# BUILDING A MODEL SYSTEM OF DEVELOPMENTAL SERVICES IN ORANGE COUNTY

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# Executive Summary

## Background

Over the past three decades there has been an increased understanding of the importance of the early years for the future development of all children. The Institute of Medicine's landmark report *From Neurons to Neighborhoods* (2000) has emphasized the importance of experiences in early childhood for the lifelong health trajectory. In 1998, California voters passed Proposition 10, the California Children and Families First Act, which provides for an excise tax on tobacco products to fund parent education, health and child care programs that promote early childhood development for 0-5s. The Orange County Children and Families Commission is responsible for allocating these revenues within the second largest county in California. It has as its focus the dual goals of healthy development and school readiness for all children, within the framework of strong families and an integrated quality service system. These goals reflect Healthy People 2010 priorities of increasing quality and years of healthy life, and reducing health disparities.

Since adoption of its first Strategic Plan (2000), the Orange County First 5 Commission has shown considerable foresight in funding a number of innovative programs targeted at early identification and intervention for children with neurodevelopmental problems. These programs have been challenged by the need to interface effectively with fragmented healthcare and education systems, and by restrictive eligibility criteria for developmental assessment and intervention services. These new programs have triggered a need for improved coordination and communication between service sectors, and have prompted a review of the organizational structure in which they operate.

## Purpose of the Study

Recognition of the need to develop a comprehensive strategic plan for a new approach to developmental services pathways in Orange County led the Orange First 5 Commission to contract with the UCLA Center for Healthier Children, Families and Communities to examine the existing system of screening, surveillance, assessment and intervention for children with developmental, behavior, and mental problems. This targeted study aimed to identify gaps in existing services, barriers to service utilization, and systems issues which currently prevent optimal service delivery. The study also aimed to develop a vision and a strategic plan for building a model system of developmental services in Orange County.

## Developmental Services: Challenges and Opportunities.

Early childhood is increasingly understood as a time of great opportunity to optimize health and promote development. There is growing consensus that achieving the optimal development of all children will require multi-sector, multi-disciplinary, systems-building initiatives that can address the needs of individual children in the context of their families and communities. A child's readiness for school is no longer defined around simple academics but in terms of overall physical, emotional, language, and social development during the first five years of life.

The emphasis on developmental optimization for all children represents a challenge for traditional developmental services which have been focused primarily on early identification and intervention for children with significant disabilities. Traditional approaches to developmental services have relied on a neuro-maturational framework in which neurological functions are regarded as being essentially "set" at birth and unfold over time. The healthcare focus has been on children's deficits, with intermittent screening being used in an attempt to document a level of deficit that will trigger eligibility for additional services. Such assessments often focused on the child in isolation, and emphasized elicitation of his or her demonstrable abilities.

A transactional model (Sameroff and Mackenzie), however, proposes that neurological, social and psychological development is a dynamic process that results from the complex interaction between the child and the care-giving environment. In this model, intermittent screening is replaced by more flexible, continuous surveillance with an emphasis on optimizing development and viewing the child in the context of his family and environment. In Orange County there is an opportunity to design a new system of developmental services which draws on the transactional model and builds on existing resources to address all aspects of child development with potential lifelong benefits for the children themselves, and extensive benefits to the wider community.

## Methods

Multiple local, state and national data sources were accessed to obtain a comprehensive picture of the demographics of the county's 0-5 population, their neurodevelopmental needs, and the resources currently available to meet those needs. Existing developmental services were examined in light of current theoretical models, with an emphasis on promising practices within the county. An extensive series of interviews was undertaken with key informants, together with focus groups of parents and providers to gain an appreciation of their perception of the current system and their visions for an ideal model. A literature review was performed to analyze current theoretical frameworks of developmental services, and to identify national and international best practice models.

## Results

### *Key Demographics and Health Indicators of the Orange County 0-5 population*

- Orange County, with 45,000 births per year (2001), is the fifth most populous county in the nation.
- Rapid population growth of over 20% in the last decade has contributed to changing demographics with over half of the 0-5 population now Hispanic/Latino; white children are the second largest group (36%), then Asian/Pacific islander (11%). The black population is relatively small (1.4%) (OCHNA 2001).
- Over 30% children in the Orange County public schools are English language learners, and that proportion is likely to rise.
- 5.7% (15,000) of Orange County children aged 0-5 years lack healthcare coverage, while 10.2% experienced a coverage gap in the last year.
- If enrolment of eligible children in MediCal, Healthy Families, California Kids and Kaiser Cares for Kids were maximized, however, less than 2,000 would

remain uninsured and could potentially be covered by a specially designated county fund.

***School Readiness Indicators***

- Teachers held maturational views regarding school readiness and strongly endorsed restrictive entrance ages and delayed entry (beyond age eligibility) for less capable children. There was strong agreement between parents and teachers that verbal communication skills were the most important criteria for kindergarten success, with ability to interact positively with others also ranking highly (ECENA 2004).
- On CHIS (2001) school readiness indicators, 74.8% of the 0-5 Orange County population was rated as in excellent or very good health (CHIS 2001).
- Over two hours of television watching daily was reported by 78.7% children 0-5, outside of current AAP recommendations.
- Only 45.1% of parents report reading to their children under 5 daily, and only 17% of children aged 3-5 attend preschool, while 30% are in childcare for over 10 hours a week and 19% are living below the poverty level.

***Prevalence and Patterns of Developmental, Behavioral and Mental Health Problems in Orange County***

- National data suggest that 12-15% of American children have a developmental or behavioral disorder (Boyle, Decoufle and Yeargin-Allsop, 1994), while up to 30-40% of parents worry that their child has a learning, behavioral or developmental disorder (Halfon et al 2002a).
- Only 0.7% of children ages 0-3 are enrolled in Orange County's Early Start program for children who have or are at risk of developmental delays, while Regional Center of Orange County serves 1.9% of county children in the 0-3 age range. Only 1.1% of children under the age of 5 years are receiving special education through the school district, yet in the K-12 public school system, 9.8% of children are identified as having special educational needs (compared with 10.1% for California). These data reveal a sharp contrast, with the majority of children ultimately needing special education not being identified prior to school entry, reflecting a lost opportunity for early intervention.
- Special Education teachers report that a greater number of children are referred to special education in 2nd and 3rd grade (65%) than in kindergarten and first grade (35%) (ECENA 2004).
- Identification of children who are emotionally disturbed peaks in the teenage years, as does diagnosis of specific learning disability at age 11-13 years. Evidence suggests that many of these problems could be detected years earlier, in some cases in the preschool years.
- Almost 1 in 2000 (0.18%) children 0-5 in Orange County are in foster care, while substantiated child abuse reports were made on 3,798 (1.5%) of them.

***Key Public Programs related to Developmental Services***

Despite recent trends towards integrated service delivery, the current system of public

programs reflects the historically fragmented nature of the system's development. Health and educational services operate in parallel, with confusing service eligibility requirements.

### *Statewide Programs*

**The Child Health and Disability Prevention (CHDP)** program is a preventive well-child screening program for children with Medi-Cal (through the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program) or up to 200% of the poverty line. **California Children's Services (CCS)** authorizes and pays for specialty care relating to specified congenital defects, diseases and injuries for families reaching financial eligibility criteria. **Medi-Cal**, California's Medicaid program, provides health insurance for low-income families and individuals without health insurance. It serves 59,000 (23%) children 0-5 in Orange County. **Healthy Families**, California's State Children's Health Insurance program (SCHIP) provides health benefits for children of low income families who are not MediCal eligible. It serves 16,000 (6%) children 0-5 in Orange County. **Regional Center** operates the Early Start program for children ages 0-3 who have or are at risk of developmental delays. Children ages 3 and above are eligible if they have cerebral palsy, epilepsy, autism, mental retardation or a similar condition.

**Department of Mental Health** offers programs for children in the community, in foster care, and with special educational needs according to AB3632. **Special Education Local Planning Areas (SELPA**) ensure free appropriate public education for all children with identified disabilities. In Orange County 4,702 children ages 3-5 are enrolled in Special Education. **Department of Child and Family Services (DCFS)** administers child protective services in Orange County, and supervises 1065 (0.4%) children ages 0-5 in foster care.

### *Commission-Funded Developmental Services Programs*

The Orange County Children and Families Commission has funded a number of programs aimed at filling identified service gaps including the **Bridges for Newborns** program which screens new mothers in 13 hospitals for a medical home, income and psychosocial risk factors. The program is linked with **Project Connections** where Public Health Nurses make home visits and perform developmental screenings for children at risk. The **Family Support Network** provides multidisciplinary developmental screenings at twelve sites throughout the county, reporting that 75% of children screened are referred on for services. The network also provides home visitation to Hispanic children at-risk of emotional disabilities.

For OC Kids provides comprehensive assessment and management for children with suspected autism and autistic spectrum disorders. The COPE/CUIDAR program is a two-stage process where parents with concerns about their child's attention attend a 10-week community parenting education program. At the conclusion of the course, parents decide whether they need to proceed on to a full developmental assessment and treatment program. The HABLA program offers bi-weekly home visiting by a trained worker, some of whom are University of California at Irvine (UCI) students to model and coach

parenting techniques that will increase verbal interaction and promote child learning and expressive language. HABLA targets low-income Latino children ages 2-4 years. Each school district in Orange County has funding for School Readiness programs. Some districts have adopted a center based school readiness approach often co-located with preschool services. The Commission has also provided funding for Preschool Nurses to be placed in preschools linked with school readiness sites. The nurses are being trained to better assess development, behavior and fitness.

The Commission also funds a Metabolic Program to allow for exclusion of a metabolic cause for neurodevelopmental problems.

***National Programs***

National Best Practice Models: The Denver System for Assessment and Referral routinely screens children using the PEDS at 9 and 18 months. Children with problems are referred to a second tier central assessment team which refers children to other diagnostic and treatment services as needed.

National Quality Improvement Efforts: The National Initiative on Children's Health Care Quality (NICHQ) and the North Carolina Center for Children's Healthcare Improvement are launching major statewide initiatives focused on improving the quality of early childhood developmental services. Using the Breakthrough Series reengineering approach to process improvement, these centers have been working with the states of Vermont and North Carolina to identify delivery problems within pediatric service delivery systems. A collaborative approach has also been used to develop, implement and test the effectiveness of solutions.

Healthy Steps for Young **Children** (Commonwealth Fund, 1992) places a developmental specialist in the primary care practice and includes a team approach to care, home visits, periodic child development screening, a child development information line, parent groups, and linkages to community resources.

The Help Me Grow program in Connecticut uses child health providers and a computerized inventory of services for developmental needs, a triage referral and case management system to help children and families access services, and educational programs for parent groups and child care providers.

The San Diego C3 program has a network of 175 providers in North San Diego. The PEDS is performed in pediatricians' offices with children scoring in a risk category being referred to a second-stage center for further screenings.

***International Best Practice Models***

There are several effective and innovative models of providing developmental services to young children that are emerging in different countries across the globe. Smart Start in England has sought to develop community based systems of assessment and referral. The Early Years project in Toronto and similar projects in Montreal and other Canadian cities are also attempting to incorporate child health and developmental services into a

more seamless system.

Platforms is the name of an initiative that is currently being developed in Melbourne, Australia. Platforms works on a three-pronged approach to coordinate systems for early childhood care. The first arm includes community needs assessment, resource mapping, and education of providers; the second phase uses the PEDS-plus, i.e. a modified PEDS with an additional dozen questions about psychosocial risk factors such as substance abuse and domestic violence; while the third arm is a collection of evidence-based interventions to optimize developmental outcomes.

Each of these innovative approaches has element that can be incorporated into the design of more effective developmental services systems for Orange County.

***Provider Capacity***

Orange County has 445 pediatricians and 945 family practice physicians, with a ratio of 557 children under the age of 5 per pediatrician compared with a statewide average of 599. Distribution of pediatricians is uneven, with areas such as Anaheim and Fullerton having a less than ideal ratio. There are limited numbers of pediatricians in a number of subspecialties including neurology and developmental/behavioral pediatrics.

***Existing Pathways in Orange County for Neurodevelopmental Surveillance, Screening, Diagnostic Assessments and Interventions***

- Despite the availability of validated tools such as the PEDS and the Ages and Stages Questionnaire (ASQ), most pediatricians in Orange County continue to rely on clinical judgment to assess development.
- National data suggest that only 50% of parents have their concerns about their child's development sufficiently addressed by providers (Bethel et al 2001b).
- Many pediatric providers lack knowledge of community-based resources and the skill to know when to refer.
- Care coordination is rarely offered and is generally sector specific.
- Options for multidisciplinary assessments are limited. Children 0-3 can be assessed by the Early Development and Assessment Program (EDAP) at CHOC or by Regional Center (RCOC) while children 3-5 receive a less comprehensive assessment through the school district.
- For children suspected of Autism, a multidisciplinary assessment is available through For OC Kids.
- Physicians report that they rarely receive correspondence from RCOC or the school district on the results of assessments.
- Children eligible for regional center (0-3) or School District Special Education (35) receive therapy services through these organizations while children not eligible for these services have limited treatment options. The coverage of speech therapy and mental health services by most health plans is also very limited.

***Data Systems and Outcome Measures***. The Commission has made a significant investment in OCERS, a state of the art data collection and tracking system to guide

program implementation and evaluation. While a number of useful process measures are emerging, the full capacity of the system to measure outcomes will only be possible with additional funding from research sources and with the academic expertise at CHOC, UCI and other institutions.

***Themes From Interviews and Focus Groups***

The first and most prominent theme featured in many interviews were difficulties in communication. This encompassed several different but related problems including difficulties with or lack of communication between parents and providers and between providers from different disciplines, organizations and institutions. Another problem that was identified was that even when providers discussed development and developmental services with other providers, they were often using different conceptual models of development and had different notions of what constituted developmental assessment and of how a service system should optimally function. The communication challenges appear to be particularly salient across sectors—early education to pediatrics and vice versa. Communication across different cultures was especially difficult and the issue of cultural competency was another closely linked theme. Many families being served have little or no English skills; yet services and information sources did not always address this need. To many families, many services, particularly those located in large institutions, lacked awareness of the perceptions and values of different cultures.

Most interviewees saw a great need for improved care coordination, and a desire was expressed for the county to develop an effective way of disseminating information about services. A particular need for good care coordination at times of transition (e.g. discharge from neonatal unit or entry into school) emerged as an important sub theme of care coordination, as especially good communication and integration of services are needed at this time. Most interviewees felt that funding streams were complex, fragmented and inadequate to address the existent needs, and that lack of provider reimbursement for developmental services was a major barrier to the provision of an effective system. Parent and family needs were only partly addressed in the current system, with providers feeling that parents needed education and empowerment to advocate for services for their children**.** Pediatricians were regarded as lacking in knowledge about child development and indeed were often viewed as a barrier to effective surveillance. Most practitioners were not using any formal tools for developmental screening/ surveillance. For children receiving services through the school district, the relationship between parents and schools was often regarded as adversarial, with school-based resources appearing inadequate to meet needs. Many interviewees felt that childcare providers could play a more active role in developmental surveillance given their prolonged contact with children ages 0-5, but there were doubts of whether pediatricians would act on the results of such surveillance.

Interviewees were generally positive about the concept of multidisciplinary assessment teams for children with neurodevelopmental problems but doubted the feasibility of sustaining funding of this type of approach, and anticipated transport difficulties for parents. The concept of a call center where parents or professionals could call for advice about navigating the system and available resources met with almost universal

enthusiasm, provided calls could be answered by a well-trained staff member. Healthcare infrastructure issues were identified with need for a closer collaboration between CHOC and UCI and a need for strong academic leadership in child development.

In a model-building exercise where interviewees were asked to conceptualize how developmental services are organized, almost all interviewees placed themselves or their own organization at the center of the chart. A number of interviewees had not conceptualized how an entire system might operate and interconnect prior to this exercise.

***Gaps in Current Services***

- Children with prenatal substance exposure (7.5% of Orange County births), children of mothers who are depressed, and children in foster care often fail to receive developmental services.
- Children who fail developmental screening tests but who pass diagnostic tests are generally ineligible for services, yet they continue to perform lower as a group on intelligence and achievement tests (Glascoe 2001).
- Although Early Start provides services for children in the 0-2 range who are at-risk of developmental delays, once those children reach the age of three years they transition out of services and are ineligible for other publicly funded programs. Often these children do not receive services again until kindergarten entry.
- Few practitioners are equipped to identify infant mental health problems, or mother-infant interactional problems and there are limited referral resources to manage these issues.
- There is insufficient funding for preventive services, especially in mental health.
- Childcare providers and preschools could play a greater role in developmental surveillance but lack tools and connectivity to other services.

## Strategic Analysis

A strategic analysis was performed to determine the nature of potential gaps in the conceptual approach, the stated mission, organizational capacity, financial capacity and commitments, and available leadership for a proposed model system.

### *Conceptual Gaps*

The finding of large conceptual gaps among providers related to underlying differences in belief systems about the role of developmental services. Providers grounded in a traditional medical model tend to focus efforts on determining physical causes and genetic predispositions while providers more oriented to a developmental model place more emphasis on socio-emotional factors, family functioning and parent-child interaction factors that contribute to the child's developmental and behavioral functioning.

### *Service Organization Gaps*

Service delivery gaps also relate in part to differing conceptualizations of the causes of developmental and behavioral problems. In order to receive services a diagnostic label must first be applied. This situation works for children with easily recognized conditions such as Down Syndrome, but presents a problem for those children who have significant difficulties yet do not "fit" a diagnostic category. Little work has been done on low-cost community interventions such as parent education and parent-child intervention groups which fall short of a traditional therapy approach yet could still meet the needs of many children and families for enhanced services.

### *Financial Gaps*

While financial gaps remain formidable, much work could be done to better educate providers within and across sectors about existing funding streams and how they work. The use of non-traditional funding sources such as local businesses and corporations also needs to be explored. Similarly, providers could be better informed about existing data on developmental services, while the joint interest of the Commission and grantees to develop a more extensive and outcomes-oriented evaluation should drive efforts to supplement commission funds with research grants.

### *Mission and Focus*

A number of individuals and groups within the county have strong visions for how developmental services should be organized and delivered in the future. However, these visions often differ and may not be converging on a common vision that all can embrace. Increased communication, discussion and understanding of different assumptions and beliefs between groups is needed in order to move towards a common and shared vision. While stakeholders across different service sectors articulate different goals for a new system, there is much common ground. For example, all would agree that optimizing the developmental trajectories for all children is an important goal that should drive the organization of developmental services. Also, most stakeholders agree that intermittent assessment of development throughout childhood is warranted. Yet, providers differ on whether less trained workers such as WIC staff and childcare providers could play a larger role in surveillance. The role of validated tools such as the PEDS or the ASQ has

yet to be agreed on. Each service sector needs to develop sector-specific goals, while place-based goals will need to reflect both the needs of cultural groups and local resources.

### *Leadership*

Orange County has a distinguished array of strong leaders across different service sectors. Great changes within sectors could result from the input of leaders from other sectors e.g. pediatricians could contribute significantly to the training and best practices of childcare providers while pediatricians would benefit from the enormous knowledge of local resources which resides with the public health nurses.

## Discussion & Options

Considering the findings of this targeted study in relation to the Commission's stated goals of healthy development and school readiness for all children, it is clear that the county's current developmental services are not producing desired results. National and county data confirm that a large proportion of children with mild and moderate developmental problems are not being identified until after school entry, so clearly are not entering school with their challenges already identified and addressed. Even when children are identified as having difficulties, they are often ineligible for therapy services until after they enter the school system and fail to learn. Children identified as at-risk for developmental problems who receive services though Early Start then drop out of services when they reach age three, leaving them at risk of later school failure. In short a great many children with substantial developmental challenges are not having their needs addressed. This study has focused on an analysis of the healthcare system and how it is performing in regard to developmental services. Our analysis of the educational and social services systems has been less detailed, and a more in-depth analysis of how these systems function in relation to developmental services would be beneficial.

The study findings reveal a "pyramid of need" for developmental services within the 0-5 population, (see Fig 1), with 100% of the population requiring ongoing developmental surveillance, up to 40% requiring some form of secondary screening or assessment, 10-20% requiring a fuller multidisciplinary form of assessment, and only 4-6% requiring the fullest level of assessment and ongoing longer-term therapy. The current developmental services system in the county is focused on identifying and serving the top tier, while the needs of those in the lower tiers are not well addressed.

Orange County now has a number of options. One option would be to continue to fund discrete programs such as CUIDAR, HABLA and For OC Kids and to let them evolve over time, forming connections in the process of their growth and evolution. A second option would be to continue several of the existing programs and to choose either a geographic area of the county or a specific service sector and target either a place-based or a county-wide sector-specific initiative e.g. ensuring that all pediatric offices in an area become medical homes delivering high quality developmental services.

