



Lessons from exemplary programs Strategies to promote healthy development in young children

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The foundations for children's health and social and emotional well-being begin before birth and are strongly influenced by early experiences at home, in health care settings, and in communities. A body of research known collectively as P.A.R.E.N.T.S. Science (**P**rotective factors, **A**dverse Childhood Experiences, **R**esiliency, **E**pigenetics, **N**eurobiology, **T**oxic stress, and **S**ocial Determinants of Health)¹ points to the critical importance of safety, stability, and nurturing in the earliest years to health and well-being in childhood and throughout the life course.²

There is increasing recognition of the unique role that children's primary health care providers play in promoting a preventive and developmental approach to children's health and well-being. Pediatric primary care providers (e.g., pediatricians, family physicians, nurse practitioners) are the core group of services for young children under age 3, with almost 9 in 10 young children seeing a health provider for a preventive well-child visit annually.³ This, in turn, has led to the development of transformational service approaches and programs that optimize the role of health care providers in supporting families' efforts to address both developmental and socio-economic risks.^{4 5}

Many pediatric primary care practices are augmenting their services or increasing linkages with other community providers to better address risks and concerns related to child development, emotional-behavioral factors, or social determinants of health.^{6 7} Through the transformation of pediatric

primary care settings, some exemplary programs and clinical practice sites have emerged. Some of these exemplary programs and practices reach families outside of the health practice by connecting to other partners that serve vulnerable families, such as home visiting, child protective services, family support, and early care and education.

The Child and Family Policy Center, with support from the Robert Wood Johnson Foundation, has convened a group of exemplary programs. The project's overarching purpose is to highlight an emerging vision that promotes child health and development. Through meetings, ongoing discussions via interactive webinars, and online surveys, the exemplary programs and practices identified key strategies and actions.

On August 8-9, 2017, representatives from 12 of these exemplary programs (Attachment A) met to build on their first year of work and to focus more intensively on care coordination, community linkages, family engagement and health equity. In each of these areas, the exemplary programs and practices specified the definition, activities, common best practice elements, and key priority actions needed to continue to move the area forward. This work will help inform efforts among these and other children's programs and practices, both within the health field and outside, who are aiming to address equity issues and improve outcomes. The following summarizes the rich discussion on care coordination, community linkages, family engagement, and health

equity, organized by priority action areas established by the group.

Care coordination

Defining Care Coordination

Often used interchangeably, the terms “care coordination” and “case management” describe a set of activities in child and family health employed to promote optimal access to a range of services and supports.⁸ Effective care coordination bridges multiple systems that serve children and families, requiring effective communication among providers and families.⁹ Notably, the American Academy of Pediatrics (AAP) and other child health leaders generally use the term care coordination, while Medicaid traditionally finances under the case management benefit.

Collectively, the exemplary programs and practices define care coordination as a patient/family centered, assessment-driven and team-based activity designed to meet needs of children, while enhancing the caregiving capabilities of families. Care coordination is part the larger process that includes family engagement, screening, assessment and referrals, and follow-up. Care coordination is operationalized by addressing interrelated needs—medical, social, developmental, behavioral, educational, and financial—to achieve optimal outcomes. It also helps families cultivate skills to utilize, advocate for, and manage resources on their own, and build on strengths.

Care coordinators’ activities

Though the specific processes and protocols surrounding care coordination vary across exemplary programs (e.g., titles given to care coordinators, their locations within programs, and approaches to connect with families), care coordinators across these exemplary programs and practices engage in certain common activities. These include:

- Help families identify priorities and set goals through a process of engaging with and understanding their desires and needs;

- Further assess, screen, and monitor child and family needs, risks, and strengths;
- Provide external referrals for families as needed (with warm hand off, warm transfer, when possible);
- Coordinate care and follow up on program referrals; and
- Team with others to ensure coordination and alignment of responses, and to effectively bridge language, culture, and community differences.

