the second draft framework. The larger work group was stratified based on individuals' roles and

experiences working with the HMG Model. The focus of the small group discussions was to review content of the framework and its alignment with the HMG Model.

- The final framework review was conducted via email. The final framework review focused on language and framing of the HMG goal concordant care framework to ensure consistency and alignment with other messaging being communicated by the National Center.

Semi-structured discussions were designed and implemented by Childhood Prosperity Lab. Two representatives from the HMG National Center team (Paul Dworkin and Kimberly Martini-Carvell) reviewed and provided feedback on the facilitator guide for the first semi-structured discussion while one HMG National Center team member reviewed and provided feedback on the facilitator guide for the remaining three semi-structured discussions (Kimberly Martini-Carvell). Semi-structured discussions were facilitated and documented by Childhood Prosperity Lab. Given the geographic diversity of participants in the work group, discussions were facilitated virtually using Zoom, a virtual meeting software. Semi-structured discussions were recorded to help facilitate documentation and supplement notetaking.

The three surveys administered over the course of the work group were designed to capture additional thoughts, reflections, and insights from the semi-structured discussions as well as begin to synthesize, review, and prioritize emerging themes. Surveys were administered via Google Forms, a survey administration software. Survey results were exported to Google Sheets, a data management software, for review and analysis. While names and emails were collected on the survey, information collected was treated confidentially. Responses shared by participants were never disclosed by Childhood Prosperity Lab.

The components that comprise the framework were identified by work group participants. Childhood Prosperity Lab leveraged information gathered during the semi-structured discussions and surveys to draft the framework. The first draft of the framework was reviewed during the fourth and final semi-structured discussion. Childhood Prosperity Lab used this feedback to create the second draft of the framework.

The second draft of the framework was reviewed during the small group discussions. Childhood Prosperity Lab designed the small group discussions in collaboration with the Executive Director of the HMG National Center. The Executive Director facilitated the small group discussions. Each discussion was scheduled for 60-minutes and questions were customized to each participant's unique value contribution and experience supporting implementation, evaluation, and sustainability of the HMG Model.

The final review of the HMG goal concordant care framework was conducted via email and focused on language, terminology, and framing. Qualitative feedback provided by work group participants was incorporated collaboratively by the Executive Director and Childhood Prosperity Lab.

Framework Components

The HMG goal concordant care framework includes four components. The first component is a definition that operationalizes goal concordant care in the context of early childhood system-building and developmental promotion, screening, referral, and linkage. The second component of the framework includes four pillars that distinguish the HMG goal concordant care framework from other initiatives designed to identify, understand, and elevate parent priorities in early childhood systems. The third component of the framework includes approaches to operationalize goal concordant care at the individual-, organizational-, and system-level. The fourth and final component of the framework consists of strategies to operationalize HMG Core Components and Key Activities in the context of goal concordant care.

Help Me Grow Goal Concordant Care Framework

Definition

Goal concordant care is a strengths-based approach to eliciting parents' goals for their child's well-being that ensures parents' goals drive the process of developmental promotion, early identification of concern and need, referral, and linkage to services.

Goal concordant care offers the opportunity for HMG to advance a paradigm shift wherein parents and caregivers are partners in decision-making, and resources provided are in concordance with the goals, aspirations, and values of the families.

Pillars

- **Trust:** Respect parents' expertise of their child's development and utilize their goals for their family in prioritizing resources and referrals.
- **Agency:** Parents' knowledge, skills, and resources are equal inputs into the goal identification and prioritization process.
- **Partnership:** A shared approach among multiple child-serving sectors that elicits and values parents' goals as a key driver for resource identification and allocation.
- **Communication:** Parents' goals are shared among partners when closing the feedback loop and in linking to community-based resources and services.

Approaches

Individual

- Elicit parent goals at the onset of engagement.
- Validate parent goals.
- Negotiate and align parent goals with provider priorities, if needed.
- Document parent goals and next steps.
- Communicate parent goals when making referrals and closing the feedback loop.
- Monitor and ensure resources and linkage are aligned with parent goals and provider priorities.

Organizational

- Systematize individual approaches to goal concordant care through training, policies, and quality improvement.
- Engage team members in capacity building activities, such as training, coaching, and mentorship, to enhance their ability and skills to implement goal concordant care practices and document their efforts.
- Provide the infrastructure necessary, such as data collection systems, to support implementation of goal concordant care practices.

System

- Maintain a coalition that champions parents' goals and needs to guide developmental promotion, early identification, referral, and linkage to community-based services.
- Document parents' goals and share in aggregate.
- Ensure universal and equitable access to early childhood services and resources that address parents' goals.
- Set community early childhood goals that are reflective of families' priorities and needs.