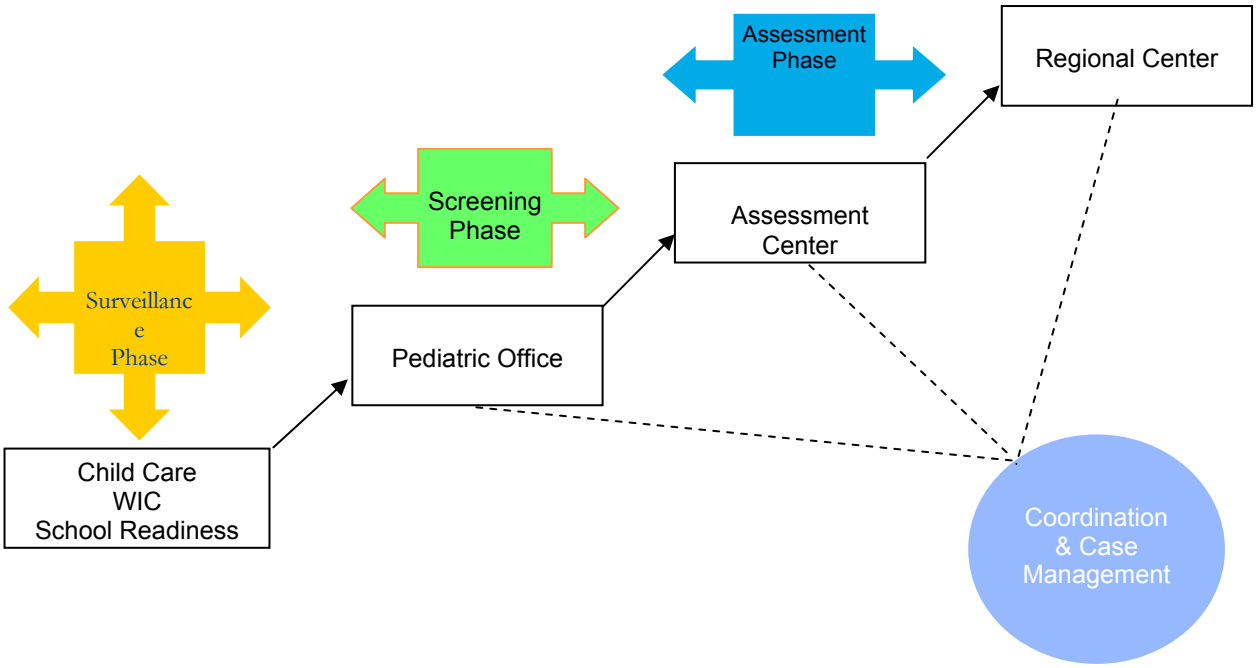
We propose that Orange County consider a third, more ambitious, comprehensive and integrated approach to creating a developmental services system. This system would, by

definition, utilize an integrated, multi-disciplinary and multi-sector approach, in keeping with the First 5 mission to create a sustainable capacity to provide services to ensure healthy development and school readiness and, with national initiatives such as the sate Early Childhood Comprehensive Systems (SECCS) initiative to create early childhood systems linking health, education, parenting and other developmental services together.

**Proposal for Model Developmental Services System for Orange County**

In response to the demonstrated hierarchy of need for developmental services within the 0-5 population in Orange County, we propose a four-level strategy which we believe is most responsive to this need (Fig 2). While focusing on the needs of children and parents, the model also addresses the needs of childcare, education and healthcare providers, and other professionals who work with this population.

**Figure 1: Model System of Developmental Services**




***Components of the System:***

First Level: Community-Based Developmental Surveillance and Supports

An effective system of developmental services requires population-wide support for optimal development, as well as a flexible, continuous surveillance system that can identify children who have specific developmental problems or who are at risk for developing these problems.

Second Level: Secondary Screening and Surveillance

National estimates suggest that 40% families will have additional concerns about their child's development or behavior. Pediatricians are in a good position to provide second-

tier services for children identified as at-risk or as having developmental problems by the community-based surveillance system. Some offices, such as those in the Healthy Steps model, have achieved this by stationing a developmental specialist in the provider's office. A complementary strategy would target systematic upgrading of the quality of the provision of developmental services in pediatric practices through additional training of pediatric providers to use the latest tools and techniques and the introduction and adoption of practice re-engineering strategies designed to improve overall practice performance of developmental services.

Third Level: Mid-Level Developmental Assessment, Treatment and Coordination Center
It is this level of assessment which is currently most lacking in the Orange County system. More than one center will be needed and at least one should have capacity to perform mobile assessments, traveling to parts of the county where transportation issues preclude client attendance at one of the centers. These centers could be co-located with existing Commission programs such as EDAP, For OC Kids, COPE/CUIDAR at School Readiness Sites, or could be located in separate facilities. The sites could also have capacity for the delivery of low-cost interventions such as parent education groups, Mommy and Me classes, language stimulation groups, and parent training classes on redirecting children's behavior and fostering longer attention spans. Some of the most challenging aspects of providing developmental services could be addressed through a dedicated care coordination unit that might include a call center and a web-based resource list associated with these mid-level centers, modeled after the Connecticut Help Me Grow program. The success of the Connecticut model and the importance of overcoming difficulties in linking and coordinating services that make up a functional delivery pathways makes this a high priority strategy.

Fourth Level: Regional Center
Regional Center will continue to determine eligibility for and deliver IDEA Part C Services. While the proposed system changes should result in earlier identification of children needing services, the referrals to regional center should be much more appropriate given the increased system capacity for detection and management of more minor developmental problems, which should prevent flooding of this service

***Strategies:***

In order to be responsive to parents, child care and pediatric providers, and communities, we suggest a set of strategies to create, roll out, and implement the system.

Time and Phasing:
Since it will take at least 5 years to get this new system fully operational, a timing and phasing strategy is important. To facilitate this phase-in process we recommend that the commission develop specific strategic and business plans for each tier of the system and the specific sectors (i.e. pediatric/child health, early education, childcare) involved.

Sector Strategy:
Because of the level of service delivery change and the introduction of important innovations, it will be important for peer-to-peer training, quality improvements, and funding to develop sector-specific strategies. Sectors include pediatric health care, child care and early education centers, and school readiness sites. Since each of these distinct service delivery sectors has a different culture, vocabulary, services, and funding, sector-

specific strategies will be necessary in order to drive the re-engineering that is essential to move each sector forward and to accomplish the goals and objectives of the overall system delivery. Since current financing options tend to be somewhat sector specific (health care uses Medi-Cal and Healthy Families, EPSDT and CHDP while developmental disabilities uses CCS and IDEA funding), it will be necessary to develop finance strategies that are sustainable within each sector.

Innovation Strategy:
Much of the work to enhance developmental services across the country has focused on the introduction of a number of innovations into traditional practice and service sectors. CUIDAR and HABLAR are two notable examples of Orange County based innovations that could have national applications and impacts. This spirit of innovation, evaluation, and spread should be supported and extended, with the Orange County First 5 Commission bringing in other supporters to provide venture capital for these efforts.

Place-based Strategies:
Since different communities in Orange County have different existing capacities and levels of need, we recommend that specific place based strategies be developed for specific communities. Whether the initial sites are cities, smaller communities or neighborhoods, it will be important to fully construct the developmental services pathway in a few localities so that implementation and feasibility issues can be addressed before attempting to implement county wide. This way the First 5 Commission can also help develop community-level and city-level leadership to support all components of the system within their respective realms.

Collaborative Strategies:
Each of these strategies lends itself to the development of collaborative learning and rapid re-engineering strategies. From our standpoint, this ability to initiate collaborations within sectors and across communities has the highest likelihood of successfully re-engineering services into the kinds of systems and pathways that are necessary to achieve the goals of this initiative. It is important that the members of the collaborative articulate a common vision, agree on a set of common goals, and define a series of measurable outcomes which can be tracked to assess the effectiveness of the new approach.

### *Financing*

Funding will need to be made available for the process of system creation and redesign. A large proportion of the services being proposed are potentially fundable under the current federal Medicaid and EPSDT guidelines. The Commission should also consider how it will build in funding for needs assessment, evaluation and capacity building to support this initiative. Strategies might include an endowed research matching fund initially created by the Commission but matched with dollars raised by CHOC and UCI from the Orange County corporate sector. In addition, the Commission could consider how it might leverage its monies within those institutions to initiate endowed professorships that would attract additional world-class faculty, and to enhance research capacity to leverage additional dollars from the National Institutes of Health and other related funding organizations.

***Governance***

Development of the new system will require a governance structure which is both strategic and responsive to the needs of the Commission and the Orange County Community. We would suggest that a steering committee comprised of key stakeholders be established together with a subcommittee structure to address the development of innovative programs; sector-specific strategies including pediatric, child care and school readiness sectors; and place-based system development, infrastructure and financing.

The significant multidisciplinary training and education needs might be best accomplished through development of a training consortium including UCI, CHOC, Cal State Fullerton and other institutions. Both feasibility and sustainability will need to be considered in a more detailed strategic and business plan where both cost and potential revenue can be more fully assessed.

**Phase 1 Implementation Outline:**
Given the necessity for a staged phase-in of the model system, we propose the following next steps to initiate the process during the initial 1-2 years.

1. ***Place-based Strategy*:** All four service levels of the model-community surveillance, secondary screening, assessment and intervention should be established in two communities in Orange County, creating an opportunity for inter-community collaboration on a small scale. This process will involve training of all the relevant providers in those two areas – pediatric healthcare providers, teachers, childcare workers, preschool staff, WIC staff and all who are in regular contact with young children 0-5. Providers will need to come together and explore new ways of working together to ensure an efficient comprehensive approach to developmental services.

2. ***Sector-based Strategy:*** At the same time as the place-based strategy is initiated in two communities, a series of sector-specific strategies will be implemented. For pediatric practices the initial focus will be on the implementation of developmental surveillance activities using a validated tool, the PEDS. A series of pilot sites will be chosen by the Commission and the AAP to pilot this initiative. This process lends itself to a collaborative learning strategy such as use of the Breakthrough series to re-engineer practices and ensure the smooth incorporation of the PEDS as a developmental surveillance tool into office practice. Continuous "Plan, Do, Study, Act" Cycles will be used to inform office practice change and achieve developmental services aims. This process will be evaluated to document levels of developmental surveillance achieved. Following use of "Breakthrough Series" type of activity, it is envisaged that best practices will spread to other pediatric providers in the county so that the momentum of the new initiative is maintained. Other interventions may also be considered within the pediatric office, including more widespread use and greater penetration of Reach Out And Read, or potentially using elements of Healthy Steps to augment the productivity of large group practices or clinics.

3. ***Establishment of Mid-Level Assessment Center*:** A planning process will begin, led by the CHOC-UCI Collaborative, for the development of a mid-level assessment center in the county focused on delivering assessment services to children with developmental and behavioral problems which fall short of eligibility criteria for regional center. The

location of the center should be decided in collaboration with the geographic focus of the place-based strategy. Financing and sustainability of the center will be key issues and a sound fiscal plan using multiple potential funding sources will be created. As the center develops it is envisaged that it will offer low-cost interventions for common childhood developmental issues, while developing its role as a community resource for education on child development.

4. ***Establish a Care Coordination Program: Care*** coordination could be provided through a call-center similar to the center that is operated by Help Me Grow in Connecticut. This call center would provide a resource for community based surveillance sites that are attempting to create better connections with pediatric providers and other service providers. The call center/coordination program would also play an essential role in linking pediatric providers with the mid-level assessment center, and to other resources for children identified as needing other community based services and referrals. Using a range of new technology, the call center/coordination program could also provide web based resources to parents, community child care and school readiness partners, pediatricians, and other early childhood developmental service providers.

5. ***Develop a Short and Long Term Funding Strategy:*** Developing a funding strategy will be essential for the success of the program. All available federal, state and local funding sources will need to be explored to ensure the viability and sustainability of each component of the system and the system as a whole. A range of local, state and federal funding strategies should be considered that could provide funding during different phases of implementation, and to cover costs associated with services, evaluation, and infrastructure development. Where needed services lack a currently identifiable funding source, alternatives in the Orange County community will be sought, e.g. donations from private foundations, individuals and corporations.

**Summary**

Orange County has built a series of promising and innovative programs in the developmental services arena. Impressive degrees of multi-disciplinary collaboration are emerging. While the challenges are formidable, the combination of effective and strong leadership within key sectors; a willingness to collaborate and to look at existing systems in new ways; and the tremendous progress that has been made in recent years within the CHOC-UCI collaborative place the county in an excellent position to move forward with implementation of the new system. The Commission needs to play a leadership role in developing a strong financial underpinning for this endeavor. The Orange County Model proposed in this report has great potential for true innovation in the field of developmental services. Both implementation and evaluation of the new model will be of national and international interest.

# Introduction

## Purpose and Outline

This report summarizes the findings of the UCLA Center for Healthier Children, Families and Communities targeted study on developmental services pathways in Orange County. The study was performed April-July 2004 at the request of the Children and Families Commission. The purpose of the study was to examine the existing system of screening, surveillance, assessment and intervention for children with neurodevelopmental needs in the County. The primary aims of the study were to identify gaps in existing services, barriers to service utilization, and other systems issues that currently hinder optimal service delivery. We begin by discussing the importance of developmental services for children's development and the need for an integrated service system to deliver them. Following the introduction, we report on the methods for the study and then give an overview of the Orange County Commission's achievements to date in the provision of innovative new programs. We discuss the findings in the light of the Commission's stated goals of healthy development and school readiness for all children 0-5 years with an analysis of the challenges and opportunities now facing the Commission. Finally, we present a series of options for the Commission to consider for next steps, followed by our proposal for a model system of developmental services in Orange County.

## The Importance of Developmental Services

Early childhood is increasingly understood as a time of great opportunity for optimizing the health and development of children. Scientific evidence has documented how experiences during early childhood, shaped by families and communities, influence future healthy development and learning. One of the more important advancements in our understanding of human health is that healthy development is a complex interaction between biological and social factors operating across the lifespan. Another conceptual advancement has been our understanding that learning begins at birth, and that all experience, both positive and negative, plays some role in shaping the developing brain thus influencing future physical, cognitive, and emotional development. These conceptual advancements emphasize that the development of children's health and learning are related and that both can be optimized by the provision of appropriate health services, early education, mental health care, and family support services.

The landmark 2000 Institute of Medicine (IOM) report, *Neurons to Neighborhoods (N2N)*, synthesizes a growing body of research from the neurosciences, child development and education, and presents a series of recommendations to assure that all children have the opportunity to realize their potential. To optimize the development of all children, certain inputs are not optional but are required including:

- Structured, dependable, nurturing relationships with parents and other caregivers;
- Families with adequate resources to provide safe, nurturing, healthy, and educationally supportive environments;
- Health care, developmental, and education services that help parents promote the optimal development of their children, and identify and mitigate potential risks and problems at the earliest and most effective possible juncture.

The Individuals with Disabilities and Education Act (IDEA), Part B of PL94–142 and Part C of PL105-17 provides special education services for children ages 3 to 21 years and early intervention services for infants and toddlers to age 3 years, respectively. The legislation mandates the identification of children with learning-related problems, evaluation of their health and developmental status, development of a plan to provide needed services including educational and related services, and guaranteed due process. These services have been the major focus of developmental services for the past 15 years with all identification and intervention efforts targeting children with disabilities.

Recent trends have focused attention on the need to deliver a broader variety of developmentally oriented services to children during the first 5 years of life. For example, there is an increasing focus on the provision of developmental services promoting optimal development through health care, which is supported and encouraged by the American Academy of Pediatrics and the Maternal and Child Health Bureau, and emphasized in health supervision guidelines. There is also a growing body of research supporting the efficacy of these services (Regalado & Halfon, 2001). Mental health for infants, toddlers, and preschool children is expanding with an array of preventive and therapeutic services provided through a variety of models (Zeanah et al, 2004). Evidence also suggests that high quality child care and preschool are important in providing optimal developmental experiences for children. These advancements in health and mental health care expertise and early childhood educational services lay the groundwork for creating coordinated and integrated service systems to optimize children's early development and readiness for school.

**Need for a More Systematic Approach**

As a result of the increasing consensus about the importance of early childhood and the efficacy of a variety of activities that can be delivered in health care and other service sectors, there is growing momentum across communities, states, and nations to seize upon opportunities to utilize new approaches to enhance early childhood outcomes. Beginning in the early 1990's, at the outset of what has been called "the decade of the brain" the U.S. Department of Health and Human Services launched *Healthy and Ready to Learn* in 1992, an ambitious new initiative that linked healthy development and academic achievement. Many initiatives garnered new support; leading to the expansions of Head Start, the launch of Early Head Start, the creation of Healthy Child Care America and many other complementary programs. Enthusiasm has been generated by major international, national, and state level initiatives tied to resources and creative methods that promote health and well-being of young children. In England, Canada, and Australia, for example, major initiatives have been launched to enhance the quality of prevention and intervention services in early childhood.

There is also a growing convergence in beliefs that the means to achieve the optimal development of all children will require multi-sector, multidisciplinary, systems-building initiatives that can address the needs of individual children as well as the context of their families and communities. The MCHB State Early Childhood Comprehensive Systems (SECCS) initiative, for example, is designed to plan for and build a more comprehensive and integrated system among the current uneven, and often ineffective, mix of services for children. Several state and national initiatives have taken up this charge and are

moving this agenda forward. In England, the national Sure Start program has already created 400 of the more than 2000 neighborhood based, multidisciplinary early childhood service systems. Since the responsibility for child and family services that influence early health and development is divided across multiple health, education, and social service sectors and programs, a more coordinated approach is necessary if early childhood services are to be delivered in an effective, efficient, and accessible manner.

In order to help different service providers from different sectors converge around a set of common goals there needs to be some agreement about a shared set of outcomes, and language to capture the results that all sectors and services are trying to achieve. To bring the health sector and education sector together it has been necessary to link the goals of child health care that focus on healthy development with the goals of early learning that focus on school readiness. National Education Goals Panel (NEGP, 2001) redefined and re-framed the concept of "school readiness" to include schools being ready for children, families and community supporting the transition to school, and children being ready to attend school. As part of that definition a child's readiness for school was no longer defined around simply academics- but in terms of their overall physical, emotional, cognitive, language and social development during the first 5 years of life. This reframing of school readiness by the educational sector created a new bridging construct that immediately became inclusive of many of the goals that have preoccupied the health sector and powerfully communicated the importance of optimizing their health and well-being within a family and community context. As multiple sectors that provide services to guarantee and enhance the health, development and school readiness of all children become more unified in vision and purpose, there is an opportunity to improve the delivery of health and other services, and to integrate these services into more responsive and effective systems of early childhood care.

**Challenges and Opportunities**

While there is a concerted effort toward optimizing early childhood services on a wide scale, there are also enormous challenges facing us. Some are relatively straightforward to manage, such as the selection of validated assessment instruments to use in the early identification of children who might benefit from early intervention services or special education. Others require a more systematic and comprehensive approach such as the implementation of those instruments within a comprehensive system of care that is effective, efficient, accessible, capable, and acceptable. There are significant challenges unique to governance at state and national policy levels such as understanding the importance of developmental services in health care, and how they should be promoted and paid for. There are inter-disciplinary challenges that emerge as people move toward integrated coordinated service delivery pathways and multidisciplinary approaches with gaps between health and education sectors at federal, state, or local levels.

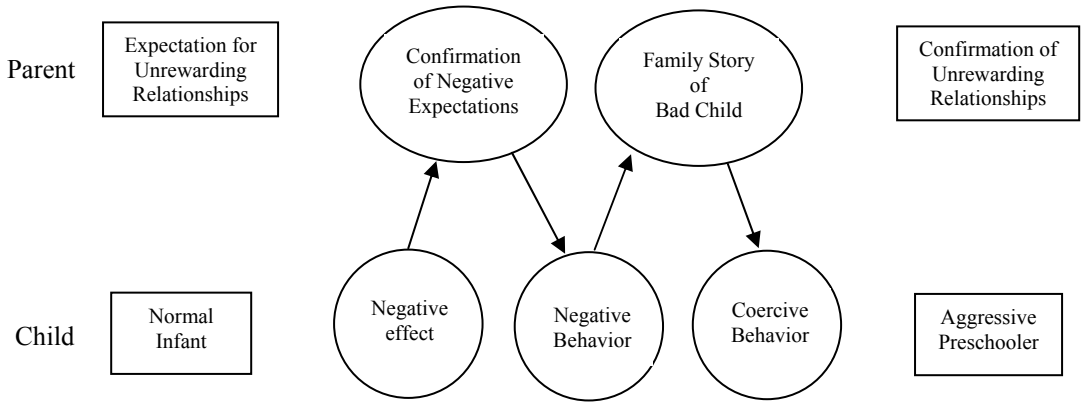
**Conceptual Challenges and Gaps**

Perhaps the most important challenges to confront are conceptual. Conceptual frameworks provide the theoretical and pragmatic basis for all aspects of system development. There are dissimilarities between service sectors in theoretical and conceptual models that contribute to the problems such as lacking a shared vision, communication across disciplines and service sectors, and, therefore, absence of effective collaboration. For example, the major theoretical framework underlying medical

approaches is a neuromaturational framework. Neuromaturational theories portray child development as an unfolding of neurological functions in a predictable pattern and time course. A certain percentage of children are born with developmental disabilities that present as deviations from the expected pattern. The neuromaturational framework has led to a focus in health care on children's deficits and on efforts to document a level of deficits that trigger eligibility and service provision. Deficits are, therefore, defined by science and by available funding. The major limitations of neuromaturational models are that they have not been predictive of developmental outcomes (Sameroff and Mackenzie, 2003) and, because they do not account for the way that development is shaped by the environment, they are not useful in informing early intervention approaches or efforts to optimize all children's development.