Common elements of best practice in care coordination

These exemplary programs engage in care coordination activities that well exceed the traditional meaning of the term; that is, identifying families’ needs and connecting them to services and resources. Their activities are more intentional and intensive, involve concerted efforts to assess and understand the family’s current position, help enhance the family’s resiliency, build on the family’s aspirations and strengths, and support and strengthen the family’s role in nurturing the child. Participants identified common practices foundational to success. These include:

- *Immediacy and seamlessness of response:* During the initial contact, whether with the child health provider or in the case of Healthy Development Services, directly to the care coordinator, the aim is to identify the family’s concerns, including medical, psychological, social, or educational needs. Once these issues are identified, the referring party provides an immediate warm handoff to a care coordinator (including a phone contact for follow-up in the case of Help Me Grow), or someone within the practice or program setting for direct follow-up (care coordinator, legal advisor, family advocate, social worker or child development specialist). Timely responses to referrals are critical to building a relationship with the family.
- *Patient/family centered, with a concerted and persistent engagement of families:* Families who have had unsatisfactory experiences with public

services and systems are more hesitant to engage with the care coordinator. Since engaging families often takes persistence and specific skills, care coordinators often benefit from training in motivational interviewing, appreciative inquiry, supervision, and reflective practices; such trainings help hone and develop skills that assist with establishing rapport with isolated and distrustful families.

- *Emphasis on fostering family capacity, strengths, and resiliency:* Most families fill roles similar to care coordinators and case managers for themselves and their young children. Through encouragement and mentoring, professional care coordinators work to build families' capacities. This support fosters family resiliency, personal growth, and the protective factors (Attachment C) that help make productive connections with other programs. Further, supporting resiliency in the families helps them become more confident and capable in their ability to support their children's healthy growth and development.
- *Recognizing the care coordinator as partner in the care team:* The role of the care coordinator requires the exercise of substantial discretion resulting in a greater understanding of the family, as compared to the primary care practitioner or staff of any individual program has. Also, care coordinators also know a wider range of concerns the family may have and the community resources they are accessing. Given this "on-the-ground" leadership role that care coordinators play in responding to a wide variety of family needs, they should be valued across the different systems they collaborate with. Participation of the care coordinator on a team in a value role provides a more interdisciplinary or transdisciplinary approach.
- *Engaging with other agencies/partners:* Because of the varied needs families may have, care coordinators are often in communication with other agencies and community partners. These relationships help care coordinators have a more

comprehensive understanding of family strengths and needs, and enable better matches between families, agencies and organizations within the community.

- *Continuous improvement and learning:* Regardless of their backgrounds and pre-service education and training, and given the diversity of the families they serve, care coordinators frequently confront new situations and needs. They often find that families take steps backward, as well as forward, and initial strategies and plans require adaptation. Strong supervision, frequent teaming and peer consultation, and reflective practice represent core features of care coordination that exemplary programs have built into the workloads and professional development of care coordinators.
- *Flexibility, humor, humility, and self-care:* Effective care coordinators can have many different professional and community backgrounds, including social, legal or public health professional training or life experiences within diverse communities. Exemplary programs have identified flexibility, humor, humility, and self-care as keys to effective care coordination, finding the work fulfilling, and avoiding burnout. Continuous training builds more competent care coordinators who are able deal with the variety of concerns facing families.

Care coordination priority actions

Focus on best practices. Identify, report on, and/or promote spread of key elements and best practices in care coordination:

- Successful care coordination approaches for families with high social risks and needs
- Roles, qualities, skills, competencies, and types of people needed for successful care coordination, including options for the inclusion of community workers/family advocates
- Approaches for overcoming barriers in communication and information sharing among providers and care coordinators
- Professional, in-service training on best practices (possibly using ECHO approach)

Explore, test, and develop new approaches to address challenges in the field. Work on design, development, and implementation of:

- Modified definition of care coordination/case management, including tiers and more intensive work for families at social risk
- A multi-site demonstration project on coordinating care coordinators
- A handbook or toolkit on how to use care coordination to support families with higher social risks and needs
- A national meeting of care coordinators and specialists from various exemplary programs (e.g., health centers, Healthy Steps, Dulce, Help Me Grow)

Advance sustainable financing for care coordination.

Identify, report on, and/or promote spread of financing and sustainability mechanisms:

- Financing mechanisms currently used by exemplary programs
- Enhanced/appropriate Medicaid reimbursement for intensive (or tiered) care coordination
- Incentives for sharing care coordination resources (e.g., for managed care or practice organizations connecting with community resources)
- Integrated cross system funding (blended and braided funds) for care coordination

Community linkages

Defining community linkages

Community linkages connect services and support coordinated systems to increase continuity, collaboration, and cross-sector sharing in all aspects of service delivery, while ensuring the privacy and rights of families.

In making community linkages, exemplary programs recognize that they must give primary attention to ensuring that referrals align with the family's desires, values, experiences, and goals. Referrals must also complement the strategies of other services and support the family accesses, including those provided in the primary health care practice. Robust

linkages among community partners are based on strong, ongoing, and evolving relationships. The strongest community linkages generally are grounded in formal, structured, and extensive partnerships among a variety of key stakeholders and build on the services, strengths, resources, referral processes, and strategies of the partners. Many often rely on relationships between the care coordination team and community organizations/providers offering resources, services, support and aid to families. These linkages also are supported by ongoing community needs assessments and advocacy for services to fill identified gaps.

