

Pathways Leadership Committee Final Report

January 2, 2008

**Presented to the Pediatric Health Services Committee and
Children and Families Commission of Orange County**

I. Executive Summary

This report represents the recommendations of the Pathways Leadership Committee convened by the Children and Families Commission of Orange County to guide a collaborative, community-focused planning effort intended to strengthen the pathway for young children receiving or in need of developmental and behavioral services in Orange County. The planning effort builds on an initial vision for a system of developmental services, as outlined in the 2004 report to the Children and Families Commission, *Building a Model System of Developmental Services in Orange County* prepared by the UCLA Center for Healthier Children, Families and Communities.

The Leadership Committee developed strategies and action steps to make the model developmental services system a reality for the children and families in Orange County by focusing on a targeted outcome for the next three to five years:

All children in Orange County will have recommended developmental/behavioral baseline screenings at milestone ages with linkage to appropriate services.

The recommended plan is designed to:

- Significantly increase the number of children screened and referred
- Ensure all services are family centered
- Manage the referral process through Help Me Grow as the system coordinator
- Provide ongoing management and measurement of the overall system of care to stimulate improvement and innovation.

The Committee developed four primary goals to achieve the targeted outcome:

- GOAL 1: Develop the infrastructure to ensure the effectiveness of the Orange County developmental/behavioral pathways system.
- GOAL 2: Develop relationships among community partners that serve children, birth through five, and their families ensuring the effectiveness of the developmental/behavioral pathways system through networking, linkages, collaborative projects and incentives.
- GOAL 3: Leverage opportunities to effect systematic change in practices and service coordination.
- GOAL 4: Raise public and professional awareness and understanding around optimizing early childhood development and encourage the implementation of developmental/behavioral screening for all children.

The Commission appreciates the time and dedication of the Committee members, and especially, Dr. Eric Handler as the Committee Chair, in successfully and collaboratively working together on the planning process.

II. Overview of the Pathways Leadership Process

A. Background

Since 2000, the Children and Families Commission of Orange County has focused many of its investments on early identification and intervention for children with neurodevelopmental or behavioral problems, recognizing the critical role these services play in ensuring healthy development and school readiness for all children. Building on these investments, in September 2004, a Commission-sponsored study was issued by UCLA's Center for Healthier Children, Families and Communities, that examined the existing developmental/behavioral service delivery system and presented recommendations to support a model system of developmental services. At the core of these recommendations was the creation of an integrated system focusing on optimizing healthy child development through partnerships among families, primary care/ service providers, and educators.

Trend data for Orange County continues to demonstrate the need for system improvements as the demand for developmental and behavioral services for young children in Orange County increases:

- From 1996 to 2005, there was a 97 percent increase in the number of children, under age 18, utilizing services through the Regional Center
- From 1996 to 2005, there was an 81 percent increase in the number of children, under age 18, diagnosed with developmental disabilities
- Of the 8,055 children receiving services in 2005, 3,451 (43 percent) were under the age of four; over 350 more children under four than were served in 2005
- Nationwide, 17 percent of children have a developmental or behavioral disability; less than 50 percent of these children are identified as having a problem prior to school entry.¹

Research from the Brookings Institute has also shown that effective interventions in young children have the potential for major reductions in future costs and developmental, behavioral and health consequences. Data from OC Regional Center indicates that many children are not being identified with developmental delays, such as speech and language, which could be effectively addressed with earlier interventions. According to 2005 data from the Department of Education, for example, only 22 percent of children qualifying for special education due to speech and language impairments were less than six years old.²

¹ 2007 Report on the Conditions of Children.

² California Department of Education, December 1 2005 reporting cycle, Special Education Enrollment by Age and Disability for Orange County.

In convening the Pathways Leadership Committee, the Commission, recognized that the current developmental/behavioral service system has many independent resources but there are gaps in services, services often have restricted eligibility for many assessments and interventions, and the services do not work together in such a way that is family-centered, effective, and easily accessible. The Pathways Leadership Committee was convened to guide a collaborative, community-focused planning effort intended to strengthen the pathway for young children receiving or in need of developmental and behavioral services in Orange County. The Committee relied heavily on the initial vision for a system of developmental services, as outlined in the 2004 report to the Children and Families Commission, ***Building a Model System of Developmental Services in Orange County***, prepared by the UCLA Center for Healthier Children, Families and Communities.