On the other hand, systems theorists have emphasized the importance of gene-environment transactions over time with less of an emphasis on the biological determinism characteristic of a neuromaturational perspective. Systems theories utilizing transactional models have received much emphasis in the social sciences, developmental psychology, and have driven much of the progress and innovation in the early intervention field, but have not impacted medical practice to any significant degree. A transactional model (Sameroff and Mackenzie, 2003) proposes that neurological, social, and psychological development is a dynamic process that results from the complex interaction between child and the caregiving environment. The focus in this model is on how child and parent (caregiving environment) adapt to each other as developmental change proceeds. This is consistent with the view that the developing brain is capable of being modified by both beneficial and deleterious experiences that can have lasting effects on the child depending upon the nature of the adaptation made (Figure 2).

**Figure 2: Transactional Model**




This has at least three important implications for early intervention. First, it underscores the major role of the family and social-emotional context in which children are raised meaning that supports for parents, particularly with child rearing responsibilities, are crucial. These supports hold for all children with or without biological or sociodemographic risks. For example, while it is widely accepted that poor nutrition, environmental toxins, drug exposure and chronic stress can harm the child's developing

brain, there is also substantial evidence to suggest that supportive, responsive caregiving can mitigate many of the adverse effects of biological risks. On the other hand, significant parental health and psychosocial problems such as maternal depression, substance abuse and family violence place heavy developmental burdens on young children with or without biological risks (Nelson, 2001; Shonkoff and Phillips, 2000). The importance of a transactional model has become even clearer as we've learned how a child's psychological and neurobehavioral development is closely linked to the quality of their health. For example, parents spend a substantial percentage of their efforts fostering good sleep hygiene during infancy. Since the quality of sleep affects physical growth and the regulation of mood, alertness, and executive functions during wakefulness, helping parents foster adaptive sleep habits can prevent the deleterious effects of sleep disturbances on infants and young children which can be wide ranging to include growth, cognitive, and socioemotional disturbances (Dahl, 1996). Other studies demonstrate that helping parents to establish harmonious relationships with their children is important to their health and psychological development. Extreme cases of child abuse and neglect, of course, can lead to growth failure or physical injury. Far short of this, however, are studies suggesting that parenting style and the quality of attachment are linked to a child's ability to manage stress (Gunnar, 1998) and to the development of asthma (Klinnert et al, 2001). Furthermore, it can be inferred that the quality of the parent-child relationship at least indirectly influences psychobiological responses to stress that affect immune function in children (Boyce et al, 1995). As more is learned about the role of early experience on health development, the potential for the early childhood service providers to reduce these types of risk and adverse exposure by promoting emotionally and cognitively stimulating parenting activities will continue to increase.
Secondly, tied to the neuro-maturational model was a notion that the role of clinical assessment was to identify children who had failed to achieve a specific level of function. While somewhat arbitrary clinical assessments and the surveillance and screening systems that are utilized to triage children into an appropriate clinical assessment are based on defining and determining specific developmental deficits – often defined by psychometric properties of particular instrument and where the second standard deviation on a particular functional variable happened to fall in the normative population. While useful for defining the lower end of the functional scale such an approach does not provide information about those children who are not failing but are not achieving their full developmental potential. Often children who did not fail, or fall below the threshold are said to be "good enough". Unfortunately many if not most parents are not interested in knowing that their child is functioning at a "good enough" level, but approach their parenting responsibilities with the hope of optimizing their child's developmental function. Parenting based on optimizing a child's development is often not well served by screening and assessment that merely provides information about whether a child is failing. The transactional models provide the basis for considering how to shift from a deficit model of child development to consider how parents and communities can enhance the availability of developmental assets in order to serve to optimize how children develop.

Third, the dynamic nature of developmental change in both child and environment underscores the futility of traditional population screening approaches for developmental problems. These approaches have been characterized by tools that are modestly accurate (at present), very inaccurate (e.g., the Denver tests), or that have poor validation. Although newer psychosocial screening tools are available, screening efforts are still

essentially child-focused, neglecting the needs of parents and families whose efforts to support their child's development is crucial. Screening approaches have seldom addressed environmental factors that influence development. Without accounting for the resources and capacities that parents bring to the child rearing equation it is difficult to assess the true nature of developmental risk or the likelihood that a child facing an number of developmental hurdles will prevail  Screening has not historically accounted for developmental change over time.  A single effort to screen is typical.  Although there are models for monitoring development at predictable developmental transitions (Brazelton), this is not the current standard of care (Schor, 2004).

Reconciling these two different perspectives is a critical issue in bridging the service gap between health care and other community services. As we move forward, we must recognize the strengths and weaknesses of the neuromaturational model and broaden the scope and increase the flexibility of services in a manner that captures the transactional nature of development as well. As the foregoing discussion illustrates, the potential impact of developmental services is profound and far-reaching. The proposed Orange County Developmental Services Initiative is poised to take advantage of these new and emerging conceptual breakthroughs, and create a service delivery system that can be maximally responsive to the rapidly evolving clinical science of child development. This will not be without its challenges given the number of individuals and institutions that have grown up and out of an older and probably less useful approach.

## Service System Barriers and Challenges

### *Child Health Providers*

Child health providers are in a unique position to assess, identify and intervene on developmental issues, problems and risks. Pediatricians provide 80% of the primary care to children zero to five, and pediatric practice guidelines as well as federal and most manage care contracts provide for children to receive nine well child visits during the first 5 years of life. Pediatric practice guidelines also suggest that all children have their development evaluated at each of these visits. Several recent studies have suggested that content and the quality of developmental services provided by child health providers is not what it should be. In one recent national survey only 57% of parents reported that their child had **ever** received a developmental assessment in the first three years of life. The same survey demonstrated that children who did not receive developmental assessments were also less like to receive appropriated guidance on developmental issues related to early literacy, discipline, social skills and other topics. In a recent survey conducted by the American Academy of Pediatrics, pediatric providers reported that they face a number of barriers in providing developmental services including constraints on time, reimbursement, inadequate training, as well as having few places to refer children and families if problems were discovered and required additional assessment or treatment.

### *Workforce Training*

The foregoing discussion of conceptual challenges brings into focus the deficiencies of the current workforce. In health care, for example, the conceptual and service models have not changed in almost a century.  The training of physicians places very little emphasis on knowledge and skills in clinical child development. Physicians spend one

month learning child development, which amounts to less than a third of what would be spent in an introductory undergraduate course. The primary care training experience is limited by faculty that typically lack expertise in child development and by service models that do not represent the realities of private practice with respect to managing high patient volumes, developing collaborative relationships with other service providers, use of effective services, or use of appropriate coding and billing practices. Although many primary care developmental services have demonstrated efficacy (Regalado & Halfon, 2001), they are unlikely to be effective when employed with the current system infrastructure.

Likewise, there is limited expertise in typical child development within other disciplines. Educators, social workers, psychiatrists, speech therapists, physical and occupational therapists, family counselors, and nurses receive limited if any child development training and most receive no clinical experience with typically developing children. Training is frequently limited to children with clinical disorders and to a narrowly focused aspect of child development relevant to one's specialty area. There are few multidisciplinary training programs thereby limiting opportunities to practice collaborative care. These service models are also highly influenced by neuromaturational and disease model philosophies, which limit their effectiveness for the vast majority of children without clinical disorders, but who may have risks requiring primarily preventive services. In other words, *prevention and promotion of optimal development are not the focus of most clinical disciplines that treat children*. Therefore, the current system of care almost completely lacks a preventive workforce. Furthermore, *there is an inherent danger in pathologizing normal development and behavior by simply transposing a disease-oriented workforce into preventive service*, especially in the current climate where there are unrealistic expectations about the newer screening tests.

### *Service fragmentation*

Much emphasis has been placed upon the challenges of navigating the dysfunctional and highly fragmented service system that exists to implement IDEA. Pediatricians have emphasized this careened for care coordination as part of the medical home concept (AAP Medical Home Statement). Certain conditions may make it difficult for different service providers and agencies to collaborate around the care of children in the current system. Diagnostic and treatment services are given by different providers, and even by different systems, which may be administered and funded separately through schools and public health, mental health, and social service systems. In spite of such barriers, communities throughout the country have made connections between providers and community resources by developing case management and coordination systems, described below.

## Financial Barriers and Challenges

There are coverage, reimbursement, and billing issues that also form barriers to developmental care. These include the lack of adequate reimbursement under existing managed care and capitation contracts for developmental health services and the assumption by most payers that developmental health services are simply part of preventive well-child care. Resolving this issue requires reviewing managed care contracts and making appropriate adjustments (George Washington University Medical Center, 2000). A provider's lack of familiarity with appropriate billing codes may also

constitute a barrier (Rushton et al., 2002). Several states, however, have implemented more appropriate reimbursement mechanisms and many individual practices and groups have educated providers about billing codes to optimize reimbursement. A systematic approach for instituting payment is necessary to ensure widespread and long-term solutions to billing problems.

## Data System Barriers and Challenges

### *Accountability Data*

Developmental services are often undervalued by accountability systems. Accountability systems that use quality measurement tools, such as the Consumer Assessment of Health Plans Survey (CAHPS) and the Health Plan Employer Data and Information Set (HEDIS) measurement system, do not measure the content and quality of developmental services or whether a developmental assessment was even given. Incorporating measures of developmental services into existing instrument sets could redress this problem.

## Orange County Challenges and Opportunities

The existence of Proposition 10 Funding has placed California in an exciting position regarding early childhood services. Designed to address the prior lack of public funding and support for early child development, this new funding stream provides flexible-use dollars to enhance healthy development and school readiness for all children. This has led to opportunities for funding innovative approaches to achieve these important goals. With this opportunity, however, has come challenge. The multiple and obvious gaps in current early childhood systems have led to demands that these monies be used promptly to fund additional services. There are problems with this approach in that added services alone will not solve the performance problems of the entire system – this will require alternative strategies at a level beyond service delivery. In addition, the longevity of Proposition 10 as a funding stream is uncertain, making services funded entirely or predominantly from this source particularly vulnerable.

The Orange County Commission has shown great foresight in its decision to analyze its existing system of developmental services, and, rather than continue to fund additional client-based services in a piecemeal fashion, to consider utilizing a portion of its funding to address long-standing system issues which must be tackled if the Commission's goals are to be met. The timing for this initiative is optimal, as both health and education sectors are re-considering their approaches to early developmental monitoring, and are beginning efforts to develop a common language around child development and to make their services more family-centered and relevant to child function. Pediatric healthcare services are transitioning from a system of intermittent developmental screening to one of continuous developmental surveillance and there is a national call for a re-engineering of primary care services to better address children's developmental needs.

The programs already funded by the Commission such as Bridges for Newborns, Project Connections COPE/CUIDAR, For OC Kids, HABLA, School Readiness Centers, Preschool Nurses and others have led to innovations in the child development field and laid the groundwork for a comprehensive new approach. In addition, the implementation of these programs has already led to cross-discipline communication and collaboration on a small scale which will need to be repeated over the whole county. As these new

programs have arisen to fill needed gaps in services, consequently the organizational structure in which the programs operate must itself grow and mature. There will be pressure to begin changes immediately and to expect results early. Neither of these goals is realistic given the extensive and multi-sector nature of the changes envisaged. Changes to the system will need to be preceded by development of detailed strategic and business plans, with a staged implementation over a multi-year timeline. Strong leadership will be needed to navigate a new approach.

Evaluation of any new approach is vital, not only to inform adjustments to the model, but also to disseminate results to the national and international research communities. Although change is challenging, the potential benefits to the community are substantial. If every child with a neurodevelopmental problem is identified early, if effective interventions are implemented promptly and if every child, to the best of his or her potential, enters school healthy and ready to learn, then tremendous benefits to society will ensue. Cost savings could be expected not only in the health sector but also in spending on special education, and in the juvenile justice system. The Commission now stands in an optimal position to begin leveraging its funding as it embarks on a new system which will be of national and international significance.

# Methods

## Study Approach

We set out to obtain a comprehensive picture of the need for and the structure, process and current outcomes of developmental services in Orange County. First, we wanted to understand the population of children that the system is trying to serve, so we undertook an analysis of the demographics of the 0-5 population with regard to population size and growth trends, race, ethnicity, family and socio-economic factors.

Second, we wanted to determine the needs of that population for developmental services to support healthy development, early learning and school readiness. We recognized that data in this area are very incomplete and that much further work is required. We tried to determine what data did exist for the county, and where local data were lacking to utilize population data from California and the US which can be extrapolated to Orange County, albeit with certain assumptions. A literature review was undertaken to determine the best available estimates of neurodevelopmental needs in the early childhood population. As yet, there are no standardized school readiness assessments universally accepted as predictive of later outcomes. Most available data relates to service use e.g. enrollment in Early Start, Regional Center, school district special education services, and foster care. Such service-based data is likely to represent an under-estimate of the true degree of population need.

Third, we examined currently available services and how well they are performing for children and families. We looked at whether services were effective, accessible, capable, continuous and acceptable to the population. We determined what kinds of innovative services and promising practices exist in the County that could be built upon or extrapolated. We looked for gaps in service provision and tried to determine the reasons for the gaps and potential strategies to fill those gaps.

County resource mapping continued with an analysis of providers in the county across disciplines related to developmental services, to determine whether the county has the capacity to provide sufficient services given the likely degree of need in the population.

Fourth, we undertook an extensive series of interviews with key informants and focus groups with parents and providers across the county to gain an appreciation for their perceptions of the current system and their visions for an ideal model.

Throughout the study process, we examined the existing system of developmental services within the county in light of existing theoretical models. The healthcare system and healthcare providers are only one of a number of service systems that need to be actively engaged if the desired outcomes of healthy developmental and school readiness for all children are to be achieved. The Readiness to Learn Trajectory (**Figure 3**) captures some of the service sectors and programs which influence school readiness. The Wagner Care Model for Child Health (**Figure 4**) indicates how the healthcare system nests within a broader spectrum of community resources and policies which impact functional and clinical outcomes. Discussion of an ideal developmental services system cannot be confined to the healthcare sector but must include the educational and social

and family services sectors and others if it is to be truly comprehensive and effective. Similarly the pathway to school readiness involves not only health and educational services but also strong family supports (**Figure 6**).

**Figure 3: Readiness to Learn Trajectory**

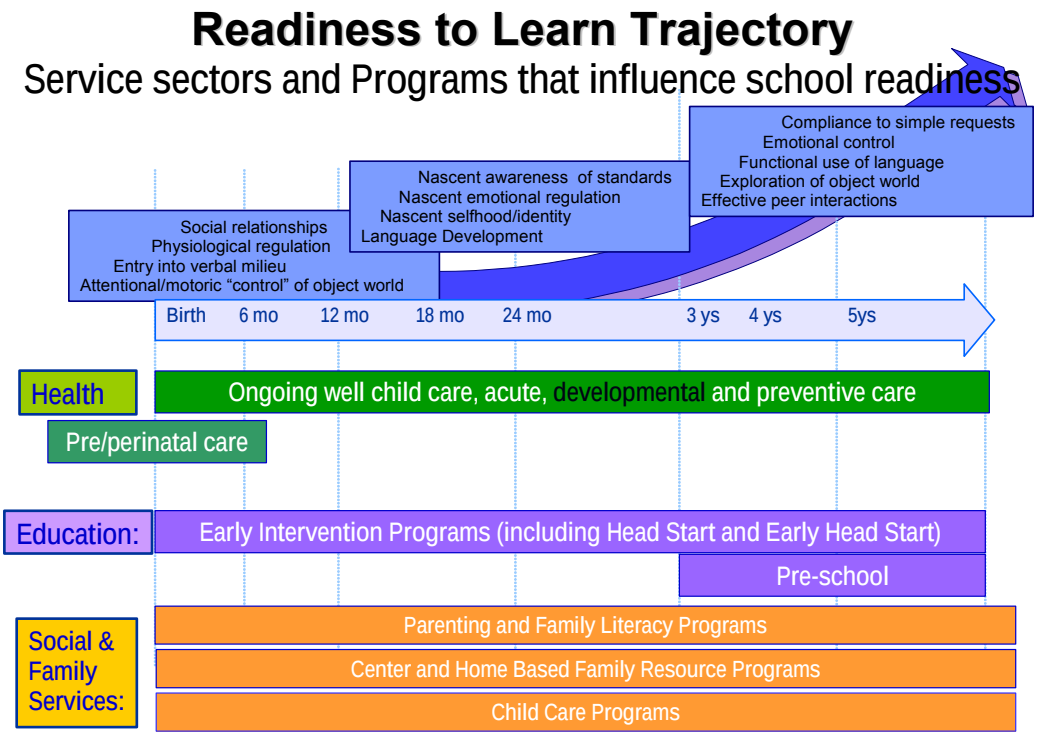


**Figure 4: Care Model for Child Health (Wagner)**

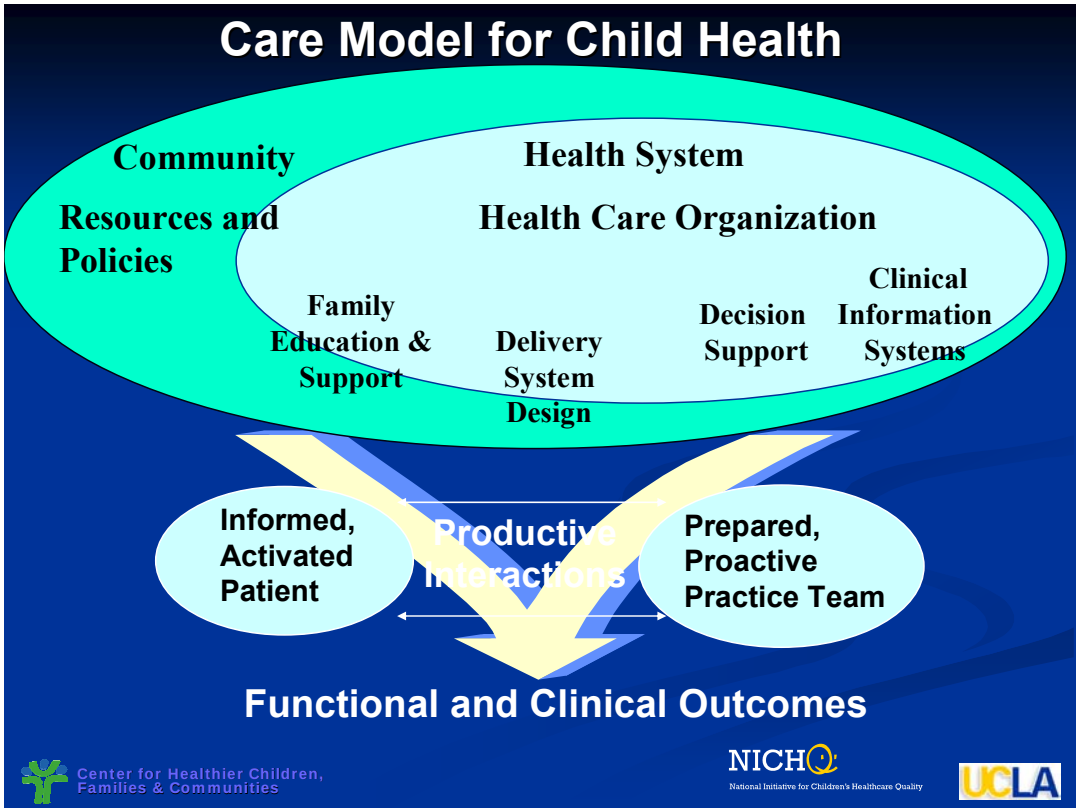
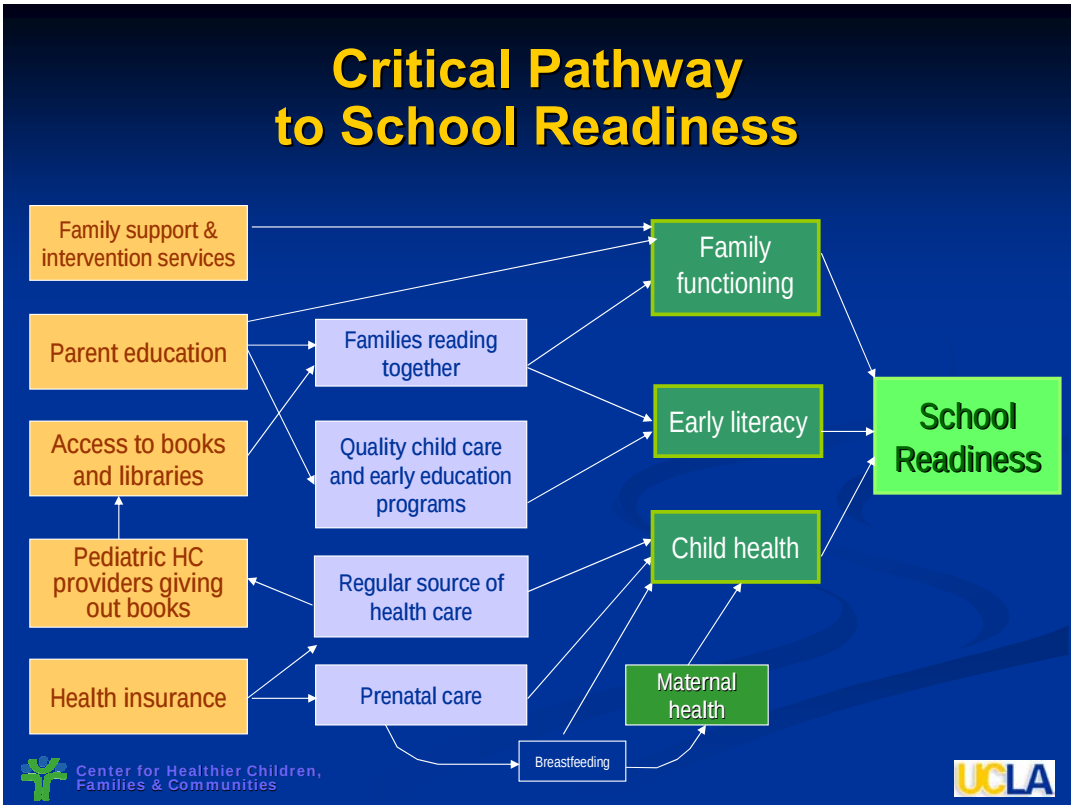



**Figure 5: Critical Pathway to School Readiness**



Similarly, throughout the study process we considered the funding streams and financial underpinnings of the existing system, and of any future system. A review was also undertaken of national and international best practice models,

The study process commenced April 2004 and a UCLA IRB exemption was obtained. Our specific methods comprised:

**Demographics of the Orange County 0-5 Population**

US census data, the Orange County Health Needs Assessment (OCHNA) Survey, the Early Childhood and Educational Needs Assessment (ECENA) Survey, the 9th Annual Report on the Conditions of Children in Orange County 2003, and other publicly available data sources were utilized. The population was analyzed for birth rate, race, ethnicity, language, parental education, family size, family structure and median household income, health insurance status, prevalence of neurodevelopmental problems, developmental disability, eligibility for regional center services, and % children ultimately requiring special education.