Community Linkages Activities

Some participating in this project are from evidence-based programs with demonstrated effectiveness across the country in improving community linkages, particularly between pediatric primary care providers and other services and supports (e.g., Help Me Grow, Healthy Steps, Medical-Legal Partnerships, Project Dulce, SEEK). Others have developed effective approaches in their unique practice or community. Key activities recommended for increasing and sustaining community linkages are to:

- Create formal and institutionalized community partnerships
- Use community, interdisciplinary team meetings to engage multiple systems
- Develop and apply referral guidelines and pathways (including warm handoff, when appropriate)
- Adopt approaches for two-way communication and information sharing
- Use quality improvement (QI) approaches to measure and improve the effectiveness of collaboration
- Invest in projects to improve collaboration and strengthen community linkages
- Share resources and develop community "utilities" that serve multiple providers and sectors
- Intentionally measure collaboration process
- Help families sign up for resources such as SNAP or health insurance

Common Elements of Best Practices in Community Linkages

Exemplary programs and practices have identified a common trend: families often fail to recognize and utilize the many resources at their disposal.

Consequently, exemplary programs sometimes have a specific liaison position whose role is to identify and connect with community resources, both professional and voluntary. For other exemplary programs, the activities of care coordination and community linkages are seen as one role. Best practices in community linkages include:

- *Identifying resources and resource gaps:* Because of their unique role of working directly with families on various concerns at one time, exemplary programs are often in the best position for both identifying specific needs of families and for advocating for the development of services and supports to meet them. Even when it is not possible to meet a need, exemplary programs play a valuable role by sharing with partners what they identify as gaps in services for families they serve.
- *Building and sustaining partnerships:* As important as it is for exemplary programs to build a trusting and authentic relationship with the families, they must also build strong, and trusting relationships with the community services and resources families need. Many exemplary programs sit in or convene meetings with community partners where they share the needs they see in families and where community resource gaps can be identified. Doing so also helps them identify specific strengths of different programs, including their particular connections with families from different racial and ethnic backgrounds and home languages.
- *Additional Strategies that Strengthen Community Linkages:* Finding opportunities that strengthen community linkages between organizations and help to better align resources for families is important. Some of the strategies exemplary programs highlighted include: 1)

engaging with other agencies through community initiatives; 2) building and supporting systems of care, including protocols, agreements, care pathways, etc.; 3) measuring referrals, linkages, and systems processes.

Community linkages priority actions

Focus on best practices. Identify, report on, and/or promote spread of key elements and best practices related to:

- Successful community linkages and partnerships programs (e.g., Part C early intervention, home visiting, nutrition, mental health, housing, etc.)
- Measuring referrals and results of referrals
- Overcoming barriers to communication among providers/agencies
- Feedback loops and bi-directional communication among providers
- Health and human services collaboration and integration

Explore, test, and develop new approaches to address challenges in the field. Work on design, development, and dissemination of:

- Guidance on alignment and sequencing of program model implementation (Healthy Steps, Project Dulce, Strengthening Families, home visiting, etc.)
- Next generation of 211 approaches
- Interdisciplinary, interagency case conferences related to social determinants of health
- Guidance for using social network or related analytic approaches to map and understand community linkages

Family engagement and leadership

Defining family engagement

Family engagement is an overarching principle and approach for involving families in decisions about themselves, their children, services, and their communities.^{10 11}

Studies across multiple fields of service tell us that family engagement includes: a) shared decision making and understandable and realistic (one step at

a time) care plans; b) enabling families to navigate, coordinate, and manage services appropriately and effectively; c) direct relationships with service providers that support parents' sense of agency; d) contact with peers and other community leaders that foster peer support and reciprocity; e) advocacy by parents on behalf of their own and other families, f) decision-making and advisory roles in service entities; and g) leadership in the community.