B. Pathways Leadership Committee

In May 2007, the Commission convened the Pathways Leadership Committee, comprised of a diverse group of leaders in health care, government, education, and community-based organizations.

Charter

The charter of the Pathways Leadership Committee consisted of the following:

- To lead implementation planning and build community consensus for an enhanced developmental services system for children and families in Orange County building on existing planning efforts, collaborations, and community resources
- To develop a community endorsed plan to build on the existing services and move forward on implementation.

A primary objective of the planning process was to identify tangible, measurable steps that the County could achieve within a three to five year planning period. The Committee prioritized the importance of setting achievable targets to demonstrate progress as well as be clear examples of the change envisioned. The adopted outcome, as shown on page six, was selected as the target for the next three to five years.

Data Driven Process

The Pathways Leadership Committee met monthly, from May through December 2007, to review research, consider the current contributions of various services, programs and sectors to the existing developmental/behavioral pathways system in Orange County, and develop recommendations to leverage those resources to optimize the existing service delivery system.

The Committee relied on available data and reports on both local Orange County data and national trends in developmental services for young children. Reports analyzed by the Committee are presented as Appendix C.

Participants

The Pathways Leadership Committee was comprised of a diverse array of organizations serving children, birth through five, including representatives from County government, community-based service providers, school districts, health care providers, and foundations. Appendix B is a listing of all committee members.

The following is a list of the organizations represented on the Committee:

American Academy of Pediatrics, CA Chapter 4
California Children's Services
CalOptima
Children and Families Commission of Orange County
Children's Hospital of Orange County (CHOC)
CHOC-UCI Neurodevelopmental Programs (including Help Me Grow)
Coalition of Orange County Community Clinics
County of Orange Health Care Agency
County of Orange Social Services Agency
Family Support Network
HealthCare Foundation for Orange County
Kaiser Permanente
Newport Mesa Unified School District
Orange County Department of Education
Regional Center of Orange County
University of California, Irvine Medical Center

The Leadership Committee was convened by the Commission and supported by Commission staff and consultants.

III. Future Vision of Orange County Developmental/Behavioral Pathways System

Using the Commission's Vision Statement that, "*All Children are Healthy and Ready to Learn When They Enter School*", the Pathways Leadership Committee identified the following outcome to guide development of an enhanced developmental/behavioral pathways system for children in Orange County over the next three to five years:

All children in Orange County will have recommended developmental/behavioral baseline screenings at milestone ages with linkage to appropriate services.