**Health and Developmental Services Needs**

Infant mortality and morbidity rates were obtained from OCHNA data. The health insurance status of the 0-5 population was determined predominantly from data from the California Health Interview Survey (CHIS). Both ECENA and CHIS data were used to determine existing school readiness indicators for the county, and attitudes to school readiness. In the absence of county-specific data a literature review was undertaken to determine the likely proportion of the early childhood population with developmental and/or behavioral issues. County data from ECENA and the California Department of Education were used to determine service utilization for Early Start, Regional Center, and Special Education.

**Existing Developmental Services**

***Structure:***

Existing key public programs impacting developmental services were documented and, where possible, utilization of those programs by the county 0-5 population was quantified.

Innovative programs funded by the Commission were site visited by members of the team and the programs evaluated for capacity, accessibility, funding source, sustainability and any evaluation data.

Promising practices nationally and internationally were identified both from the literature and from knowledge of the study team and were examined for existing evidence-base and effectiveness.

### *Personnel*

Data from the Pappelbaum and Turner report and the AAP Pilot report (Mathias) were examined to determine provider capacity to deliver developmental services to the population. Numbers of pediatricians, family practitioners, school and public health nurses, and specialist providers such as developmental-behavioral pediatricians, child neurologists, child psychiatrists, were determined, as were numbers of audiologists, child psychology and psychiatry services, speech therapists, occupational and physiotherapists. Comparison of these data with population demographics allowed estimates of provider: client ratios.

### *Process*

Existing county processes for developmental screening and surveillance, anticipatory guidance about child development, community based interventions for prevention or treatment of developmental problems, assessment of children with neurodevelopmental problems, and longer-term therapy options were evaluated using a combination of county data and informant opinion. Where county data were lacking, data were extrapolated from nationally reported surveys such as the National Survey on Early Childhood Health (NSECH).

### *Outcomes*

A literature search was undertaken for any existing outcomes data on Orange County Developmental Services programs. Program staff were also asked for any unpublished process and outcomes data. Data from OCERS and reports from POMS were examined.

## Key Informant Interviews

The personal opinions and perspectives of key providers and representative consumers formed an important part of system evaluation. Over 40 **key informants** were identified in collaboration with the Commission drawn from agencies and organizations serving children with neurodevelopmental problems e.g. CHOC, UC Irvine, Regional Centers, School Readiness Centers, Commission-funded programs. A wide range of disciplines were included -parents, early intervention providers, physicians, program directors, county health department staff, educators and health plan administrators. Each potential interviewee was contacted by email or letter and invited to take part in the targeted study. Interviews were held at a place and time convenient for the interviewee. The interviews were enthusiastically received, with 100% of those being asked to participate agreeing to take part. The average length of interview was two hours.

A **semi-structured protocol** asked detailed questions on methods and tools for developmental screening and surveillance, and the routes whereby children who screen positive or who are identified as at-risk are referred for further assessments. The types of interventions available, eligibility criteria and barriers to obtaining interventions were explored. Open-ended questions were used, and frank comments encouraged. Over half of the interviews were conducted face-to-face with the remainder being completed by telephone.

Providers were asked how **hypothetical cases** such as a six-month-old with feeding and sleeping problems with a depressed mother, and a 10-month-old baby with motor delay who recently arrived in the country would access developmental services.

All interviewees were encouraged to think at a systems level, beyond the functioning of their own clinic or program, and to envision an "ideal" or "model" developmental services system. To facilitate this process, a **model building exercise** was used where interviewees were asked to arrange key services and programs such as "pediatric provider's office," "regional center," "hospital," childcare center," "school readiness center" into a cohesive system with arrows depicting flow of clients through services. This exercise was very well received and yielded many valuable insights into how developmental services are conceptualized by different groups within the system.

**Focus groups**

A separate semi-structured **focus group protocol** was developed which was relatively undirected to allow new perspectives on the issues to emerge. For parent focus group recruitment fliers were placed in facilities serving children with neurodevelopmental problems inviting parents to participate in a group discussion to voice their thoughts on services related to child development. The flier was posted in both English and Spanish and translation services were offered for the group to allow non-English speakers to attend. In practice one parent focus group utilized a translator and one was conducted entirely in Spanish with a bilingual bicultural interviewer.

Parents responding to the flier were given a number to call outside of the service facility to arrange their attendance. This method was chosen to minimize the possibility that only selected parents might be invited to the focus groups, and to ensure that Spanish-speaking parents would be able to attend. Two focus groups with parents (10-12 parents per group, approximately **22 parents** in total), and **one** focus group with nurses (**10 nurses**) were held.

**Funding streams** were analyzed using data from Cal Optima, CHDP, EPSDT-mental Health, CCS, private insurers, IDEA-Part C and local school districts. Potential partners in quality improvement initiatives were identified through the study process.

# Results

In this section we describe the characteristics of the Orange County 0-5 population, highlighting changes in demographics over the past decade that have implications for the delivery of developmental services within the county. Second, we present our findings of population need for developmental services, and describe a hierarchical pyramid of neurodevelopmental needs –basic, low, moderate and high for children 0-5. Third, we describe existing developmental services within the county, highlighting new programs funded by the commission. We then present key themes emerging from informant interviews and focus groups which reflect the important feelings, thoughts and perceptions of those involved with delivery and consumption of developmental services. Lastly, we describe important gaps identified in the existing service delivery system.

**Demographics of the Orange County 0-5 Population**

Orange County is the fifth most populous county in the nation and, in California, is second only to Los Angeles County in population size. There are 265,249 children (2002) in the 0-5 age group, with just over 45,000 births per year, and these children are largely concentrated in small neighborhoods rather than evenly spread throughout zip-codes.

Orange County has undergone very rapid population growth, with a 20% increase over the last decade. Much of this growth results from young adults moving into the area and having families. Consequently, public school enrollment in the county has risen by 31% in the last decade. Almost half of the children in the 0-5 age group are Hispanic/Latino (see Table 1) in households where Spanish is the first language, Currently, 31.1% children in Orange County public schools are English language learners.

**Table 1: Population of Orange County aged 0-4 years (OCHNA 2001 Survey)**

| Number of children | %of 0-4 population | Ethnicity |
|---|---|---|
| 78,777 | 36.4% | White Non-Hispanic |
| 2,929 | 1.4% | Black Non-Hispanic |
| 101,006 | 46.6% | Hispanic/Latino |
| 467 | 0.2% | American Indian |
| 23,863 | 11% | Asian/Pacific Islander |
| 8,972 | 4% | Other Race/Ethnicity |
| 216,614 | 100% | All race/Ethnicity |

The black population in Orange County is relatively small, while Asians/Pacific Islanders represent the third largest ethnic group. Comparison of tables 1 and 2 reveals that the Hispanic population of Orange County is growing.

**Table 2: Population Characteristics in Orange County and California**

| Characteristic | Orange County | California |
|---|---|---|
| Total population | 2,938,507 | 35,116,033 |
| Population under 5 years old | 216,014 (7.6%) | 2,563,470 (7.3%) |
| Persons with a disability aged 5+ | 434,000 | 5,923,361 |
| Race: White | 64.8% | 59.5% |
| Black | 1.7% | 6.7% |
| American Indian | 0.7% | 1.0% |
| Asian | 13.6% | 10.9% |
| Native Hawaiian/PI | 0.3% | 0.3% |
| Other | 14.8% | 16.8% |
| Ethnicity: Hispanic/Latino | 30.8% | 32.4% |
| White (non Latino) | 51.3% | 46.7% |
| Foreign Born | 29.9% | 26.2% |
| Language other than English spoken at home | 41.4% | 39.5% |
| High school graduates | 79.5% | 76.8% |
| Bachelor's Degrees or higher | 30.8% | 26.6% |
| Persons per household | 3.00 | 2.87 |
| Average family size | 3.48 | 3.43 |
| Median Household income | $58,820 | $47,493 |
| Per capita income | $25,826 | $22,711 |
| Persons below poverty | 10.3% | 14.2% |
| Families with children under 5 years below FPL | 20,686 (12.7%) | 366,539 (19.0%) |
| Families with single female head of household and children under 5 years, below FPL | 5,664 (30.7%) | 147,900 (44%) |

From US Census data (http://quickfacts.census.gov/qfd/states/06/06059.html)

## Health and Developmental Services Needs

### *Infant Mortality and Morbidity*

Infant Mortality Rates for Orange County are comparable with those for California (5.3/1000) and the U.S. (6.9/1000). Although the Non-Hispanic Black population in the county is small it shares the same high infant mortality rates as are reported California-wide and nationally for this ethnic group (11.2 per thousand for black infants vs. 4.3 per thousand for white and 4.7 per thousand for Hispanic).

In Orange County 89.3% births receive early prenatal care. Children born with low birth weight (<2500g) comprise 5.9% all births (c.f. 6.3% for California and 7.7% nationally). Overall, 1% newborns have very low birth weight (<1500g).

### *Health Insurance Status*

Data from the California Health Interview Survey (CHIS) show that approximately 5.7% (15,000) of Orange County Children aged 0-5 years lack health coverage. That number rises to 10.2% if we include children who had some coverage gap in the last year. Medi-

Cal insures 22.6% children in this age group, while 12% class a community health center as their usual source of care.

Based on CHIS Survey data it is estimated that 85% of Medi-Cal eligible children and 70% Healthy Families eligible children are currently covered through those programs in Orange County. Of the 15,000 or so children aged 0-5 years estimated to lack coverage, 8,000 (53.8%) are probably eligible for Medi-Cal, while 2,000 (13.7%) are eligible for Healthy Families yet remain unenrolled. This leaves approximately 5,000 children who are not eligible for either program and who lack health insurance coverage. Two other health insurance products are available for low-income families not eligible for Medi-Cal or Healthy Families – California Kids and Kaiser Cares for Kids. In addition, CHDP Gateway now allows for a period of presumed Medi-Cal eligibility for a 60-day period following attendance for a CHDP examination for children who are uninsured.

If enrollment were maximized for all children to these four programs then the number of children ages 0-5 within the county remaining uninsured would be very small (probably less than 2,000) and could potentially be covered by a specially designated county fund.

**School Readiness Indicators**

The ECENA (Early Care and Education Needs Assessment for Orange County) (March 2004) examined school readiness indicators and attitudes. The ECENA K-3 teacher survey found that teachers held maturational views regarding school readiness and strongly endorsed more restrictive entrance ages and delayed entry (beyond age eligibility) for less capable children, despite lack of evidence for this approach.

The majority of parents and teachers agreed that good verbal communication skills and ability to interact positively with other were important skills for kindergarten success. Teachers placed less emphasis on academic skills than parents e.g. 83.4% parents but only 55.8% teachers felt that knowing letters of the alphabet was important. Most school districts do not have publicly available data on grade retention rates, but assert that retention rates are very low, retaining either none or <5% children.

School readiness indicators (CHIS) for Orange County are shown in Table 3. A large proportion of children (78%) exceed AAP recommendations in number of hours of TV watched daily, with only 45% being read to daily.

**Table 3: Orange County School Readiness Indicators (CHIS 2001)**

| School Readiness Indicator | Orange County % (95%CI) | California % | National % |
|---|---|---|---|
| Health Excellent or Very Good | 74.8 (68.4-81.2) | 75.1 | 85.0 |
| 2+ Hours of TV Daily | 78.7 (69.1-88.3) | 66 | |
| >2 Hours of Media Daily | 79.3 (69.7-88.8) | | |
| Daily Reading | 45.1 (37.8-52.4) | 46.6 | 58 |
| Social Events at least twice a month | 85.5 (80.2-90.9) | 82.4 | |
| In Child Care | 30.2 (23.9-36.3) | 36.1 | 28 |
| In Preschool (Ages 3-5) | 16.9 (10.0-23.9) | 22.4 | |
| Below 100% FPL | 18.9 (11.8-26.0) | 23.4 | 19 |
| Limited English Proficiency | 29.9 (16.1-43.7) | 33 | |

Parent concerns about their children at school entry appear common. National data (Zill and West, 2000) reveal that according to parents, nearly 1 in 5 children entering kindergarten (18%) is more active than his or her peers, 13% have difficulty paying attention for long periods and 11% have difficulty articulating words or communicating with others. These children are likely to be more vulnerable to poor grades and lesser academic attainment.

**Prevalence of Neurodevelopmental Problems**

In practice no robust data currently exist on the true prevalence of neurodevelopmental problems in children in Orange County in the 0-5 age group. The definition of "neurodevelopmental problems" remains imprecise and open to interpretation. According to recent estimates, 12-15% American children have developmental or behavioral disorders (Boyle, Decoufle and Yeargin-Allsop, 1994). A larger group of parents with young children - 30 to 40%- worry that their child has a learning, behavioral or developmental problem (Halfon et al, 2002a).

An approximate estimate of the number of children with neurodevelopmental problems in the county can be inferred from those receiving additional services (see Table 4), although this is likely to be a significant under-estimate. While 9.8% children in the K-12 public school system are receiving special education, only 1.7% are enrolled in Early Start and Special Education prior to the age of five years. Late identification of problems represents a lost opportunity for early intervention which might even obviate the need for later services. Numbers served by RCOC are increasing, however, rising by about 10% a year and RCOC now serves about three times as many children as a decade ago (9th Annual Report Conditions of Children in Orange County 2003). More detailed data from Regional Center on diagnostic categories of children enrolled, and ages at enrollment would shed significant light on the performance of the current system in terms of very

early diagnosis of specific conditions such as autism and speech and language delay, and this data is being requested.

**Table 4: Children served by Early Start, Regional Center and Special Education in Orange County**

| | Children as % of Total 0-5 | Other Counties' Totals | Statewide Percentages |
|---|---|---|---|
| Parents in ECENA 2001 survey indicating child has special needs | 3.2% (equivalent to 8,320 children) | | |
| Children Birth-3 Early Start (DDS) program caseload | 0.7% (1695) | San Diego 0.6% Alameda 0.6% Sacramento 0.8% | 0.7% |
| Children Birth-3 Regional Center caseload (2001) | 1.9% (2367) | | |
| Children in School Districts' Special (0-5) Education caseloads | 1.1% (2559) | San Diego 1.6% Alameda 1.2% Sacramento 1.4% | 1.4% |
| Total 0-5 enrollment in Early Start and Special Education | 1.7% (4254) | San Diego 2.2% Alameda 1.9% Sacramento 2,3% | 2.1% |
| Students in K-12 system in special education | 9.8% | | 10.1% |

**Special Education**

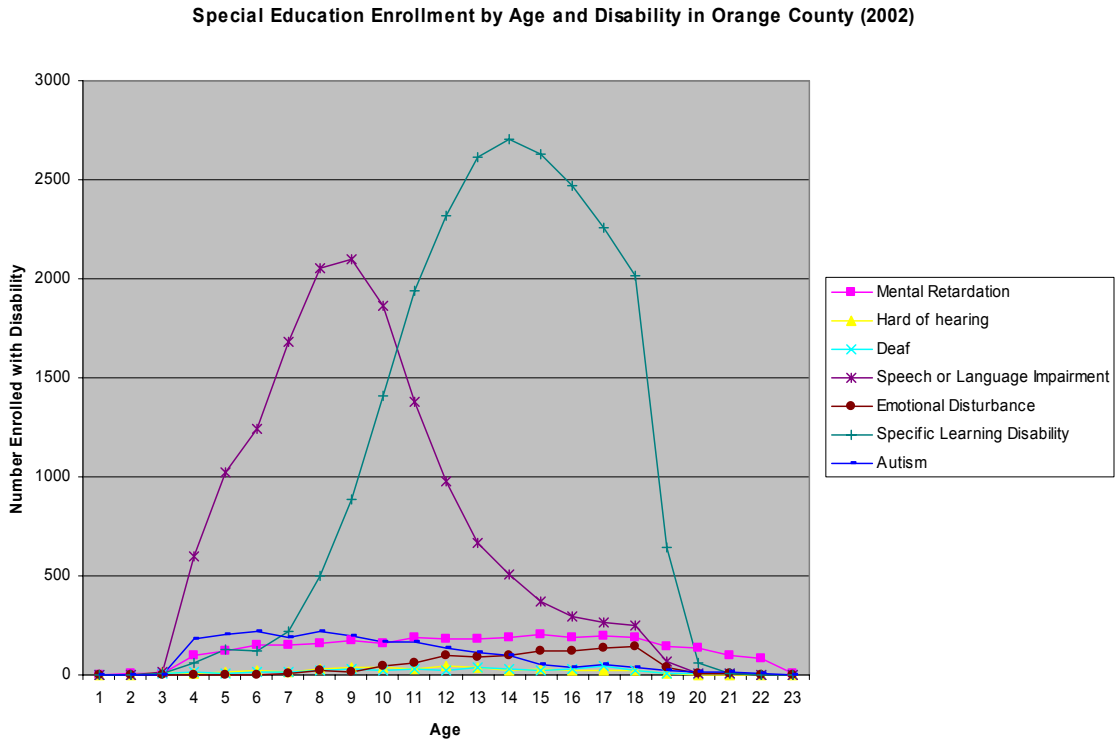
Even after children enter the school system, detection of developmental problems is delayed. Special Education teachers report that a greater number of children are referred to special education in 2nd and 3rd grade (65%) than in kindergarten and first grade (35%). Data from the California Department of Education for Orange County show that the peak of identification of case of speech and language impairment is actually around age 7-8 years (Table 5 and Fig 7), with diagnoses of emotional disturbance and specific learning disabilities not peaking until the early teenage years. Evidence suggests that many of these problems could be detected years earlier, in some cases in the preschool years.