One study concluded that: "Patient engagement has been called a critical part of a continuously learning health system, a necessary condition for the redesign of the health care system, the 'holy grail' of health care, and the next 'blockbuster drug of the century'."¹²

The exemplary programs and practices in this project are operationalizing the concepts of family-centered practice in multiple ways. From their perspective, such efforts must:

- Emphasize family engagement and family-driven care, with families at the center of the care planning process.
- Maintain a commitment to family-centered, strength-based services that respect the diversity and unique needs of children and families.
- Ensure consistent and meaningful, routine two-way communication between providers and families.
- Promote and maintain family dignity and integrity by supporting their active involvement in identifying, promoting, improving, and managing child development and health in ways meaningful to them.
- Engage parents in a reciprocal relationship to enhance family resilience, build knowledge of parenting and child development, and offer concrete support in times of need.
- Ensure family-driven care planning process

Family engagement activities

The exemplary programs highlighted the following as important activities that engage families:

- Engage families in advocacy, advisory groups.

- Select providers and train them (e.g., motivational interviewing, reflective practice, diversity informed practice) to ensure they can engage and relate to families they are serving.
- Evaluating, surveying family experience and satisfaction.
- Building capacity of families to be advocates in service design and in place-based initiatives.
- Standards of quality for family engagement, strengthening and support.

Common elements of best practices in family engagement

Discussions among these exemplary programs reflect a number of values and best practices related to family engagement, including the following:

- *Building trusting relationships*: Effective health care and other services for families with young children are based on building a trusting and reciprocal relationship with parents. Exemplary programs work on building positive relationships with families. Training in cultural competency, family engagement models, and listening to the family are all ways that help care coordinators better understand the family and its needs.
- *Families at the center of the care planning process*: A commitment to family-centered, strength-based services must be present. This means that families are recognized as the drivers and decision makers of the services and support they need and want. Care coordination trainings in skills such as listening and motivational interviewing, and engaging in reflective practice supervision, help care coordinators engage with families as partners.
- *Families' perspectives are essential to service quality*: Exemplary programs are engaging parents in ways that promote quality improvement (QI). Measures of consumer satisfaction, family input on service design, and other methods can inform QI projects.
- *Intentional peer learning opportunities*: Fostering or developing mechanisms for peer support and mutual assistance, (e.g., family support groups) creates opportunities for parents to build social

relationships as well as skills in leadership, advocacy, or advisory group roles.

- *Families engaged in leadership and development of programs and agencies:* These exemplary programs and practices routinely offer families opportunities to participate in advisory boards and other governance bodies. Parents are encouraged to share their experiences and be actively involved in organizational decision making. They intentionally create processes where families' voices influence the way the agency develops and delivers programs.

Family engagement priority action

Focus on best practices. Identify, report on, and/or promote spread of key elements and best practices related to:

- Reducing structural barriers and creating welcoming environments to better serve people of color, families living in poverty, and people with disabilities
- Use of well-visit planner, pre-visit questionnaires, and other tools to empower families
- Integration of strengths-based approaches into practice and health records
- Successful approaches for engaging families and for family-centered care in primary care practice
- Effective ways to gather input and feedback from children and youth, parents, and other family members

Explore, test, and develop new approaches to address challenges in the field. Work on design, development, and dissemination of:

- Project ECHO approach for training on family engagements
- Other training approaches across disciplines (e.g., physicians, nurses, community health workers, social workers)
- Information and training related to two- and multi-generational strategies

Advance state of the art in measurement. Work on design, development, and dissemination of measurement approaches such as:

- Validated tools and metrics to assess family engagement
- Tools to assess families experience of the overall system of children's services (i.e., not just a visit or the health practice)
- Approaches and tools to assess provider/practice actions using the patient engagement framework advanced by Carman et al.
- Replication or update of the Commonwealth Fund survey of families

Promoting Health Equity

Defining Health Equity

For general purposes, Braveman and her colleagues have offered the following definition of **health equity**:

Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.¹³

In essence, health equity means that everyone has a fair opportunity to be in optimal health, and often requires removing economic and social obstacles to health such as poverty and racial discrimination.

Similarly, Healthy People 2020 defines health equity as:

Achieving the highest level of health for all people. Health equity entails focused societal efforts to address avoidable inequalities by equalizing the conditions for health for all groups, especially for those who have experienced socioeconomic disadvantage or historical injustices. (Promoting Health Equity Activities)

The exemplary programs and practices all use intentional actions that promote health equity. Intentionally using a health equity lens while working with families and other programs is critical. Exemplary programs may use a combination of a culturally competent training approach, a

measurement approach, or some other action.