Current State of Developmental Services in Orange County

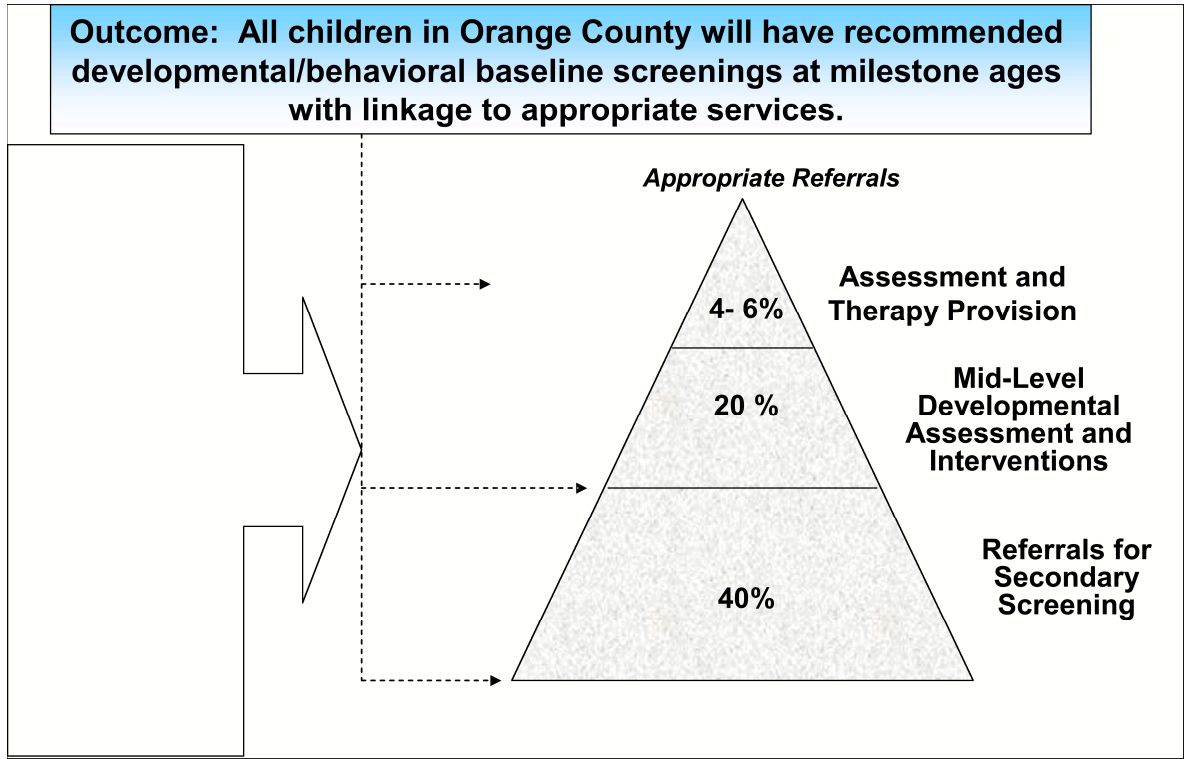
Despite progress made in the last five years, evaluators of the current system for developmental services have noted that the system lacks coordination, is insufficient in identifying children with developmental delays and focuses on "screening out", i.e. requiring children to meet a certain criteria before they are eligible for services. As a result, the current system is often marked by failures for children to be identified with developmental delays are not always identified at an early age, with appropriate referrals, frustrations by parents and providers.

Future State

The future state envisioned by the Leadership Committee would enable all children, over 262,000³ children birth through five, to receive regular developmental screens as part of their primary care at periodicities as defined by the American Academy of Pediatricians or other similar groups. The UCLA Center developed the fundamental model which the Children and Families Commission has adopted as a framework for addressing the developmental needs of all children while optimizing their growth and development. The model has been used by the Commission in designing the successful LEAPS program pilot, implemented in the Newport-Mesa Unified School District. The Committee, adapting the UCLA model, as illustrated in the pyramid graphic on the following page, envisioned a system which optimizes the growth and development of all children, recognizing that children will require a range of services, from community-based support to more intensive treatment services.

³ 2000 US Census

Figure 1: Proposed Model for Developmental Pathways



IV. Recommended Goals & Strategies

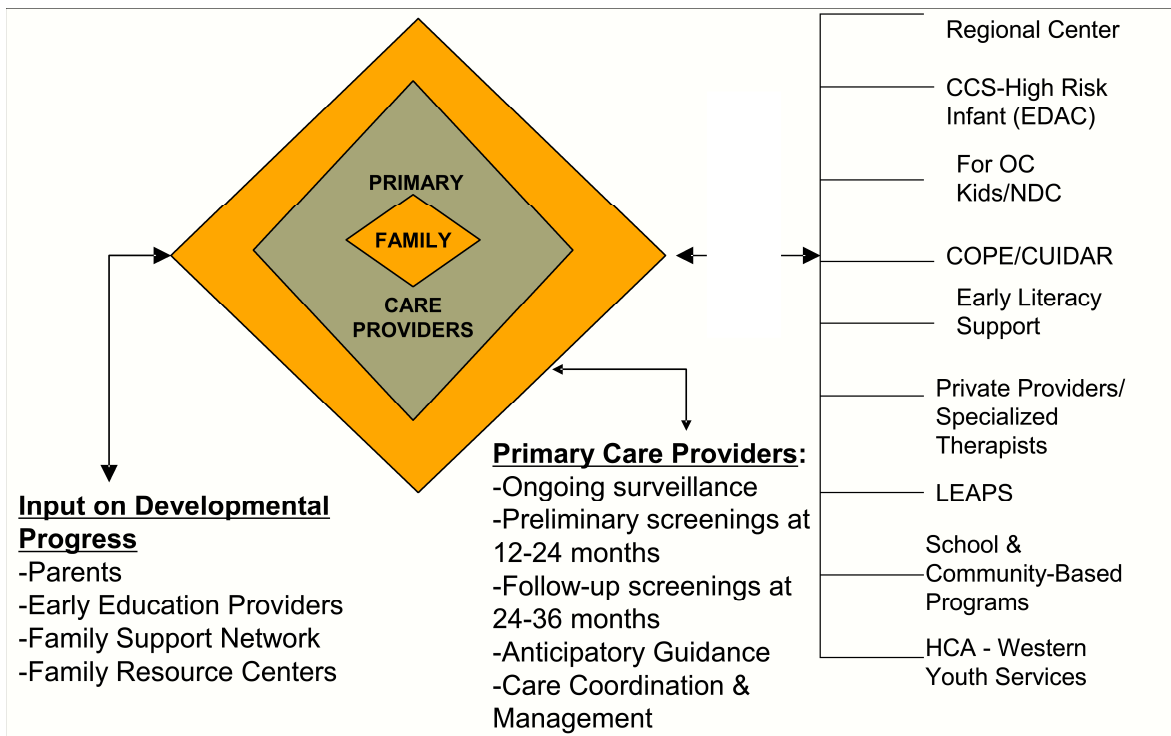
The Pathways Leadership Committee identified the following goals and strategies to be implemented over the next three to five years to achieve significant progress in improving the developmental/behavioral pathways system. The strategies are organized around four primary goals intended to: build infrastructure, develop relationships among partners, strengthen service coordination, and raise awareness. Detailed action steps for the strategies are included in Appendix A.