The data presented in Table 5 represent only data from the Department of Education and do not include Regional Center data, hence the data for number of children ages 0-3 in the various diagnostic categories are not inclusive of all children across the county. Data for ages 5 and up should, however, be complete for children in the public school systems. The 10.1% children in Special Education in California compares with 10.25% nationally (Office of Special Education 2004 accessed at www.futureofchildren.org)

**Table 5: Special Education Enrollment by Age and Disability in Orange County (2002)**

| Age | Mental Retardation | Hard of hearing | Deaf | Speech or Language Impairment | Emotional Disturbance | Specific Learning Disability | Autism |
|---|---|---|---|---|---|---|---|
| 0 | 0 | 2 | 0 | 1 | 0 | 0 | 0 |
| 1 | 7 | 2 | 3 | 2 | 0 | 3 | 0 |
| 2 | 11 | 16 | 7 | 14 | 0 | 9 | 2 |
| 3 | 100 | 9 | 13 | 598 | 2 | 61 | 180 |
| 4 | 121 | 15 | 9 | 1,023 | 2 | 128 | 201 |
| 5 | 148 | 21 | 14 | 1,246 | 1 | 123 | 219 |
| 6 | 152 | 16 | 17 | 1,683 | 9 | 217 | 187 |
| 7 | 159 | 33 | 23 | 2,050 | 19 | 499 | 216 |
| 8 | 171 | 39 | 33 | 2,100 | 15 | 884 | 198 |
| 9 | 158 | 39 | 26 | 1,861 | 47 | 1,411 | 167 |
| 10 | 191 | 27 | 27 | 1,378 | 57 | 1,939 | 169 |
| 11 | 181 | 43 | 21 | 975 | 96 | 2,317 | 136 |
| 12 | 184 | 39 | 36 | 666 | 93 | 2,612 | 111 |
| 13 | 190 | 21 | 29 | 505 | 97 | 2,708 | 97 |
| 14 | 205 | 28 | 23 | 374 | 123 | 2,631 | 52 |
| 15 | 186 | 23 | 34 | 296 | 125 | 2,471 | 37 |
| 16 | 197 | 22 | 48 | 268 | 135 | 2,257 | 52 |
| 17 | 187 | 25 | 24 | 247 | 142 | 2,012 | 35 |
| 18 | 143 | 6 | 9 | 71 | 38 | 647 | 26 |
| 19 | 139 | 1 | 9 | 10 | 6 | 58 | 14 |
| 20 | 99 | 1 | 6 | 5 | 6 | 8 | 13 |
| 21 | 81 | 2 | 2 | 2 | 0 | 3 | 7 |
| 22 | 10 | 1 | 1 | 1 | 0 | 1 | 2 |

**Figure 6: Special Education Enrollment by Age and Disability in Orange County (2002)**




## Children in Foster Care

Children in foster care represent a special group at high risk of developmental, behavioral and emotional problems. In Orange County in 2003, 3,215 children were placed in foster care, representing 0.36% of the 0-18 population, while 476 children (0.05%) were placed in adoptive homes in 2001-2002. In Orange County in 2001-2002 there were 25,607 child abuse claims filed, representing 2.93% of the childhood population. The Orange County Department of Child and Family Services supervises 1065 children ages 0-5 in foster care. National data suggest that all of these children will have special mental health and developmental needs. The prevention of this morbidity is a very important goal as children who are unable to remain with their biological families are at increased risk for school failure and poor developmental outcomes.

Data for 2003-2004 reveal that 8,149 referrals were made on children ages 0-5 years in Orange County to the Department of Children and Family Services, representing non-duplicated referrals on 3.3% of the 0-5 population. Of these, 3,798 (1.5% of 0-5s) were substantiated and 2,001 (0.8% of 0-5s) were inconclusive (see Table 6).

**Table 6: Orange County Children with One or More Referrals (April 1, 2003-March 31, 2004)**

| Type of Report | Number of Children ages 0-5 | % of Children ages 0-5 |
|---|---|---|
| Substantiated | 3,798 | 1.5% |
| Inconclusive | 2,001 | 0.8% |
| Unfounded | 1,401 | 0.6% |
| Assessment Only | 949 | 0.4% |
| Total | 8,149 | 3.3% |

## Existing Developmental Services in Orange County

### *Key Public Programs*

Despite the recent trends towards integrated service delivery, the current system of public programs reflects the historically fragmented nature of the system's development. The system would not be designed this way if it were developed today. Key public programs are described in Table 7.

**Table 7: Descriptions of Key Public Programs for Children with Neurodevelopmental Problems**

***Child Health Disability Prevention (CHDP)***

The Child Health Disability and Prevention (CHDP) program is a preventive, well-child screening program for infants, children and teens who have low to moderate income. Children in Medi-Cal (birth through age 20) are eligible for CHDP under the regulations of the federal Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. State and county CHDP funds cover children (birth through age 18) who are ineligible for Medi-Cal or Healthy Families up to 200% FPL. Children in Head Start and State Preschool programs are eligible for regular assessment.

Through CHDP, children can obtain regular, preventive health assessments to identify health problems. Those children with suspected problems are referred for necessary diagnosis and treatment. Private physicians, county health departments, clinics, and some local school districts provide CHDP health assessments.

In 2003, the CHDP gateway was established to facilitate enrollment of eligible children into existing public insurance programs. Provider offices and clinics will help to enroll children in temporary Medi-Cal or Healthy Families coverage for up to 60 days while awaiting complete eligibility determination for these programs.

***California Children's Services (CCS)***

California Children's Services (CCS) authorizes and pays for specialty health care services for eligible children with serious and/or chronic medical conditions such as birth defects, HIV/AIDS, cerebral palsy, blood disorders, heart disease, cancer, and endocrine and metabolic disorders. Services provided include diagnostic evaluation and treatment services. Therapy services are provided through Medical Therapy Units located in public schools for a narrower population of children with neuromuscular and orthopedic problems.

CCS providers must be approved by the State. Some hospitals have Special Care Centers to provide comprehensive care for children with certain diagnoses.

The program is open to children under 21 years of age who have a CCS-eligible medical condition and are residents of the county in which they apply for CCS services. Children must also meet financial eligibility including those served by the Medi-Cal or Healthy Families programs, or with an annual income of less than $40,000 or who are projected to spend more than 20% of annual family income on treatment of the CCS-eligible condition. Those children who receive therapy services at Medical Therapy Units are not required to meet financial eligibility requirements since all income levels are eligible.

The ***High Risk Infant Follow-up (HRIF)*** program provides outpatient clinic services and developmental monitoring for high risk infants (ages 0-2) who meet certain medical and financial criteria. The Medically Vulnerable Infant Program (MVIP), which has largely superseded the HRIF program, serves infants from birth to three years of age who

have graduated from CCS approved neonatal intensive care units (NICUs). MVIP provides a multitude of family-centered services including home visits, health care coordination, comprehensive assessments, monitoring and interventions, referrals, and counseling for parents and caregivers of medically vulnerable infants. Nearly 2,000 infants and their families are served each year through this program.

***Medi-Cal/Healthy Families***

Medi-Cal, California's Medicaid program, provides health insurance for low-income families and individuals without health insurance. The main eligibility categories include public assistance (e.g. Cal WORKS/SSI recipients), medically needy/medically indigent, and federal poverty level programs. Jointly funded by the state and federal governments, it serves 59,000 children 0-5 in Orange County (CHIS, 2001). The Cal Optima program is Orange County's main provider of Medi-Cal managed care.

Healthy Families (California's State Children's Health Insurance Program) is funded by the state and federal governments to provide health benefits for children of low-income families who do not qualify for Medi-Cal and do not have access to private insurance. It provides a commercial benefits package, modeled after state employee benefits, and requires co-payments and premium contributions.

Healthy Families covers 16,000 children 0 to 5 in Orange County (CHIS, 2001). The Healthy Families program is administered through private managed care health plans which contract with the state to provide heath services to children. There is a $5 co-payment for most non-preventive services, including emergency room visits, and a $250 annual co-payment maximum. No co-payment is required for routine, preventive care visits.

***Regional Center***

The regional center system in California is an entitlement program designed to serve individuals with developmental disabilities of all ages (regardless of income) and to assist their families in their care. Regional Centers are "payers of last resort" so they will not pay for services that can be funded through generic sources (e.g., Medi-Cal, CCS, the school district, or private insurance).

There are 21 regional centers in the state. The regional center serving Orange County is the Regional Center of Orange County. The Regional Center has four offices in Orange County, in Santa Ana, Westminster, Orange and San Juan Capistrano. Although they receive state funding, Regional Centers are not state agencies but rather private, non-profit organizations with local control under contract to the State Department of Developmental Services. Each center has its own local Board of Trustees.

Children age 3 years and above are eligible for Regional Center services if they have the following: cerebral palsy, epilepsy, autism, mental retardation, or a condition that would require similar services as those required for children with mental retardation. The eligible medical condition must also be substantially disabling.

***Early Start***

California's Early Start program provides family-centered early intervention services to eligible infants and toddlers, birth to three, who have, or may be at risk for a developmental disability or delay. This program receives federal funding through IDEA (P.L. 105-17). Services include: service coordination, therapy services (speech, physical and/or occupational therapy), vision and hearing services, infant development programs, medical services, parent support, counseling, respite and training; nutrition/feeding services, assistive technology, including assistive devices or services, psychological and social work services and transportation and related costs necessary for a child to receive services. There are no income requirements and all services are free of charge.

Children are eligible for Early Start if they are under age three and meet one of the following conditions: 1) has a delay in at least one area of development (cognitive, physical and motor, communication, social and emotional or adaptive) 2) has a condition with a known probability of causing a disability or delay, and 3) is at high risk of having a developmental disability. Early intervention services may be provided by school districts, regional centers, and public and private agencies that are all part of California's Early Start Program in the community. Where and how services are delivered is determined together by the family and early intervention team. For example, services may be provided in the home, at a center or agency program with other babies, in childcare or in other natural settings.

Family Resource Centers located in Regional Centers are part of the Early Start program and provide information to families of children with developmental disabilities. Comfort Connection Family Resource Center is located at the Santa Ana Regional Center. All Comfort Connection staff members are parents of children with special needs and use their parenting expertise to guide parents seeking information related to their children with special needs.

School districts provide Early Start services for low-incidence disabilities such as deafness, blindness and severe orthopedic disabilities. The school district and Regional Center work together to provide services to children enrolled in the Early Start program.

***Mental Health***

The Child and Youth Services of the Department of Mental Health offers programs to enable children with mental health needs, including those with serious emotional disturbance (SED) to access treatment and support. Children who receive these services include those who are wards or dependents of the juvenile court with mental health needs, children in psychiatric inpatient facilities, youth in the community who have mental health needs, and children who receive special education services who have been identified and referred by the schools under AB 3632.

***Special Education***

Special education is instruction individually designed to meet the unique needs of

children with disabilities ages 3 to 22. It provides them with a "free appropriate public education" (FAPE) under Section 504 as guaranteed by the Individuals with Disabilities Education Act (IDEA). The 504 eligibility includes learning disabilities, ADHD, and "other health impairments." It is more expansive than the regional center definition of eligibility. Special education includes the necessary services and supports for students whose educational needs cannot be met by simply modifying general instruction programs. Education for children with disabilities includes independent living skills in addition to academics. Parents are members of the IEP team and no planning or provision of special education services can be provided without the participation and/or consent of the parent.

The Orange County Special Education Local Planning Areas (SELPAs) are responsible for the implementation of the Orange County Special Education Local Plan for special education, and for insuring a free appropriate public education to all students with identified disabilities. Orange County has 13 separate SELPAs. As of December 2002, there were 4,702 children ages 3 to 5 enrolled in Special Education, with a total of 50,236 among all age groups served by this system (California Department of Education Special Education Division, 2002).

***Department of Children and Family Services***

The Department of Children and Family Services (DCFS) administers Child Protective Services in Orange County. DCFS provides safety and protection for children who have been or are at risk of, being abused, neglected or exploited. Family preservation and child safety are the focus. Within DCFS, Child Protective Services includes four programs: 1) Emergency Response, 2) Family Maintenance, 3) Family Reunification and 4) Permanency Planning. The Orange County Department of Child and Family Services supervises 1065 children ages 0-5 in foster care; this accounts for 0.4% of the 0-5 population in Orange County (Needell B et al, 2004).

## Commission-Funded Developmental Services Programs

### *Bridges for Newborns Program*

This program commenced February 2000 with screening of all mothers who gave birth at 10 hospitals in Orange County for access to a healthcare home and socio-demographic factors. Moms were interviewed at the bedside, and then followed up by phone at 2 weeks and 2 months to determine whether they had found a pediatrician. "High risk" families are referred to the public health nurses Project Connections for home visits based on the Old's Model, and the baby is referred to a "high risk provider" such as the Children's Bureau Prevention Center which provides psychosocial and environmental assessments and has links with mental health services. Medically high risk infants are followed in the Developmental Clinic. Children are generally screened at two month intervals using Ages and Stages. Pediatricians are not involved in this process.

For families who receive the screenings and home visits it is possible to develop a relationship and rapport with the nurses which they see as valuable. One weakness of the program is that by the nature of the screening tool, higher SES mothers generally fall in the minimal or no risk category, and the nurses are concerned that they are missing mothers with depression and other issues.

### *Project Connections*

This Commission funded project provides healthcare coordination and performs in-home developmental screening utilizing public health nurses. Coordination of care is provided through trained lay providers called Promotoras. Project Connections receives 57% of referrals from the Bridges program. The program makes approximately 5,000 referrals per year. The Commission is funding a data tracking system-OCERS and this may assist in future evaluations and outcome studies.

### *Family Support Network – Developmental Screenings*

The Family Support Network (FSN) is funded by the Commission to provide developmental screenings and health evaluations at twelve community sites located throughout Orange County. Seven early intervention providers from different disciplines (mental health, OT, PT, speech, visual impairment specialist, RN, regional center representatives) come together to provide on-site screenings at the invitation of various groups (family resource centers, head starts, churches etc.) once a month. Low income areas are targeted. Children who qualify for regional center services (0-3 years) have intake on-site while children ages 3-5 years who fail screening are referred to special education with a letter sent at a later date. Two months after screening, the Family Support Network follows up with the family.

Data collected for a 6 month period show that 759 children were screened of whom 578 (75%) were referred. This represents a very high referral rate and may indicate selective attendance at screenings of children who are suspected of having developmental problems. It might also indicate that the screenings are producing many "false positives." Detailed follow –up data would be required to determine outcomes following further assessments. The FSN appears well linked to other health and social services resources in the County.

### *Family Support Network- Early Childhood Mental Health Outreach*

This Commission-funded program provides in-home visitation to Hispanic families who have a child between the ages of 0-5 who has been identified as at-risk for severe emotional disability.

### *Early Development and Assessment Center (EDAC)**

The Early Development and Assessment Center (EDAC) now provides services at CHOC and Aliso Viejo, with case management provision to UCI's developmental (NICU) follow-up clinic. There are approximately 900 visits per year to the program and any child 0-3 can be seen. Most referrals come from NICUs in and around Orange County, while about 20% referrals come from Community Pediatricians.

There is one developmental pediatrician involved with the program in addition to a variety of specialists, such as occupational therapists, physical therapists, psychologists, social workers, speech and language therapists, and registered dieticians . The medical director is a neonatologist and medical input concentrates on the medically fragile infants. There are three focus areas – apnea clinic, fragile feeding clinic and developmental assessments. Every effort is made to obtain third party payer authorization and payment for visits. However, revenues generated from insurance billing are a very small part of the program's operating expenses.

In practice, there is some phone triaging prior to cases being seen at EDAC – if the child seems to be exhibiting features of autism, he will be referred directly to For OC Kids. If the problem appears very mild e.g. speech articulation problem or mild delay, they may be referred for parent support. EDAC is well linked with public health nurses. There is a necessary focus on early nutrition due to data that suggest premature babies often do not receive proper supplemental nutrition. At the EDAC Clinic development is assessed using the Bayley Scales of Infant development. Eligible children are referred to regional center, milder problems receive anticipatory guidance, and some may be eligible for therapy through their insurers. EDAC no longer sees children after the age of three. The transfer into the school system is viewed as problematic, with many families feeling they get reduced services.

### *For OC Kids**

This program provides for comprehensive assessment and management for children with suspected autism or autistic spectrum disorders in Orange County. It is staffed by 1.5FTE pediatricians, a neurologist 2-3 sessions a week, a developmental/behavioral pediatrician 1 session per week and 1 Nurse Practitioner who provides education and outreach.

The program is funded by the Commission and revenue generated from insurance billing is an insignificant part of the operating expenses. Evaluations are followed by referral to regional center or the school district. While it was initially envisaged that "For OC Kids" would be a "one-stop shop", in practice it has been very challenging to get therapists on-site due to difficulties with scheduling sufficient volumes of patients for them to see and difficulties with insurance clearance. There is a private speech therapist, a playgroup, an

OT/PT and one psychologist on-site who performs interventions. Efforts at recruiting 2.0FTEs – pediatric neurologists and/or developmental pediatricians have been unsuccessful due to the high cost of housing and living in Orange County and doubts as to the sustainability of the program. There is no funding for training of medical students or residents in this area. About 500 new patients a year are assessed. There are no existing outcomes data.

### *COPE and CUIDAR**

The COPE/CUIDAR model is a two stage process which attempts to circumvent the problem of screening for a condition like ADHD where there is relatively low prevalence and a high false-positive rate on screening. Parents of children ages 3-5 years who have some concerns about their child's attention or development are recruited from childcare centers or school readiness centers. Parents then attend a 10-week community parenting education program designed to facilitate parents to talk about their experiences. Childcare may be provided. Sessions are offered in both English and Spanish and parents are encouraged to self-select whether they need to come back for further sessions. At the completion of the classes, parents decide whether they need to go on to a developmental assessment center where they see a developmental pediatrician for further assessment and possibly medication. To date there has been little opportunity to evaluate the program's effectiveness, but only 20% parents attending classes go on to have a formal assessment. The program is currently Commission funded so sustainability is an issue, and the providers would like to expand to other sites.

### *Metabolic*

The Metabolic Program at CHOC and UCI is supported in part by Commission Funding. The exclusion of a metabolic cause for any child's developmental delay is an important consideration for physicians managing children with neurodevelopmental problems. A population of the size of Orange County undoubtedly needs a metabolic program which can provide this service. The proportion of children with neurodevelopmental problems who prove to have a metabolic problem is, however, relatively small, though as high as 1-2% in one series of children referred to a tertiary center from international data. Patterns of referrals to the metabolic program could not be fully determined from this study, but physicians do not generally refer all cases of developmental delay for metabolic screening.

### *HABLA*

The Home –Based Activities Building Language Acquisition (HABLA- Spanish for speak) program is a preschool intervention program targeting Latino Children. Its purpose is to increase the school readiness of disadvantaged children aged 2-4 years by uniting faculty and students at UCI with the Santa Ana Unified School District, local Family Resource Centers, Americorps/VISTA, FACT, and the national Parent-Home program.

HABLA offers low income, low-SES families in Santa Ana, primarily from two large housing projects, bi-weekly visits to each child and parent (or caregiver) conducted in the home by extensively trained, bilingual staff members. Children are eligible if they are

living below the poverty line with parents having less than 12 years of formal education. Home visitors, some of whom are UCI students, use toys and books (both Spanish and English are available) to model and "coach" parenting techniques that will increase verbal interaction, and promote child learning and expressive language. The emphasis is on dialogic reading – that is, on interaction (i.e., how to talk *with* the child rather than *at* the child). The interaction is very important, not just one-way speech, and there is good evidence that this approach helps with early literacy and language. All the toys and books stay in the home for continued use. Preliminary evaluations indicate that primary language skills of children in the HABLA group are significantly better than controls and that the program has a positive impact on school readiness. HABLA's secondary goal is increased college matriculation for minority students who serve as home visitors. A small number of HABLA "graduate" parents have returned to the program as employed home visitors.

*Denotes program funded under the CHOC-UCI Collaborative.

***School Readiness Centers***

Orange County has 26 separate school districts. As part of the State First 5 School Readiness Initiative, 13 of those districts were identified as having low (<3) API scores, and were eligible for State School Readiness funding. The remaining 13 districts were then funded by the Children and Families Commission of Orange County for school readiness activities. Representatives from all 26 school readiness programs meet monthly to exchange best practices. Each district has an identified school readiness coordinator. Some districts have two – one funded by the State and the other by the district. Some districts have chosen to utilize their school readiness funding to develop hubs or centers, while others have programs across schools.

Harper Preschool is located at one school readiness site – this preschool is an integrated setting for children with special needs. Regional Center sends children to Harper preschool after the age of three years. In South San Clemente and San Juan Capistrano, "Learning Links" is a drop-in center located on a school site. Developmental screenings are offered at the center. The success of these activities will be evaluated as part of the state School Readiness Evaluation.