Strategies

HMG is a system model that leverages existing resources and infrastructure to develop and enhance comprehensive, coordinated approaches to early childhood system-building within communities. HMG is characterized by the implementation of four Core Components that each have four Key Activities, as outlined in Table 2. The work groups hypothesized that HMG's impact can be enhanced by integrating goal concordant care strategies into this existing infrastructure.

Table 2: HMG Core Components and Key Activities

| Core Component | Key Activities |
|-------------------------------------|---|
| Centralized Access Point | <ol style="list-style-type: none">1. Specialized child development line2. Linkage and follow-up3. Researching resources4. Real-time directory maintenance |
| Child Health Care Provider Outreach | <ol style="list-style-type: none">1. Physician champion2. Training on surveillance and screening3. Training on referral and linkage4. Closing the feedback loop |
| Family & Community Outreach | <ol style="list-style-type: none">1. Engage community partners2. Networking3. Community events and training4. Marketing |
| Data Collection & Analysis | <ol style="list-style-type: none">1. Data monitoring and reporting2. Sharing data across partners3. Continuous quality improvement4. Community change through data |

Centralized Access Point

The Centralized Access Point (CAP) typically takes the form of a call center that serves as a coordinated portal for family members, child health providers, and other professionals seeking information, support, and referrals for children. The CAP connects children and their families to needed services leveraging care coordination professionals charged with: providing education and support to families around specific developmental or behavioral concerns or questions helping families recognize typical developmental milestones; providing referrals to community-based supports; and providing continuing follow-up to ensure successful linkages and all needs are met.

The work group recommends integrating goal concordant care approaches through two Key Activities:

- The specialized child development line utilizes a strengths-based approach to elicit parent goals for their child's well-being.
- Care coordination professionals share parent goals when linking families to community-based supports and review parent goals when following-up.

Child Health Care Provider Outreach

Child health care providers are uniquely positioned to identify children at risk of adverse developmental outcomes or delays. They have near universal access to young children and provide ongoing monitoring of developmental status during well-child visits, including developmental promotion and early identification through periodic developmental surveillance and screening. However, due to the structure and requirements of the well child visit, child health care providers often face challenges in identifying early signs of developmental or behavioral concerns. Even when needs are recognized, keeping comprehensive and updated information on community resources is difficult and ensuring successful connection to those services is time consuming.

The work group recommends integrating goal concordant care approaches through two Key Activities:

- Conduct targeted outreach to child health care providers that focuses on eliciting and attending to parent goals as a key element in developmental surveillance.
- HMG Care Coordination professionals include parent goals when closing the feedback loop with child health care providers on referral and linkage.

Family & Community Outreach

Family & Community Outreach is essential to promoting the use of HMG. Personnel supporting the goals of this Core Component work to engage families and providers through meetings, forums, public events, and fairs, as well as helping families learn about child development and

the role of HMG. This community presence encourages support and utilization of HMG and facilitates efforts to gather and update information embedded within the HMG Resource Directory at the Centralized Access Point. Parent engagement is a critical component of this work and is needed to ensure the types of resources HMG Care Coordinators refer families to reflect a family-led agenda.

The work group recommends integrating goal concordant care approaches into three Key Activities:

- Facilitate networking events and trainings for early childhood service providers on the importance of eliciting and attending to parent goals.
- Conduct family events that encourage and validate parents' communication of their goals.
- Market HMG as a system that leverages parent goals to coordinate resources and services.

Data Collection & Analysis

Data Collection & Analysis ensures ongoing capacity for continuous improvement. Affiliates collect data associated with each of the HMG Core Components. The collection of a set of shared metrics across the National Affiliate Network advances understanding of collective impact and informs the national narrative regarding the impact of HMG on children and families across the country. The collection of community-specific metrics enable HMG affiliates to benchmark progress, identify areas of improvement and gaps, inform partnership-building efforts, and guide quality improvement projects.

The work group recommends integrating goal concordant care approaches into two Key Activities:

- Share data - inclusive of parent goals - across a minimum of two child-serving sectors.
- Continuous improvement efforts are guided by data, including parent and provider goals.

Next Steps

Convening a work group to develop a HMG framework for goal concordant care was the first phase of this project. The next phase includes soliciting feedback on and refining the framework from professionals with expertise in early childhood system-building and those with experience implementing HMG with fidelity to the Model. Once complete, the third phase of the project will include convening a Learning Community to test the enhancements described above and assess their impact on key outcomes, including: HMG implementation, parent satisfaction with HMG, provider satisfaction with HMG, and coverage and penetration of HMG in communities.