The challenge for the Leadership Committee was to develop strategies and action steps to make the model developmental services a reality for the children and families in Orange County. The recommended plan is designed to:

- Significantly increase the number of children screened and referred
- Ensure all services are family centered
- Manage the referral process through Help Me Grow as the system coordinator
- Provide ongoing management and measurement of the overall system of care to stimulate improvement and innovation.

As shown in Figure 2, below, the Leadership Committee vision is doable through partnerships and coordination among the key providers in Orange County.

Figure 2: Proposed Integrated System



GOAL 1: Develop the infrastructure to ensure the effectiveness of the Orange County developmental/behavioral pathways system.

Strategy 1: Build system capacity to maximize the identification of all children with developmental/behavioral needs and ensure resources are available to address their identified needs upon referral.

Strategy 2: Adopt a universal release of information form to assist in authorizing information sharing to improve care coordination and delivery of services to young children and their families.

Strategy 3: Promote implementation of validated assessment and screening tools that are recommended by the American Academy of Pediatrics (AAP).

Strategy 4: Support ongoing system monitoring and evaluation to continually assess and promote innovation and improvement in the developmental/behavioral pathways system.

GOAL 2: Develop relationships among community partners that serve children, birth through five, and their families ensuring the effectiveness of the developmental/behavioral pathways system through networking, linkages, collaborative projects and incentives.

Strategy 1: Promote networking opportunities among community partners that provide services to children birth through five and their families to ensure effective collaboration and service coordination.

Strategy 2: Develop and sustain linkages among community partners to ensure that children and families are referred to needed services.

Strategy 3: Develop and sustain collaborative projects that promote relationships among community providers.

Strategy 4: Utilize incentives (e.g. policies, innovative financing, etc.) to facilitate and sustain relationship-promoting strategies.

GOAL 3: Leverage opportunities to effect systematic change in practices and service coordination.

Strategy 1: Build strategic alliances as existing and new opportunities emerge to improve the delivery of coordinated developmental and behavioral services.

Strategy 2: Implement developmental/behavioral screenings of children, birth through age 5, with community partners and in coordination with other state and national screening initiatives such as the ABCD pilot.

Strategy 3: Ensure and sustain a trained and culturally competent workforce to support screening, assessment, and provision of needed intervention and treatment services.

Strategy 4: Support increased surveillance of children, ages birth through 5, by early education and community-based service providers (e.g., WIC, social service agencies). Ensure providers have the tools and skills to recognize children who may be at risk of a developmental delay or behavioral issue and to provide the appropriate referrals.

GOAL 4: **Raise public and professional awareness and understanding around optimizing early childhood development and encouraging the implementation of developmental/behavioral screening for all children.**

Strategy 1: Launch a public awareness campaign aimed at Orange County families, providers and the general public.