***Preschool Nurses***

The Commission has provided funds for nurses to be placed in preschools linked with school readiness sites. A preschool nurse training program will be commencing in the Fall teaching nurses how to better screen development, behavior and fitness. Training in ASQ, PEDS or the Denver will be given. The preschool nurses have a lower caseload than school nurses so should be in a better position to help parents. Links are forming between the preschool nurses and the local AAP. Nurses are working on better utilization of resources and outreach screenings at daycare centers.

**National Developmental Services Best Practice Models**

***Denver System for Assessment and Referral:***

This program routinely screens children using the PEDS at 9 and 18 months. Children with problems are referred to a second tier central assessment team which conducts further assessments and refers children to diagnostic and treatment providers in the community.

National Quality Improvement Efforts: The National Initiative on Children's Health Care Quality (NICH-q) and the North Carolina Center for Children's Healthcare Improvement, are launching major statewide initiatives focused on improving the quality of early childhood developmental services. Using the Breakthrough Series reengineering approach to process improvement these centers have been working with the states of Vermont and North Carolina to identify delivery problems within pediatric service delivery system and using a collaborative approach to develop, implement and test the effectiveness of solutions.

***Healthy Steps for Young Children:***

This program, launched by the Commonwealth Fund in 1992, places a developmental specialist in the primary care practice and includes a team approach to care, home visits, periodic child development screening, a child development information line, parent groups and linkages to community resources. The model would be expensive to replicate on a large scale but early findings suggest the model provides better developmental and behavioral services.

***Help Me Grow***

This program in Connecticut grew out of the ChildServ program based in Hartford. Child health providers are trained in effective developmental surveillance and monitoring; there is a computerized inventory of services for developmental needs; a triage referral and case management system to help children and families access services; and educational programs for parent groups and child care providers. There is widespread community awareness of the program, and 41-64% referred children were still receiving services at follow-up.

***San Diego C3***

This program has a network of 175 providers in North San Diego. The PEDS is performed in pediatricians' offices with children scoring in a risk category being referred to a second-stage center for further screenings. Based on the results and parent wishes the child is either referred for a full developmental assessment or for classes on parenting topics.

**International Best Practice Models**

There are several effective and innovative models of providing developmental services to young children that are emerging in different countries across the globe. Smart Start in England has sought to develop community based systems of assessment and referral, the

Early Years project in Toronto and similar projects in Montreal and other Canadian cities are also attempting to link child health and developmental services into a more seamless system.

***Platforms*** is the name of an initiative that is currently being developed in Melbourne, Australia and works on a three-pronged approach to coordinate systems for early childhood care. The first arm includes community needs assessment, resource mapping, and education of providers; the second phase uses the PEDS-plus i.e. a modified PEDS with an additional dozen questions about psychosocial risk factors such as substance abuse and domestic violence, while the third arm is a collection of evidence-based interventions to optimize developmental outcomes.

Each of these innovative approaches has elements that can be incorporated into the design of more effective developmental services systems for Orange County.

## Provider Capacity for Developmental Services Provision

### *Physicians*

Based on data from the HRSA Primary Care Service Area project, Orange County has 445 pediatricians and 945 family practice physicians. The County averages 557 children under the age of 5 per pediatrician compared with a statewide average of 599. (Pappelbaum and Turner report).

The ratio of children to pediatricians varies across communities from a low of 219 children aged <5 years per pediatrician in Newport Beach (Median income $82,374), to a high of 1,078 in Anaheim (median income $32,205). An "ideal" ratio of all children 0-18 years to pediatrician has been suggested as 1,200-1,400 (DeAngelis C. Final report of the FOPE II Pediatric Workforce Workgroup. Pediatrics2000; 106(5) cited in Pappelbaum and Turner report). Several areas in Orange County exceed this ideal ratio including Anaheim, Fullerton, San Clemente and Westminster. CCS data lists 322 pediatricians who serve children with CCS-qualifying conditions in Orange County.

Access to primary care services for children who are uninsured is limited, and in practice is furnished by only a handful of providers in the CHDP program. Children on Medi-Cal and Healthy Families have much broader access, with approximately 1,000 primary care physicians available to serve the 155,000 Orange County children covered by Medi-Cal.

Based on CalOptima and CCS specialty data there are limited numbers of physicians in certain subspecialties, especially child development (1), orthopedics (1), and pediatric otorhinolaryngology (1), and child psychiatry(6). Based on key informant interviews the number of developmental/ behavioral pediatricians is actually 4, but 3 of them do not currently practice full time. Developmental/behavioral pediatrics, not just in Orange County but across the US, is a specialty which has not yet defined its niche. Reimbursement for services provided by these pediatricians is so low that it is not possible to run a full-time clinical service and earn a viable salary. Developmental-behavioral pediatricians, if they are practicing their specialty at all, are in academic settings devoting part of their time to research.

### *Nurses*

The ratio of students per school nurse varies from a low of 1,264 students per nurse in Fountain Valley Elementary School District to a high of 16,195 students per nurse in Fullerton Joint Union High. None of these ratios meets the National Association of School Nurses recommendation of no more than 750 students per school nurse. While this shortage principally impacts the K-12 population, it also affects those children aged 3-5 years who are receiving special education through the school districts.

California Board of Nursing data list 939 nurse practitioners in Orange County; however, it is not known how many of these are pediatric nurse practitioners. There are 366 Public Health Nurses, not all of whom work with children. There are 40FTEs in Community Nursing. These public health nurses are highly trained and are likely to have specialized knowledge in child development. They play an active role in developmental surveillance and have a wide knowledge of county resources.

### *Developmental Specialists, Therapists and Mental Health Providers Serving Children 0-5 Years in Orange County, June 2004*

Based on known numbers of providers licensed in each specialty, and % serving children 0-5 years derived from random calling of providers, a best estimate of providers was determined (D Mathias, AAP Pilot projects, Commission Report).

If these estimates are correct, and it is known that there are 265,249 children in the 0-5 age group in Orange County, then the ratio of providers to children is as shown in Table 8. As it is known that 9.8% of Orange County students receive Special Education, and it can be argued that this group of children would potentially benefit from early intervention services, the ratio of providers to this 9.8% of the population is also listed. Taking a broader definition of neurodevelopmental problems as potentially affecting 18% of the population, these ratios are also given in Table 7.

**Table 8: Ratios of Providers to Children with Neurodevelopmental Problems Ages 0-5 Years in Orange County**

| Discipline | Number in Orange County | Ratio of provider to children 0-5yrs (265,249) | Ratio of provider to children 0-5 ultimately needing special education (25,994) | Ratio of provider to18% 0-5 population with neurodevelopmental problems (47,744) |
|---|---|---|---|---|
| Psychiatry | 79 | 1:3357 | 1:329 | 1:604 |
| Child Psychiatry | 6 | 1:44,208 | 1:4332 | 1:7958 |
| Psychology | 540 | 1:491 | 1:48 | 1:98 |
| Marriage and Family Therapist | 1175 | 1:226 | 1:22 | 1:45 |
| Audiologist | 160 | 1:1658 | 1:162 | 1:331 |
| Speech Pathologist | 1183 | 1:224 | 1:22 | 1:45 |
| Licensed Clinical Social Worker | 611 | 1:434 | 1:42 | 1:87 |
| Occupational Therapist | 594 | 1:447 | 1:44 | 1:89 |
| Developmental Pediatrician | 4 | 1:66,312 | 1:6498 | 1:13,262 |

The small number of developmental pediatricians per capita is compelling. Assuming that each developmental pediatrician could see 500 new patients a year, then even to achieve the goal of all children ages 0-5 who would ultimately need special education seeing such a pediatrician only once prior to school entry, a minimum of 13 developmental pediatricians would be needed across the county to achieve that single aim alone. If the aim was broadened to include the 18% children thought to have neurodevelopmental problems, and visits increased from once prior to school entry to once per year then over 50 developmental pediatricians would be needed.

### Capacity for Intervention Services through School Districts

Once children reach the age of three years, responsibility for provision of early intervention services rests with the individual school districts. For children whose problems are only identified for the first time either around or after the age of three years, assessment and intervention occurs for the first time through the school district. Each school district employs a number of therapists to deliver these services. The types and intensity of therapy services offered vary significantly between the different school districts.

Parents and providers generally describe that the intensity of services available through the school district is significantly less than through regional center or Early Start, and the transition process is challenging. For example, data from California Department of Education indicate that in Orange County there are 15,376 children receiving special education with a diagnosis of specific language impairment. School districts employ a total of 463 speech/language/hearing specialists which gives a case load per specialist of 33 children across all age ranges 3-18 years. In practice, group therapy is often the only option; however, this approach is not always suitable for all children with severe impairments or behavioral problems.

**Developmental Surveillance and Screening**

Existing data, and key informant opinion, suggest that physicians currently do a good job of detecting children who have severe neurological and developmental problems e.g. cerebral palsy, Down Syndrome, severe mental retardation. These conditions are often detected at or before birth, and referral to regional center is prompt. Key informants consider the current surveillance system as adequate regarding referrals to the county's metabolic disorders program. Neurologists and endocrinologists typically make these referrals based upon a suggestive clinical presentation. For children with mild to moderate neurodevelopmental problems such as autism, speech and language impairment, specific learning difficulties, emotional issues and mental health problems early diagnosis appears to be unusual, with pediatricians generally regarded as lacking knowledge in this area. Even when a physician does detect a problem, they are likely to advise a "wait and see" approach, leading to delayed diagnosis and lost opportunities for early intervention. Intervention services such as Regional Center report that pediatricians currently play little role in referral of children with mild to moderate developmental problems to services. These referrals generally come late from the families themselves, and pediatricians may even be viewed as a barrier to early referral by providing families with false reassurance.

Although the AAP recommends use of validated developmental screening and surveillance tools such as the PEDS and the Ages and Stages Questionnaire, in practice use of these tools by pediatricians in Orange County is rare. Reasons cited echo recognized national issues with lack of time to perform screens and assessments, lack of reimbursement for developmental services, and lack of places to refer children identified as being at-risk or with mild problems not eligible for Regional Center. Most pediatricians, in keeping with national trends (AAP 2000) use informal assessment techniques, which may be inaccurate or biased.

**Education and Anticipatory Guidance in Pediatric Primary Care**

The health visit represents an important opportunity to advise parents on key child-rearing topics such as interaction with infants, child's temperament, sleep habits, promotion of learning and literacy and discipline. National data suggest that, as with developmental assessments, doctors do not routinely use structured teaching approaches in clinical practice (Chambers et al 1979). Instead of tailoring discussions to the particular needs of a family, providers tend to discuss general development, a technique that has been shown to be less effective than responsive and personalized discussions (Dworkin et al, 1987).

In Orange County several practices have successfully implemented Reach Out and Read and anticipatory guidance is clearly incorporated into primary care, however it is uncertain how personalized or responsive the approach is. National data suggest that there is room for improvement in these doctor-patient interactions. The National Survey of Early Childhood Health (2000), a telephone survey of more than 2,000 parents revealed that more than 80% of parents wanted physicians to ask about psychosocial and family issues that could affect a child's development. However, fewer than half of all parents were asked about such issues as substance abuse, violence in their communities, or emotional support in their lives (Halfon et al 2002a).

Topics that parents did not discuss with their pediatrician but would have liked to included toilet training, guidance and discipline, child care and reading (Inkelas et al, 2002a). Parents whose children had a regular physician for well-child care were more likely to discuss key topics with the physician than parents whose child did not have a regular provider, even when taking into account the location of care (e.g. community clinic vs. private group practice) (Inkelas et al., 2002b). Similarly, half of parents interviewed in the Promoting Healthy Development Survey (Bethell et al 2001b) reported that their concerns about their child's development were addressed insufficiently by their child's health provider.

In Orange County the CUIDAR/COPE program offers a 10-week parenting course aimed at parents of children ages 3-5 years who have concerns about their child's attention. The course is used both to educate parents about parenting practices and to allow for peer-peer interactions and support. The program also educates parents about child behavior so that by the end of the course, parents can make a decision about whether their child needs to be referred for further evaluations and services. In this way the parent education replaces a formal screening test as a method of identifying children with more significant problems. This is an interesting and innovative approach, which currently lacks data to determine its effectiveness.

**Intervention in Primary Care**

Intervention services include counseling in the office setting, telephone information lines, and home visitation. Once a neurodevelopmental problem has been identified, the physician must decide whether the problem can be addressed by guidance in the office setting or whether onward referral for specialist assessment or intervention is warranted. This decision requires a significant amount of skill and insight on the part of the physician, and a knowledge of potential community resources for developmental assessment and intervention. Many physicians lack confidence in this area which may contribute to reluctance to embark on large-scale developmental surveillance initiatives. The scope of developmental services that any single child health practice can offer is partially determined by the availability of services in the community and links between the pediatric office and those community resources. For example, if a community does not have services for depressed mothers, then pediatric providers are unlikely to screen for this condition, as they have no place to refer. In Orange County, there are very few links between pediatricians and psychiatrists or psychologists that might address maternal mental health issues. One pediatrician runs a "Health Club" at her practice which provides support for mothers, but this is rare.

Orange County Mental health providers report that they receive very few referrals from pediatricians for mental health interventions in children ages 0-5 years. Similarly the few mother-infant programs in the county are generally not referred to by pediatricians. Given the nationally reported rates of behavioral problems in young children, this lack of referral is significant.

Orange County has two telephone information lines – the 211 service, and the maternal and child health Info Line which can advise parents with concerns. In practice these lines are not well publicized to physicians and few providers seem to refer parents to them. The ability of the staff at the call center to answer questions about child development is uncertain.

**Care Coordination**

Care Coordination refers to the management of service needs such as referrals for diagnostic assessments or specialist consultations. In Orange County few physician practices are able to offer care coordination services and those that do are generally not reimbursed for this service and doubt its long-term sustainability. For those children whose developmental problems are eligible for regional center, care coordination is provided through RCOC by the child's case worker. Even this service can be problematic when there are frequent changes of case workers. Care coordinators are generally discipline or service specific. Families may have several care coordinators who do not communicate with each other.

**Assessment Services for Children Suspected of Neurodevelopmental Problems**

In Orange County there are limited options for providers for onward referral of children suspected of having neurodevelopmental problems. For children in the 0-3 age range requiring a multidisciplinary approach, referral can either be made to the EDAC Program whose main clinic is at CHOC or to Regional Center. Some physicians prefer to refer children to another specialist for an opinion e.g. neurology, genetics or a developmental-behavioral pediatrician. In practice these latter referrals might actually act as a barrier to the child's entry into an early intervention program, as the primary care physician assumes that the neurologist or developmentalist has made the referral and vice-versa.

The EDAC (Early Development and Assessment Center), funded by the Commission, is open to children ages 0-3 years and is free of charge. It offers a full developmental assessment using the Bayley Scales of Infant development. If the child is found to be eligible for services through regional center, then a referral will be made to RCOC. If not, development will continue to be monitored by EDAC. Some children who are regional center clients continue to be monitored by EDAC for issues related to their prematurity. EDAC is well connected to services in the Community, and many of its patients are former NICU graduates who are referred at hospital discharge for ongoing monitoring. EDAC offers a comprehensive service but there is no developmental pediatrician on the team, and the medical role is limited, focusing on apnea and feeding issues.

Regional Center of Orange County (RCOC) offers a multidisciplinary assessment to any child suspected of having a developmental problem. In practice not all children referred

to regional center are assessed as there is some "telephone triaging" of cases to refer children who would not appear to be eligible for regional center services to other agencies. There is little information on this process or how well it operates. Communication between pediatricians and regional center is very limited. For eligible children, therapy services – principally speech, occupational therapy, physiotherapy and psychology will be provided and coordinated through Regional Center until the child's third birthday, when therapy becomes the responsibility of the child's school district.

Children ages 0-5 years with a suspected diagnosis of autism or autistic spectrum disorder are referred to For OC Kids, a multidisciplinary assessment and intervention team focusing on this condition. Children are referred on to Regional Center (0-3) or the School District (3-5) for services if found eligible.

Children ages 3-5 with suspected neurodevelopmental problems are referred on to their local School District for any assessments and therapeutic services. In practice, many of the pediatricians in Orange County are not familiar with all of these teams and potential referral routes. Communication between the pediatricians and these diagnostic services is very limited. Many pediatricians do not understand the various age cut-offs, eligibility criteria and therapy services available. When patients get "stuck" in the system, physicians often lack the skills and knowledge of systems to intervene and ensure that their patients receive appropriate management.

**Therapy Services**

Children eligible for Regional Center or School District Special Education receive therapy services through these organizations. Children not eligible for services have very limited treatment options through their insurance plans. For children who are uninsured, options are extremely limited and in some cases may be non-existent. For some children referral to services outside the health sector would be beneficial e.g. Early Head Start, Head Start, Preschools, Tutors and School Readiness Centers. However, providers in Orange County generally lack the staff and knowledge on how to make these referrals to follow up on the referral process.

**Data Systems and Outcome Measures**

The Orange County Commission has made a significant investment in OCERS, a state of the art data collection and tracking system to guide program implementation and evaluation. Process and ultimately outcomes data measurements will be possible utilizing this system, however its capacity has not yet been fully realized. A number of programs have faced difficulties with IRB approvals, and with finding staff time to collect and enter data. Most programs have not yet been able to utilize much of the data due to the lack of staff and to some degree expertise for analysis. Full capitalization on the promise of the OCERS system will only be possible with additional funding from research sources and with the academic expertise of CHOC and UCI.

The Public Health Nurse Home Visiting Program (part of Project Connections) is based on the Old's model which has been demonstrated to be effective in other settings. Similarly, the HABLA program has collected preliminary data which show benefit of the program on the outcome measure of language development, and the HABLA approach is similar to other programs reported in the literature which have a moderately strong

evidence base. The EDAC program has collected a significant amount of data but has lacked funding and staff to analyze and publish the data. Similarly, For OC Kids would like to collect more data and perform an outcomes study but lack funding for this endeavor. The lack of funding for research and, in some cases, the lack of staff to perform the research make an assessment of outcomes and hence effectiveness of many of the programs very challenging.

**Themes from Interviews and Focus Group**

Principal themes emerging from the interviews and focus groups are reported together with quotes that illustrate an important aspect of the theme.

***Communication between service providers and families is poor.***

Any child with a neurodevelopmental problem must interface with health, early intervention, and educational systems. Some children also need social services and mental health services. Each of these individual systems is complex, fragmented and difficult for parents and professionals to negotiate. Communication between these areas is often difficult or non-existent. Communication difficulties were noted between parents and providers and between providers from different disciplines. Even when providers discussed development and developmental services with other providers, they were often using different conceptual models of development, ideas of what constituted a developmental assessment, and what the service system might optimally look like. The communication challenges appear to be particularly salient across sectors- early education to pediatrics and vice versa.

> *"I think some exchange of records takes place between doctors and mental health providers (and vice-versa), however it may not happen very often"*

> *"There is no contact at all with pediatricians during the process; regional centers never talk with pediatricians"*

Communication about a child's diagnosis was particularly disappointing for some parents, particularly Spanish-speaking parents, who felt that they didn't understand their child's diagnosis other than its name, whether there was a cure or treatment for the condition, or whether they had done something to cause the problem. They didn't know who, of all the service providers along the way, was responsible for answering these questions.

> *" The doctor at the regional center said my child had autism but I still am not sure what that means."*

Many services lacked a family-centered approach, and many families faced linguistic and cultural barriers to clear communication. Experienced community workers all noted the need for formation of personal relationships between the different disciplines and emphasized the importance of face to face contact**.** Many interviewees acknowledged the work of the commission in this area, but felt that collaborations were sometimes limited to the higher administrative levels and did not trickle-down to workers dealing with the families.

*'Linkages is a nice buzz word, but it's more about relationships. People move around a lot e.g. the entire personnel of an agency could disappear but they will turn up in other agencies…it's more important to make relationships with individuals."*

***Cultural Competency/Sensitivity***

Communication across cultures is particularly challenging. Many families being served have limited or no English skills yet services and information provided do not always address this need. Parents who were not themselves born and raised in the U.S. may have only a vague knowledge of the organization of the health and educational systems and have very little idea of how to interface with them.

Several Spanish-speaking mothers were single and felt that they would have benefited from services for parenting challenges or mental health resources. They also unanimously agreed that they felt unwelcome at their children's preschool. Even though they agreed that the staff was courteous, they felt that preschool didn't know them very well or their culture and made little effort to make them feel a part of the program. This was in spite of the fact that the preschool had opportunities for parent participation.

*"When my husband left us, I felt depressed. I have no family in this country. I wished I had known that there were programs that could help me. My son became very angry and aggressive; he has been very difficult to handle."*

*The teachers here are nice but I still feel that I don't belong here. I don't feel that I can talk to them. None of them speak Spanish."*

Many services did not seem aware of the perceptions and values of different cultures, although providers in community settings seem more aware of these issues than those located in large institutions. Several interviewees warned of the dangers of cultural stereotyping and emphasized variation within cultures- e.g. Latino families who have lived in the US for three generations may be culturally distinct from a Latino family of first generation migrants.