Examples include:

- Highlight cultural competency as a value underpinning the work and program approaches, such as using diversity informed practice
- Recognize the ethnic make-up and home languages of the community being served
- Provide resources and time to increase cultural competency of staff
- Give attention to practice that addresses issues of new Americans, refugees, immigrants, privilege and class
- Include parents in leadership activities in program

Common elements of best practices in promoting equity

Exemplary programs use specific strategies to intentionally address health equity:

- *Hire staff from diverse backgrounds*: Making sure that the program hires bilingual, bicultural staff that as much as possible, represent the community they are serving.
- *Staff training on cultural competency (i.e., Cultural and Linguistically Appropriate Services (CLAS), health equity trainings)*: Cultural competence is a process. Ongoing training, support, and reflective practice help staff continue to increase their skills in cultural competence.
- *Engage parents*: Important to engage parents in peer support activities and as champions in the community.
- *Data collection*: Collecting data on who makes up the community being served is key to implementing culturally competent services. Collecting information on the make-up of the community allows measurement by race/ethnicity, income, geography, and other factors. As changes in race and ethnicity occur, exemplary programs ensure that community services evolve to meet current needs.

Health equity priority action

Focus on best practices. Identify, report on, and/or promote spread of key elements and best practices related to:

- Reduce language, practice and cultural barriers within and across systems to better serve people of color, families living in poverty, people with disabilities
- Secure resources to expand community social supports, family support, recreation and other types of support in the community
- Public education campaign (including use of the arts) to inform about the impact of poverty, discrimination, and trauma on child and family development (including narratives about how people overcome adversity through support and resilience)

Explore, test, and develop new approaches to address challenges. Work on design, development, and dissemination of pediatric practice strategies that promote health equity such as:

- Tools to reduce structural barriers (e.g., creating a welcoming environment, diversity in front office, bathroom design, training to reduce bias)
- Guides to implementing CLAS standards or otherwise improve cultural and linguistic responsiveness and competency
- A toolkit on working with diverse family cultures in today's America
- Approaches for service delivery in underserved urban and/or rural communities
- Approaches for serving new Americans, refugees, immigrants, and others

Advance state of the art in measurement. Work on design, development, and dissemination of measurement approaches such as:

- Validated social determinants of health questionnaire/tool for use in pediatric primary care settings
- Core measures/indicators set for social determinants of health

- Data collection and other approaches to address the problem of insufficient data available by race, income, and language status
- A guide to data collection for measuring unequal treatment and disparities

Conclusion

The starting point for these discussions was twofold:

1) the work that exemplary programs have done over the years that has improved services to families, and 2) their constant striving for continuous improvement in how they provide services. Such dialogue has led to a general consensus on effective approaches in these areas years of family support and outreach. Priority actions offer a blueprint of specific strategies and activities that can improve these areas and as a result provide more effective services to families. Some of these priority actions are broad strategies, while others represent specific activities that can be implemented by a program.

Given the unique communities and populations the exemplary programs serve, as well as the availability of resources in those communities, they continually modify their strategies to better meet families' needs. Thus, these strategies should not be seen as a one-size-fits-all approach; what is needed varies by location and population demographics. These approaches represent a myriad of strategies, which can be combined with current work and tailored to different structures of systems and organizations serving families. Many of these strategies are already used in various forms and intensity by family and child-serving systems. Sharing these best practices offers the opportunity to assess the presence and intensity in the engagement and communication they do with families and partners.

Attachment A: Health equity and young children

Exemplary programs

1. **Child First**, *Connecticut National Office*
www.childfirst.org
2. **Early Childhood Comprehensive Systems**, *NICHQ national office; Florida site*
<http://www.flmiechv.com/>
3. **Healthy Development Services**, *San Diego, AAP - California Chapter 3*
<http://first5sandiego.org/healthy-development-services/>
4. **Healthy Steps**, *DC national office; Illinois site*
<https://www.healthysteps.org/>
5. **Help Me Grow**, *Connecticut national office*
<https://helpmegrownational.org/>
6. **Maricopa Integrated Health System Medical Home**, *Arizona*
<http://mihs.org/>
7. **Medical-Legal Partnerships**, *GWU national office; Chicago site*
<http://medical-legalpartnership.org/>
8. **MYCHILD & Project LAUNCH**, *Boston, MA* <http://www.ecmhatters.org/Pages/ECMHMatters.aspx>
9. **Primary Health Care, Inc.**, *Des Moines, IA*
<http://www.phcinc.net/>
10. **Project DULCE**, *Center for the Study of Social Policy national office; Vermont site*
<https://dulcenational.org/>
11. **Safe Environment for Every Kid (SEEK)**, *University of Maryland*
<http://www.umm.edu/programs/childrens/services/child-protection/seek-project>
12. **The Children's Clinic**, *Long Beach, CA* <http://www.thechildrensclinic.org/>

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