Strategy 2: Encourage all parent education programs to support families in promoting health childhood development.

Next Steps: Pathways Leadership Plan Implementation

To ensure continued progress towards implementation of an enhanced Pathways system, the Committee recommends that a Partnership Collaborative, comprised of representatives of key agencies and institutions, be formed to:

- Serve as stewards for the project;
- Elicit support for endorsement of Pathways Leadership plan;
- Monitor implementation of recommended strategies;
- Ensure accomplishment of goals;
- Support continued long-term implementation, and
- Evaluate system changes.

It is recommended that the Commission continue to serve as the convener to this next stage of development and provide the initial staff resources to coordinate the implementation process.

APPENDIX A: Pathways Leadership Committee Goals, Strategies and Action Steps

GOAL 1: Develop the infrastructure to ensure the effectiveness of the Orange County developmental/behavioral pathways system.

1. Build system capacity to maximize the identification of all children with developmental/behavioral needs and ensure resources are available to address their identified needs upon referral.
 - a. Explore implementation of an early intervention pilot for children, ages 3 to 5, in the Newport Mesa Unified School District. The pilot would teach Spanish-speaking parents how to support their children's speech and language (S&L) development in order to reduce the risk of early speech and language delays, support school readiness efforts, and expand capacity of early literacy resources to provide services to at-risk children. The pilot would include a review of best practices to identify the optimal program model and would be linked to the Commission's Early Literacy Program aimed at promoting school readiness and success through community, family, and school-based partnerships.
 - b. Continue to support School Readiness Nurses (SRNs) in their unique and important role to provide support within communities around developmental services in the areas of surveillance, screening and referrals. Work to ensure that SRNs have the necessary resources, tools and training to:
 - Establish linkages with primary care providers and community-based service providers serving children, birth through five, and their families;
 - Utilize validated screening tools that are recommended by the American Academy of Pediatrics (AAP) in their July 2006 Policy Statement;
 - Foster strong relationships with their school districts and have a thorough understanding of the intervention services offered by their district;
 - Develop the skills and knowledge to create individualized intervention plans for all at-risk children;
 - Utilize AAP as a resource for school nurses;
 - Utilize Help Me Grow as a resource for families; and
 - Share best practices among the SRN network.
2. Adopt a universal release of information form to assist in authorizing information sharing to improve care coordination and delivery of services to young children and their families.

- a. Implement pilot to test universal consent prototype, assess its value and review challenges. Ensure the form addresses the following principles:
 - Written at 4th grade reading level
 - Available in English, Spanish and Vietnamese
 - Clients will be advised that services will not be withheld should they choose not to sign the universal consent
 - Compliant with HIPAA, FERPA, CA law
 - Non-covered entities would need to follow the standard of covered entities
3. Promote implementation of validated assessment and screening tools that are recommended by the American Academy of Pediatrics (AAP).
4. Support ongoing system monitoring and evaluation to continually assess and promote innovation and improvement in the developmental/behavioral pathways system.
 - a. Establish processes and outcome metrics to measure system performance and encourage innovation including setting continuous improvement goals.

GOAL 2: Develop relationships among community partners that serve children, birth through five, and their families ensuring the effectiveness of the developmental/ behavioral pathways system through networking, linkages, collaborative projects and incentives.

1. Promote networking opportunities among community partners that provide services to children birth through five and their families to ensure effective collaboration and service coordination.
 - a. Help Me Grow, in collaboration with several strategic partners, will sponsor regional networking breakfasts for organizations providing services to young children, with a focus on developing relationships among Orange County community programs and service providers.
2. Develop and sustain linkages among community partners to ensure that children and families are referred to needed services.
 - a. Ensure Help Me Grow, in partnership with community providers, serves as a key linkage between families, pediatricians, and developmental/behavioral resources.
 - b. Help Me Grow and High Risk Infant Follow-up (e.g., CCS/EDAC/Regional Center/other) will partner to pilot enrollment of infants at-risk for developmental delays or behavioral issues due to perinatal difficulties but who do not meet eligibility criteria for enrollment in High Risk Infant Follow-up, into the Help Me Grow Ages and Stages

Developmental Monitoring Program. Help Me Grow will inform primary care physicians of families in their practice who enroll into the monitoring program.