*"There are large groups of Hispanic, Pacific Islander and Vietnamese. In these groups there are cultural needs which must be met when talking about special needs."*

*"We need to reach more of the 'closed' ethnicities in the county. In some cultures, there is a lot of shame when the child is less than perfect, especially in the Vietnamese community."*

*"Latinos have a different perspective on preventive care. You go to the doctor when you are sick, not for preventive services. This is a public education, social marketing issue."*

*"In Mexico you send kids to school and you don't get involved. If you take that attitude here your kids won't get services."*

Interviewees commented that culture is not restricted to race or ethnicity. Different professions, institutions and even subspecialties have quite distinct cultures. Socio-economic cultures also exist. The awareness of poverty and homelessness within the county varies across services.

> *"Poverty is a culture and creates numerous barriers. It is difficult to navigate the system and all of the problems are compounded by poverty."*

***Coordination of Care***

Most interviewees saw a great need for improved coordination of care. Even those providers who were trying to deliver care coordination had incomplete knowledge of the system and of the potential services available. Case management provided by different programs (e.g. CHDP, CCS, Public Health Nurses) was limited. Referrals made commonly lack follow up for multiple reasons.

There was a great expressed need for the county to develop an effective way of disseminating information about services.

> *"Overall view of developmental services is that there are lots of services with poor centralization or integration."*
>
> *"It's a challenge for parents to navigate the system. They need care coordination. Who do I call? Do I qualify? Is this service right?"*
>
> *"Knowledge dissemination about the system is crucial."*
>
> *"We do a terrible job of continuity…we switch people from place to place, especially kids in foster care."*

Need for service coordination at time of transition emerged as an important sub theme of care coordination, as especially good communication and integration of services is needed at this time. Unfortunately, many families find service transitions difficult. Transitions in need of further planning included discharge from the NICU into the community, transition from regional center to school-based intervention at age 3, and transition into the school system at age 5.

***Funding Streams/Reimbursement/Insurance***

Almost all interviewees regarded lack of provider reimbursement for developmental services as a major barrier to the provision of an effective system. The pediatric specialty of developmental pediatrics is not well developed and has not yet established a solid fiscal foundation. Many providers in the developmental field were worried about pay and sustainability of services in the long term.

Providers and parents reported problems with split CCS/IDEA Part C eligibilities, and with funding for services through the school districts. There was general confusion regarding the organization of these funding streams. Many providers commented on the general lack of acceptance by insurance companies that developmental services are needed. Funding of mental health services was viewed as particularly restrictive.

Immigrant fear of accessing services for fear of being classed a "public charge" was mentioned by several interviewees.

> *"There is no money to pay for preventive services (in mental health)."*
>
> *"There is a great need for health insurances to start funding developmental services – this needs to be talked up with insurers."*
>
> *"Low reimbursement rates for developmental pediatricians make it difficult to impossible for them to practice outside of a research setting. Developmental pediatrics is a thankless job."*

***Parent and Family Needs***

Many providers commented on the need to educate parents and to empower them to seek needed care for their children. Family Support networks, parent support groups and Family Resource Centers were seen as very valuable for parents, however there were some concerns that too many groups might be competing for funding and duplicating services.

Orange County is a setting of wide economic contrasts from the very affluent coastal suburbs to poverty and homelessness in urban areas. The daily struggle for basic requirements of food and shelter overwhelm many families and make child development optimization a necessary low priority. It is hard for providers whose own life experience is predominantly privileged to comprehend the scope of these needs.

> **"***Parents feel desperate, frustrated and overwhelmed...they need a knowledgeable advocate."*
>
> *"I wish I could have had a Family Resource Center for my kids because my grandchildren are doing so well as a result of the FRC."*
>
> *"Even as we health professionals face challenges dealing with managed care, parents also have cultural issues, low SES, literacy problems – so far them, this is a real issue and problem."*
>
> *"One child lived on the couch with his Mom – other families lived in the bedrooms. The child did not want to come to school because the only time he had alone was when everyone else was out of the house. It is hard to comprehend this…when the resort area is so wealthy."*

***Role of Pediatricians and other professional groups***

In general pediatricians were regarded as lacking in knowledge about both child development and the services available for interventions. In fact, pediatricians were often viewed as barriers to effective surveillance.

> *"My pediatrician said my son was just fine when he had autism. I learned about the regional center from a worker at the WIC program."*

Some parents reported strong relationships with pediatricians and felt that they always listened and found a solution with them to their problems. Other professionals generally had a very low opinion of pediatricians, and many agencies reported virtually no contact with pediatricians.

Pediatricians themselves frequently reported that they were doing a good job despite incredible barriers and lack of reimbursement for their efforts. Public health nurses are highly trained and knowledgeable but generally work independently and are not well linked to medical homes.

> *"The physicians are incredibly busy, overworked and need volume to pay the bills. They don't have the time to do a good assessment. Maybe someone other than the physician can do this."*
>
> *"Most physicians do not know what's out there."*
>
> *"Doctors are not always responsive to parent concerns."*

***Developmental Screening/Surveillance***

There was general agreement among providers and agencies that most pediatricians were not using any formal developmental assessment tools. A few practices used the Denver II, usually at only one point during the 0-5 years. Practitioners who felt they were already doing a good job of surveillance felt that addition of validated tools would be redundant.
Providers also questioned available resources for children who had problems but were not eligible for regional center services.

> *"Developmental screening works reasonably well, but some kids fall through the cracks… Is this just a speech delay or is this a developmental problem can be hard to assess at the time."*
>
> *"At 9 months every child gets a Denver II administered by an N/P. From 2 months to 18 years parents receive a written handout developed by the practice with questions drawn from the domains of the Denver. Parents check boxes and if any concerns are noted they are reviewed, moving on to more detailed questions."*
>
> *"In my own practice I do a physical before the child enters preschool or school and I always include a developmental assessment, so in my case it would be redundant to then have a PEDS."*

***Role of Schools***

The relationship between parents and school districts in relation to services for children with special needs was often regarded as adversarial. Knowledge on eligibility for services was fragmented. Services varied between school districts. School were clearly trying to address the problems but appeared to have inadequate resources to achieve this.

*"I feel some children over age 3 are too much for school district to handle….the school district can't provide the same sort of detailed evaluation as regional center and does not include genetics and other specialists input."*

*"The school district 'does its best' but does not have the resources for this problem."*

*"The school district referral process is difficult for parents…sometimes schools lie to parents and tell them their children aren't entitled to an assessment."*

***Role of Child Care providers***

The concept of childcare providers playing a more active role in developmental monitoring was raised by the interviewers. Many interviewees felt that childcare providers' contact with young children over extended time periods placed them in a potentially good position to play a role in developmental surveillance. However, parents expressed doubts that pediatricians would act on the results of such surveillance.

Parents felt that if they were to hand the result of such surveillance to a receptionist, the doctor might never see it, or might only glance at the form. Parents felt that if they took the form and handed it directly to their pediatrician it might be addressed, but only if the information was specific.

Interviewees raised the difficulty that parents of children with special needs have in finding them childcare placements. Several interviewees recommended additional education about child development for childcare providers.

*"Childcare facilities, preschools and schools have daily exposure to kids – they should have more education and training. They should be part of early identification and screening."*

*"Another big issue for children is once they are identified as having special needs, placement in preschool or Head Start is almost impossible."*

***Multidisciplinary Assessment Teams***

Interviewers introduced the concept of multidisciplinary assessment teams, especially for those children scoring in a risk category following screening or surveillance. Interviewees were generally supportive of a multidisciplinary assessment team concept. However, doubts were expressed about the feasibility of funding this approach, especially in the longer term. Concerns were also expressed about transport issues in a center-based model.

*"Regional Center Orange County gets lots of calls from non-RC families wondering what to do and where to go for developmental assessment. If these kids are 3 years or older, they can get a school district assessment."*

*"There is a need for a multidisciplinary assessment team to make sure that all the child's needs are being addressed and the most pertinent problems are being taken care of."*

### *Call Center*

The concept of a call center, where parents or professionals could call in for advice about navigating the system, eligibility and services was raised by the interviewers. This concept met with almost universal enthusiasm, and there was a perceived need for such a service.

Interviewees felt it would be essential to have a trained person answering the phone- not a phone tree, and that person's skill level was regarded as crucial but difficult to define.

Some interviewees felt the service would work best if linked to an academic medical center – and others commented that it should not duplicate existing info-lines. The need for continual updating of resources was identified but regarded as challenging.

> *"I was in practice for years before I worked out all those crazy abbreviations – IDEA, RCOC ….there is a need for more information from people who know the system."*
>
> *"People need to know who to call…I don't know who to call!"*
>
> *"There would have to be a belief/comfort level that the person's (answering the phone) intelligence and compassion were enough to carry the ball."*

### *Health Care Infrastructure*

Most physicians interviewed saw a need for strong academic leadership in this area. Most non-physicians interviewed did not raise this issue. Both physicians and non-physician providers saw a need for closer collaboration between CHOC and UCI.

Some interviewees felt that Orange County's public health services were not well developed and were widely regarded as "services for poor people." The healthcare system generally lacked good data collection, with the data that was collected regarded as process rather than outcomes focused.

> *"Neither CHOC nor UCI appears to have a public health focus."*
>
> *"We have a public health image problem…many sectors such as schools in affluent areas do not want public health services."*
>
> *"Organizations and providers do not know where their money is going to come from…there is budget fluctuation."*

### Results of Model Building Exercise

Interviewees revealed widely differing concepts of how an ideal developmental services system might operate, and many had not previously considered how the entire system was designed. Most interviewees instinctively placed their organization or discipline at the center of the organizational structure. Only one interviewee placed the family at the center of the organizational chart.

Table 9 summarizes the main barriers reported to the study team to effective operation of a developmental services system within the County and potential solutions suggested either by the key informants or parents interviewed, and informed by existing knowledge of best practices. This table is not prescriptive, but rather presents the types of solutions envisaged by the community.

**Table 9: Key Barriers to Delivery of Effective Developmental Services in Orange County with Potential Solutions**

| Barriers to Effective Developmental Services | Potential Solutions |
|---|---|
| Delayed identification of children at risk in the prenatal and perinatal period | Increased awareness and education of obstetric providers, expansion of Bridges model. |
| Lack of new parent education about child development | Include child development teaching in antenatal classes. Give information on developmental services to parents of newborns. |
| Lack of Health Insurance | Maximize Medi-Cal and Healthy Families enrollment.<br>Establish Orange County Fund for services to the small number of chronically uninsured. |
| Lack of a Medical Home | Educate parents about benefits of a medical home.<br>Educate providers about tenets of a medical home. |
| Lack of skilled developmental monitoring | Encourage providers to use formal validated tools such as PEDS and ASQ.<br>Sensitize pediatricians to the importance of early child relationships, parent support, and temperament.<br>Emphasize continuous surveillance over occasional screening.<br>Broaden monitoring to include childcare providers, WIC sites, and preschools. |
| Lack of infant mental health services | Partner with Cal State Fullerton who have an emerging program.<br>Increase provider awareness of socio-emotional development. |
| Pediatricians too willing to adopt a "wait and see" approach | Provider education.<br>Responsibility of developmental surveillance shared between pediatrician, nurse practitioner, pubic health nurses, preschool staff, childcare providers and parents. |
| Lack of services for children not eligible for regional center (0-3) or school-based intervention (3-5) | Improve documentation of low-cost community-based programs.<br>Facilitate provider referral to these programs. |
| Reduced services for children who transition out of regional center at age 3 years | Prepare parents for transition.<br>Educate parents and providers about community resources.<br>Develop additional services to bridge this gap. Expand HABLA and CUIDAR |

| | |
|---|---|
| | approaches. |
| Poor provider reimbursement for developmental services | Advocate directly with Orange County health plans for enhanced provider reimbursement.<br>Educate physicians on maximizing billing codes for services. |
| Poor communication between health, education and social services sectors | Organize joint across-discipline trainings.<br>Small workshops with "mixers" to maximize formation of relationships across disciplines.<br>Education about theoretical frameworks guiding services systems. |
| Lack of knowledge about community-based services | Develop centralized web site and call center. |
| Lack of community knowledge about importance of "The Early Years" | Use the media to communicate this message to the general public.<br>Partner with the "Help Me Grow" show and run a weekly program on aspects of early child development.<br>Develop an "instant recognition" logo and name to describe the new model developmental services system.<br>Partner with industry to advertise this new approach. |
| Lack of support for families with children with developmental problems | Streamlined referrals from providers to parent support through the family resource network. |
| Lack of outcomes measures to guide program development | Provision of academic leadership through CHOC-UCI.<br>Development of data systems and identification of existing data, e.g. ages at intervention entry, numbers of children in early start, regional center and special education which can be utilized in program assessment. |

## Gaps in Services for Children in Orange County

### *Conceptual Gaps*

Different providers have different conceptual models of how the system should operate. These largely reflect different underlying theoretical frameworks e.g. neuromaturational model vs. transactional model. Even providers who operate from similar conceptual frameworks may, however, have quite different ideas about how the overall system is, or should be organized. Many providers within the system do not have a clear picture of the system as a whole, even within their own service sector. There is no one person, group or agency that has a clear view of all parts of the system.

### *Service Delivery Gaps*

The following specific service area were noted to have gaps, however this is not a comprehensive list of all service gap areas.

### *Prenatal Substance Abuse*

The National Household Survey on Drug Abuse indicated that 2.8% of pregnant women reported drug use, including cigarettes, alcohol, and illicit substances, and this is likely to be an underestimate. Cocaine accounted for 10% reported use. Illicit drug use is higher among non-white women and those without a high school diploma (Messinger et. al 2004). Other estimates have been as high as 11% women testing positive for substance exposure (Vega et. al 1993). For Orange County the same survey estimated that 7.49% births are substance exposed.

Prenatal exposure to alcohol can produce effects ranging from mild learning difficulties to fetal alcohol syndrome. Although children with prenatal substance exposures are at increased risk for adverse developmental outcomes, they do not necessarily qualify for Regional Center services unless they also have at least one measurable delay or symptom, so opportunities for early intervention are lost. Orange County has directed resources toward this issue, with a public health nurse visiting program to pregnant mothers with a history of drug use, and the Bridges program which offers home-visiting after birth to mother identified as at-risk. Despite these efforts, further awareness of this issue among obstetric providers and collaborative programs are needed to maximize developmental outcomes for these children.

### *Maternal Depression*

Depression is a relatively common problem, especially among lower-income single mothers. Mothers who are depressed are less likely to respond adaptively to the emotions of the infant or young child, which may lead to shorter attention span and less motivation to master new tasks. For a child who already has a health or developmental problem this factor might have a synergistic effect leading to a poorer outcome. The recognition and treatment of maternal depression is currently suboptimal. In many cases the only physician a mother has contact with is her child's pediatrician. Although pediatricians are in a good position to screen for maternal depression, the mother is not the pediatrician's patient. This results in problems for the pediatrician in raising the issue and in referring the mother for appropriate treatment. Orange County pediatricians need to have raised awareness of this problem and much better links with community support

and mental health services to address it effectively. Depression is relatively common even among affluent women where it is very likely to be overlooked.

### *Children in Foster Care*

Children in foster care are at high risk of poor physical and mental health both due to their experiences in impoverished often chaotic home environments (Szilagyi, 1998; Halfon et al 1995) and in placements that are not well suited to serve their complex needs. Developmental delays are present in approximately 60% of preschool children in foster care (Szilagyi, 1998). One study estimates that 70% children in foster care demonstrate moderate to severe mental health problems and that fewer than 5% children are without psychological symptoms (Swire and Kavaler, 1997). Children in foster care utilize mental health services at a rate 15-20 times higher than the general pediatric population (Halfon et al 1992). Challenges with fragmentation of healthcare, frequent placement changes, and poor information flow between providers have been well documented. In Orange County many children in foster care are served at Orangewood children's center, however there is no centrally integrated approach to their neurodevelopmental needs.

### *Children with Sub-Threshold Developmental Problems*

Many children would benefit from developmental services but do not meet criteria that would make them eligible for IDEA Part C services or other programs. Children who fail developmental screening tests but who pass diagnostic tests have been shown to continue to perform lower as a group on intelligence and achievement tests than do children who pass screening assessments (Glascoe, 2001). These children might still benefit from parenting programs, social services, and enhanced learning experiences at home or in preschool, e.g. Head Start, Title 1 programs, or tutoring.

### *Children Ages 3-5 Years with Mild or Moderate Developmental Problems.*

Early Start provides services for children in the 0-2 age range who are "at risk." However, once these children transition out of Early Start at age 3, they are ineligible for other publicly funded programs. Once children with mild-moderate problems are released from Regional Center at age 3, they often do not receive services again until kindergarten entry.

Even when children do qualify for services through the school district, they are often less intense than those through Regional Center or Early Start, e.g. the district only offers speech therapy in a group setting rather than 1:1. While resources are scarce, best evidence suggests that increased intervention in the early pre-school years might reduce or even obviate the need for more expensive special educational approaches later on. While much more research is needed in this area, the current emphasis on later special education would appear to be a less cost-effective strategy than earlier interventions.

### *Infant and Early Childhood Mental Health Issues*

There is growing evidence of the importance of the quality of early relationships for the future developmental trajectory. As such the concept of infant mental health is gaining validity, and the importance of intervening if there is a problem with the infant or the mother-infant dyad is gaining acceptance. Most pediatric providers in Orange County are not well attuned to the possibility of infant mental health or mother-child interactional or

relationship difficulties. Consequently morbidity in this area is usually not addressed representing a lost opportunity for intervention at a critical time. Resources for management of infant mental health problems are also very limited, however the resources which do exist report that they receive very few referrals from health professionals. Mental health services often carry a stigma, and the community may be reluctant to embrace a need for these services. Even if that is the case, far greater use of preventive services, e.g. Mommy and Me classes, Early Parenting classes and Video Modeling, would have great potential to improve the quality of these early relationships with the possibility of lifelong benefit.

**Gaps in System Performance**

***Prevention:***

There was a wide belief that insufficient funding was allocated for preventive services. This was especially emphasized in the field of mental health. Several providers suggested a re-examination of funding streams to determine whether funding for more prevention activities could be identified. A significant number of at-risk children could potentially be identified prenatally and intervention begun with parents on mental health issues and child development education before the child is born.

***Early Identification:***

While some children are identified early and receive services, many who would benefit from preventive services and early intervention are not recognized. The County's public health nurses and family resource center staff seem much more pro-active in this area and place a high priority on this function. While some pediatric health care providers are similarly pro-active, some providers appear to afford this area a much lower priority. Childcare providers, preschool teachers and others who have contact with young children have not been formally charged with identification to date, and may be reluctant to raise issues with parents

***Assessment:***

Children who are eligible for assessment at regional center receive the most comprehensive assessments, however even then there may be difficulties with coordinating all aspects of the assessment process, and including relevant subspecialty opinions (e.g. genetics, neurology). Opportunities for multidisciplinary assessment are otherwise very limited. Even the teams at EDAC and For OC Kids can offer some of the components of a full multi- or inter-disciplinary evaluation. Mental health professionals are not always included in the team approach, and these areas may not be being fully addressed.

***Treatment:***

Therapy options are generally good for that small proportion of children eligible for regional center, otherwise options are very limited. The types of therapies received by each child are generally determined by the regional center team. It appears rare that the child's primary care physician is involved in these recommendations, and as physicians report that they rarely receive correspondence from regional center and vice versa,

primary care physicians are generally unaware of the rationale behind a child's therapy approach and do not have input to it.

**Gaps in Service Sector Performance**

***Pediatric care:***

Significant gaps in the knowledge, skills and training of many primary care pediatric providers about child development and developmental services were reported throughout the study. Although exceptions certainly exist, in general healthcare providers are only weakly linked to education, intervention services and community based organizations. Even where local collaborations have formed around school readiness initiatives and other early childhood issues pediatricians are rarely, if ever involved. Over time, pediatricians appear, if anything to be becoming more separated from these services rather than more integrated. This situation has significant consequences for the functioning of developmental systems.

***Childcare:***

Childcare providers have prolonged contact with at least 30% of the Orange County early childhood population, so are in a good position to observe child behavior over time in a natural setting and to identify emerging difficulties. Despite this, traditionally child care providers have not received training in developmental surveillance or in communication of concerns to parents. A valuable role which childcare providers could be playing is not being utilized. As developmental and behavioral problems daily impact caregiver's interactions with the child, many childcare providers would be enthusiastic about a closer collaboration with health and early intervention services. Similarly, many would benefit from enhanced training in managing challenging behaviors, and in enhancing developmental potential of the children in their care.