3. Develop and sustain collaborative projects that promote relationships among community providers.
4. Utilize incentives (e.g. policies, innovative financing, etc.) to facilitate and sustain relationship-promoting strategies.

GOAL 3: Leverage opportunities to effect systematic change in practices and service coordination.

1. Build strategic alliances as existing and new opportunities emerge to improve the delivery of coordinated developmental/behavioral services.
 - a. Collaborate with County Health Care Agency to pursue funding opportunities through Proposition 63 and EPSDT that support the planning and implementation of developmental/behavioral services, with a particular emphasis on ensuring services for at-risk populations.
 - b. Collaborate with California Children’s Services (CCS) to ensure effective implementation in Orange County of their High Risk Infant Follow-up Quality Improvement Initiative to maximize the neurodevelopmental outcomes of California’s high-risk infants by age three years.
2. Implement developmental/behavioral screenings of children, birth through age 5, with community partners and in coordination with other state and national screening initiatives such as the California ABCD pilot.
 - a. Launch an American Academy of Pediatrics (AAP) pilot program to train and support primary care provider offices, health clinics, and child care facilities in South County to effectively screen 1600 children.
 - b. Implement a physician incentive program, coordinated by CalOptima, to encourage primary care provider screenings of children, birth through age 5, in Santa Ana and Anaheim. The pilot will include the development of internal capacity to train all participating provider offices through a “train-the-trainer” model.
 - c. Implement a pilot through Help Me Grow to develop and coordinate an Ages and Stages Questionnaire monitoring program to support health care providers’ screening efforts. Pilot will include, but not be limited to, the distribution of a screen tool, scoring and tracking of screens over time, and providing results to individual families and health care providers.

- d. Establish a group, convened by the Children and Families Commission, to coordinate primary care provider outreach and training activities by all participating pilots to prevent overlap in provider outreach and enrollment and manage future expansion of pilot initiatives.
3. Ensure and sustain a trained and culturally competent workforce to support screening, assessment, and provision of needed intervention and treatment services.
 - a. Develop, in collaboration with Help Me Grow and AAP, a comprehensive and standardized training curriculum that will be used Countywide to train all participating ABCD pilot sites (pilots listed under Strategy 2) and other screening initiatives, with specific modules for medical providers, early education/child care providers and community-based organizations.
 - Develop specific modules for medical providers, early education/child care providers and community-based organizations, including a “train-the-trainer” module to be used by pilot programs to train participating providers.
 - Develop a surveillance, screening and resource referral algorithm, tailored for usage by medical and non-medical providers, to serve as a guide to the appropriate referral process.
 - b. Support increased surveillance of children, ages 0 to 5, by early education and community-based service providers (e.g., WIC, social service agencies). Ensure providers have the tools and skills to recognize children who may be at risk of a developmental delay or behavioral issue and to provide the appropriate referrals.
 - c. Convene a multi-agency working group that would consult on the review and evaluation of existing training resources and best practices to support the adaptation of these materials for use in a training curriculum for early care educators and community-based service providers working with children and their families. The training would include information about key early childhood developmental issues, surveillance methods, and information about appropriate referral and screening resources. The working group would also assist in identifying the target population to be trained and explore opportunities for partnering with other institutions around training (e.g., Children’s Home Society, resource and referral agencies, community colleges).

GOAL 4: Raise public and professional awareness and understanding around optimizing early childhood development and encouraging the implementation of developmental/behavioral screening for all children.

1. Launch a public awareness campaign aimed at Orange County families, providers and the general public.
 - a. The campaign would focus on the following key areas:
 - Understanding of appropriate healthy child development/behavioral health;
 - Need for recommended developmental/behavioral screenings for all children at milestone ages; and
 - Role of Help Me Grow and the services it provides.
2. Encourage all parent education programs to support families in promoting health childhood development.
 - a. Parent education programs would provide culturally appropriate information on child developmental milestones and behavioral health; inform, motivate and activate parents to seek out developmental/behavioral screenings, and promote parents' active role in their child's development.

APPENDIX B: List of Pathways Leadership Committee Members

Eric Handler, MD	County of Orange Health Care Agency, CHAIR
Alan Albright	County of Orange Health Care Agency, Children and Youth Services
Dini Baker, RN	Children's Hospital of Orange County
Nancy Bowen, MD	County of Orange Health Care Agency
Anne Broussard	County of Orange Child Care Coordinator
Gertrude Carter, MD	CalOptima
Joseph H. Donnelly, MD	University of California, Irvine Medical Center CHOC-UCI Neurodevelopmental Programs
Lynn Einarsson	California Children's Services
Doris Flander	HealthCare Foundation for Orange County
Patricia Glancy	Regional Center of Orange County
Dillon Henry	Orange County Department of Education
Rebecca Hernandez	Help Me Grow
Troy Jacobs, MD	County of Orange Health Care Agency
Pamela Kahn	Orange County Department of Education
Kathy Kolodge, RN, BS	Children's Hospital of Orange County
Marc Lerner, MD	American Academy of Pediatrics, CA Chapter 4
Alyce Mastrianni	Children and Families Commission of Orange County
Dian Milton, RN	American Academy of Pediatrics, CA Chapter 4
Fred Richmond	Coalition of Orange County Community Clinics
Michael Riley	County of Orange Social Services Agency
Michael Ruane	Children and Families Commission of Orange County
Linda Smith	Family Support Center
Natalie Walper-Gerdes, RN	Newport-Mesa Unified School District/LEAPS Program
Natasha C. West, MD	Kaiser Permanente
Janis White	Regional Center of Orange County

Consultant Support:

Christina Altmayer	Altmayer Consulting
Helen DuPlessis, MD, MPH	UCLA Center for Healthier Children, Families & Communities
Neal Halfon, MD, MPH	UCLA Center for Healthier Children, Families & Communities
Deena Margolis	Altmayer Consulting
Shirley Russ, MB ChB, MPH	UCLA Center for Healthier Children, Families & Communities

APPENDIX C: Pathways Leadership Committee Resource List

Detailed below is a bibliography of the resources reviewed by the Pathways Leadership Committee in the course of their work.

1. ***Beyond Referral: Pediatric Care Linkages to Improve Developmental Health.*** Amy Fine and Rochelle Mayer, Georgetown University. December 2006.
2. ***Building a Model System of Developmental Services in Orange County.*** Prepared by UCLA Center for Healthier Children, Families and Communities. September 2004.
3. ***Children's Care Connection Fact Sheet.*** Prepared by C3 staff, San Diego, California.
4. ***Developmental Services in Orange County Resource Map.*** Prepared by Commission Staff for presentation to the Pediatric Health Services Committee. September 2004.
5. ***Developmental Services in Orange County.*** Prepared by Commission. May 2007.
6. ***First 5 CA Special Needs Project Screening & Service Protocol Flowchart.*** Prepared by First 5 CA Special Needs Project. March 2006.
7. ***First 5 California Special Needs Project: Orange County Demonstration Site Year 2 Case Study, LEAPS: Learning, Early Intervention, And Parent Support.*** Prepared by the California Institute on Human Services (CIHS) at Sonoma State University. February 2007.
8. ***First 5 LA - Early Developmental Screening and Intervention Initiative: A Brief Introduction & Implementation Plan.*** Prepared by First 5 LA.
9. ***Funding a Model System of Developmental Services in Orange County.*** Prepared by UCLA Center for Healthier Children, Families and Communities. October 2005.
10. ***A High-Performing System for Well-Child Care: A Vision for the Future.*** David Bergman, Paul Plsek, and Mara Saunders. October 2006.
11. ***Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening.*** American Academy of Pediatrics (AAP) Policy Statement. July 2006.
12. ***Los Angeles County Early Identification and Intervention (EII) Group Fact Sheet.*** Prepared by Commission. May 2007.

13. ***The Quality of Ambulatory Care Delivered to Children in the United States.*** Rita Mangione-Smith, MD, MPH; Alison H. DeCristofaro, MPH; Claude M. Setodji, PhD; Joan Kessey, BA, David J. Klein, MD; John L. Adams, PhD; Mark A. Schuster, MD, Phd; and Elizabeth A. McGlynn, PhD. October 2007.
14. ***The Science of Spread: How Innovations in Care Become the Norm.*** Thomas Bodenheimer, MD. September 2007.