***Specialty Care:***

There is a shortage of developmental pediatricians in Orange County. While this results in part from funding issues, developmental pediatricians are not yet accepted members of many teams dealing with child development issues. In most service sectors the potential contribution that these providers could make is not well understood, consequently there is little drive to find mechanisms to employ them. The pediatrician on a child development team is sometimes viewed as being there to contribute primarily their knowledge of physical medicine and to exclude a physical cause for the child's presentation. Access to geneticists was highlighted by some informants as an issue. For children who lack health insurance, access to specialists is particularly restricted.

***Financial Gaps***

The funding streams impacting developmental services are multiple and complex and are not well understood other than by a very small number of individuals in each service sector. In the health sector, most physicians have a very limited knowledge of actual and potential funding streams. Physician training predominantly occurs in large teaching hospitals where designated financial services staff are responsible for the fiscal aspects of health care. Consequently, trainees gain very little knowledge of this important area.

The majority of developmental services in Orange County are not based in hospitals but in the community. In some cases physicians find themselves for the first time managing budgets and funding issues with limited administrative support. This has the potential to negatively impact the time they can spend on tasks more suited to their training such as patient care, teaching and research. Many healthcare professionals have little knowledge of funding outside of their sector (e.g. from education or social services) which might be applied collaboratively to funding from other sources to enhance their programs.

Funding for Early Start for children at-risk of developmental problems is only active through to age 3 when intervention services generally must stop unless the child is eligible for special education. Funding for special educational services through the schools is widely regarded as inadequate for the task, as evidenced by high student: provider ratios.

Children who are CCS- eligible are funded for services related to their condition through CCS but not for other services they might need unrelated to their primary problem. Many procedures and therapies required by children with developmental issues require prior authorization from insurers. In many cases insurers will not pay for these services, or deny claims for services already performed. These funding idiosyncrasies are not well understood by parents or physicians resulting in large amounts of time being spent by providers grappling with difficult eligibility issues. This represents lost time to the health service when physicians could be delivering enhanced patient care.

***Data and Information Gaps***

The Commission has taken a very active role in strongly encouraging program evaluation to inform better client services and to allow analysis of the effectiveness of its funded programs. Some programs have experienced difficulty in complying with OCERS reporting. In some cases providers have had to obtain IRB clearance from their own institutions to allow reporting of this information. This process can be time consuming and utilizes resources designated for other areas. Provider perceptions are also important as some providers see little point in submitting the OCERS data which they see as predominantly process rather than outcome orientated i.e. they doubt the overall usefulness of the process.

Many providers expressed a desire to perform more research on the work they are doing but cited lack of resources and in some cases lack of skill as barriers. Many providers do not understand the reasons behind the Commission's policy of not funding research and see it as short sighted. The opportunities presented by the OCERS data system have not yet been fully realized.

The OCHNA and ECENA reports together with the 9$^{th}$ Annual report on the Conditions of Children in Orange County are excellent, well-researched studies whose results have penetrated the Orange County provider Community. Despite this, some providers such as primary care physicians do not have a high degree of awareness of the information in these publications.

# Analysis

Having described the current situation regarding developmental services in Orange County, we now perform a strategic analysis of these findings in relation to potential for development of a new system.

## Gaps Analyses

### *Conceptual Gaps*

Providers hold differing belief systems about the role of developmental services. Some providers still regard their role as principally to exclude the presence of serious underlying pathology or to identify that small percentage of children eligible for regional center services. Their motivation to look beyond this group to the much larger proportion of children with milder problems is therefore limited as they do not regard it as part of their professional role. The reasons for this belief system are multi-factorial and relate to beliefs and attitudes that were instilled during training. To a great extent this belief system is reinforced by insurers who place little emphasis on developmental services and in general do not reimburse them.

Conceptual differences are not confined to the healthcare sector but also influence education. Teachers who hold strong neuromaturational views are more likely to advocate for delayed kindergarten entry and grade retention as appropriate strategies to prevent school failure, rather than the additional evaluations and interventions which would be suggested by an educator with a more transactional model of child development.

The causes of many of the milder forms of developmental delay remain unclear, and providers and even parents differ in their understanding of the likely causes. Providers grounded in a traditional medical model tend to focus their efforts on determining physical causes, genetic predispositions, and potential environmental triggers. Providers from other disciplines and some physicians are more oriented to a transactional model which places far more emphasis on socio-emotional factors, family functioning and interactional factors as contributing to the clinical picture. Consequently services such as genetic consultations will be emphasized as a component of care in the medical model, with mental health interventions forming a less central part of management while in the social work model the emphasis will likely be reversed.

### *Service Delivery Gaps*

These also relate in part to differing conceptualizations of the causes of developmental and behavioral problems. It is well recognized that in order to receive services a diagnostic label must be applied. This situation benefits those children who have an easily recognizable condition such as Down Syndrome, but presents a problem for those children who have significant difficulties yet do not “fit” a diagnostic category. This also results in pressure within the system to label a child as having a condition (e.g. autism) in order to open up a funding stream for the delivery of needed therapy services. Misapplication of labels can, however, have lifelong consequences for the child. The lack of mid-level assessment centers for children with moderate neurodevelopmental

problems relates to funding issues but also may reflect a lack of knowledge about the true prevalence of these conditions with the exception of the COPE program. Little work has been done on low-cost community interventions such as parent education and parent-child intervention groups which fall short of a traditional therapy approach yet could still address the needs of a large number of children and families for enhanced services. Even children with identified conditions who are well linked to services may not have all their needs addressed, particularly in the socio-emotional and mental health domains.

### *Financial Gaps*

While these are recognized as one of the principal challenges to an efficient developmental services system, there is much work that could be done to enhance existing efforts in this arena. First, providers and parents could be better informed about funding streams, eligibility criteria, and realistic expectations of intervention services. More knowledge in this area would allow providers to be better guides in navigating the system for their patients, and in understanding how to maximize services or "play the system."

Providers could be better educated about funding streams outside of their own service sector. This could help individual patients but could also assist with cross-discipline understanding of service limitations and eligibility requirements.

### *Data Gaps*

The joint interest of the Commission and its grantees in developing a more extensive and outcomes-oriented evaluation of services should drive efforts to supplement Commission funds with research grants to enable innovative studies within the county. Existing data and evaluations of programs should be more widely distributed so that providers and parents alike know the strength of the evidence-base of the services they are accessing. The expertise at CHOC and UCI needs to be utilized to bring this goal of outcomes assessment to fruition. Such a partnership could drive significant attraction of external research funding. Expertise is needed not just in clinical studies but also in health services research and epidemiology.

# Strategic Analysis

## Vision

A number of individuals and groups within the county have strong visions for the future of developmental services. In some cases, however, these visions differ significantly and may even be mutually exclusive. For example, providers grounded in the medical model view an ideal system as one in which children with identifiable physical causes for their neurodevelopmental problems are rapidly identified and referred for diagnosis and therapy services. They view the management of those children who do not have identifiable causes for their problems, provided they are not severe, as largely falling outside of the health arena. This view is not confined to physicians but is also held by some educators and interventionists who are most comfortable working in an area separate from the medical model. They see little or no role for physicians in the management of these problems.

Parents, however, clearly do seek advice from their healthcare providers about developmental and behavioral issues. They seek help from education and health sectors and are confused by the lack of communication between these groups. Parents seek family-centered care and in their vision of an ideal system all services would collaborate and coordinate to provide a comprehensive system of family support, education, intervention and healthcare.

A new group of practitioners are seeking a "middle ground." They realize that child development is not exclusively the province of pediatricians, and are developing a new vision where health, education and social services sectors work together collaboratively to better meet family needs. Within this group, there is a spectrum of beliefs about the ideal nature of the pediatrician's role. Some view the physician as one of a group of professionals involved with children with neurodevelopmental issues – a team member whose role might be limited in the absence of identified pathology. Others view an expertise in child development as so integral to the practice of pediatrics that they see no choice but for the pediatrician to become an expert in this field, and a natural "captain of the ship" for a multidisciplinary team.

To some degree these differing visions can co-exist, however they make forward movement difficult as new initiatives move off in different directions. The visions are more likely to converge if there is increased communication, discussion and understanding of beliefs between groups, with movement toward a common shared vision. The visions are likely to diverge and become more polarized when funding is limited and proponents of the differing views must compete for funds.

## Goals

While stakeholders across different service sectors articulate different goals for a new system there is much common ground. Many of these differences stem from different cultural and world views. Most stakeholders agree that some intermittent assessment of development is warranted throughout childhood. However, the goals diverge in important ways. Some practitioners readily embrace the concept of less trained workers such as childcare providers and WIC staff playing a larger role in surveillance; others see problems and even dangers in this approach. The frequency of assessment is also

debated with some calling for some evaluation of development at every well child visit, as is recommended by the AAP periodicity schedule, while others view this as impractical and would argue for less frequent evaluations. The role of validated tools such as the PEDS also varies from use as a formal screen, to a more flexible use as a tool to aid discussion of development with parents. Much more discussion is needed before common goals can be articulated. Each sector will also need to develop sector-specific goals and objectives which articulate the role of that particular sector in contributing to the final goals of healthy development and school readiness for all children. Similarly, place-based goals will need to reflect the specific characteristics of that geographic location regarding cultural groups and local resources, while innovation goals will be specific to those new strategies, with measurable objectives to track progress towards the final goals over time.

**Leadership**

Orange County has a distinguished array of strong leaders across different service sectors. While capable of providing leadership within their own service sector, these individuals also have the potential to work across sectors, and to come together to create a common vocabulary to move the developmental services system initiative forward. This capacity for cross-discipline collaboration has not yet been fully realized. These leaders could effectively support each other across sectors developing a pathway for innovative change. Great changes within a service sector could result from input from leaders in other sectors e.g. pediatricians could contribute significantly to the training and best practices of childcare providers, while pediatricians would benefit from the enormous knowledge of local resources which resides with the public health nurses.

**Promising Practices**

A number of the innovative practices in the county around developmental services hold much promise. The HABLA program and Project Connections stem from a strong evidence base and have great potential for positive population impact if they could be rigorously evaluated and expanded. The COPE/CUIDAR Program offers a relatively low-cost intervention (parenting classes) as a first step in evaluation of children with attention problems, apparently decreasing the need for more expensive evaluation and treatment services later on. This concept of providing a lower cost intervention as a first step is one that is worthy of much further attention in other child development areas. The For OC Kids model provides a successful multidisciplinary collaboration and has achieved impressive community mobilization around the condition of autism. The inter-agency collaborations fostered by this initiative deserve replication on a larger scale.

**Financial Capacity**

Common funding barriers cut across sites and programs, and almost all programs funded by the Commission doubt their sustainability if commission funding were withdrawn. Doubts as to the longevity of programs have a significant negative impact on staff morale, ability to recruit new staff, and long-range planning efforts by the programs themselves. The situation also makes leveraging of funding very challenging e.g. to apply to a research funder for grant funds takes at least one calendar year even if the application is initially successful. The provider runs the real risk of funding for the core

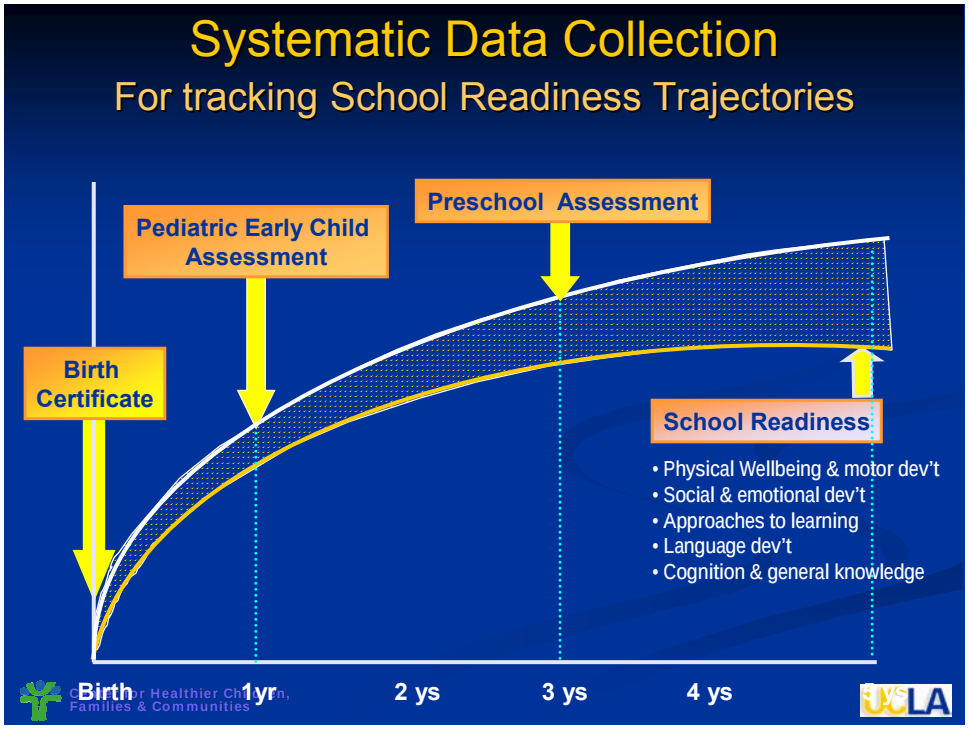
program being withdrawn prior to or shortly after research funding being received. This is an added disincentive to apply for additional funding.

**Data Systems**

While the great need for added research in this field has already been stated, new types of data tracking are also required to provide capacity to measure the health development of young children and their developmental trajectories. In an ideal system (Figure 7) developmental surveillance and screening data would be linked with preschool and school readiness data to give a comprehensive longitudinal picture of the child's developmental trajectory. Data on school readiness trajectories are important for policy formation and planning, since the two major policy goals of First 5 are to improve the school readiness of all children and to reduce the disparities (social gradients) in school readiness outcomes.

The Commission has made a strong start in this regard with its implementation of the OCERS data collection system with capacity to collect clinical and administrative data over time. While this allows potential to track changes in individual cases during early childhood, additional analysis efforts will be needed to fully operationalize this goal. While OCERS provides the mechanism for data collection, new "operating systems" will need to be developed with appropriately skilled evaluators to begin to plot school readiness trajectories. Orange County has the potential to build on its existing data systems to achieve this important aim. Greater use of existing data sources within the county such as special education entry data and regional center data will assist with measuring outcomes over time.

**Figure 7: Systematic Data Collection for Tracking School Readiness Trajectories**



## Discussion

### *Performance of Orange County Developmental Services*

Considering the findings of this targeted study in relation to the Commission's stated goals of healthy development and school readiness for all children, it is clear that the county's current developmental services are not producing desired results. National and county data confirm that a large proportion of children with mild and moderate developmental problems are not being identified until after school entry, so clearly are not entering school with their challenges already identified and addressed. Even when children are identified as having difficulties, they are often ineligible for therapy services until after they enter the school system and fail to learn. Children identified as at-risk for developmental problems who receive services through Early Start then drop out of services when they reach age three, leaving them at risk of later school failure. In short, a great many children with substantial developmental challenges are not having their needs addressed.

The study findings reveal a "pyramid of need" for developmental services within the 0-5 population (see Figure 8), with 100% of the population requiring ongoing developmental surveillance, up to 40% requiring some form of secondary screening or assessment, 10-20% requiring a fuller multidisciplinary form of assessment, and only 4-6% requiring the fullest level of assessment and ongoing longer-term therapy. The current developmental services system in the county is focused on identifying and serving the top tier, while the needs of those in the lower tiers are not well addressed.

**Figure 8: Pyramid of Needs for Developmental Services**

# PYRAMID OF NEEDS FOR DEVELOPMENTAL SERVICES

Regional Center Assessment and Therapy Provision
Only 4-6% children will need the highest level of multidisciplinary assessment and ongoing therapy.

Mid-Level Developmental Assessment and Interventions

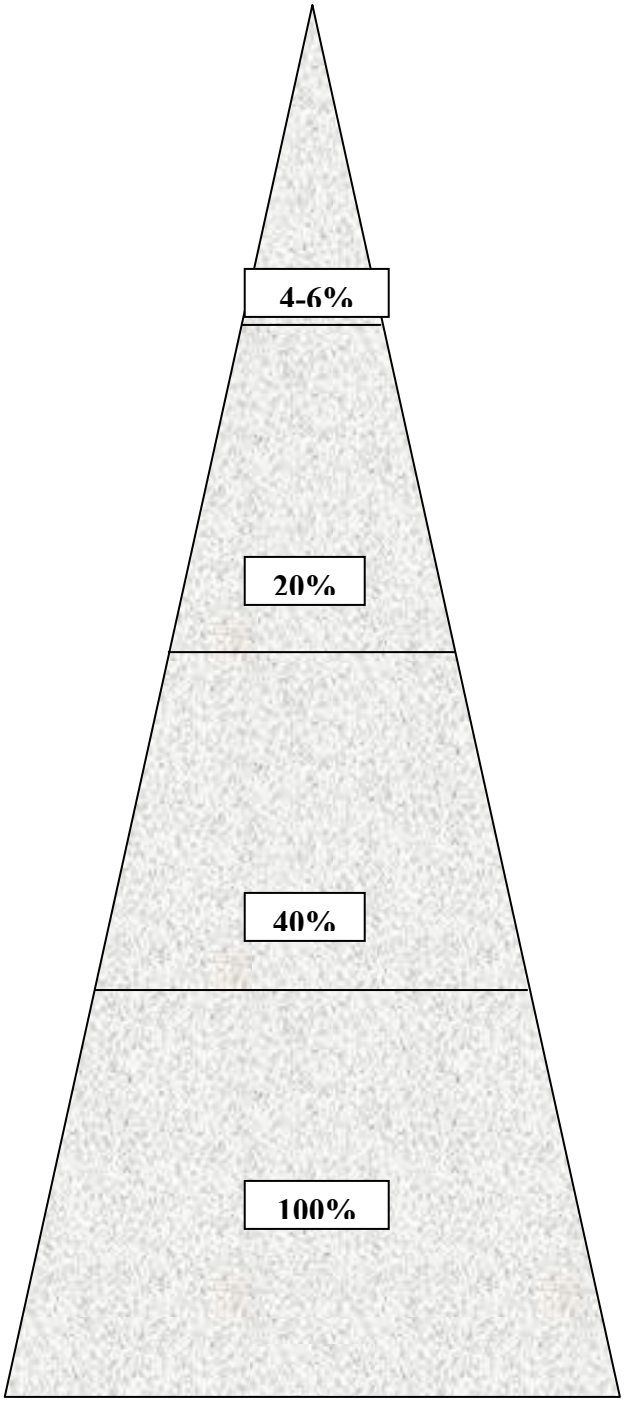
A smaller number of children, up to 20% of the population will need a specialized multi-disciplinary assessment, with referrals for community-based interventions.

Secondary Screening/ Surveillance

National estimates suggest up to 40% families will have additional concerns about their child's development or behavior, requiring secondary screening or surveillance by a pediatric healthcare provider or developmental specialist.

Community-Based Developmental Surveillance

- All children need developmental surveillance.
- Process should be continuous and flexible.
- Include community providers – Childcare and family day care, WIC and Pediatric healthcare providers.



The current system of developmental services in Orange County performs poorly on measures of *effectiveness* as it is not achieving the desired result. Similarly, issues of *cost –effectiveness* cannot yet be addressed because the system is not yet effective. The *accessibility* of developmental services to the population is sub-optimal. Pediatricians have a central role in the provision of developmental surveillance, yet few providers use validated tools, and the degree of penetrance of this activity into primary care practices is unclear but assumed to be similar to other parts of the country. While other providers such as public health nurses and family resource center staff have taken a much more pro-active stance on developmental screening and surveillance their numbers are small, hence impact of their programs at a population level is very limited. With a provider to patient ratio of 1:13,000 for the children in the 0-5 population suspected of neurodevelopmental problems, access to specialist developmental pediatricians is highly limited.

*Access* to multi-disciplinary assessments is largely limited to those children who are likely to be eligible for regional center services, to children suspected of autism, to those receiving neonatal high-risk follow up, and to those referred to the school district for consideration of special educational services. Children with somewhat milder problems that do not meet diagnostic or severity thresholds for regional center referral or services, that may be even more responsive to appropriate interventions, generally do not have access to a multi- or inter-disciplinary assessment, and appropriately directed intervention services. Access to therapy services is dependent on a diagnosis which many children fail to obtain under the current organization of services. For children not eligible for regional center or school based interventions, access to therapy services is very limited due primarily to cost and lack of insurance coverage.

Not all developmental services currently being provided are *appropriate* for the population. While establishment of eligibility for regional center services confers access to therapy services, many families then face transport, language and cultural barriers which limit the usefulness of these interventions. Some ethnic groups within the population appear reluctant to access services, and the reasons for this require much further research. They may relate to a stigma associated with being labeled as having a developmental disability, or may relate to language factors and lack of providers in this field who are members of the group's native culture. Many public health and mental health services suffer from an "image problem" and families from higher socio-economic groups are reluctant to access them, even when their child has an established need for intervention.

The *capability* of the current system has been called into question, with some providers lacking knowledge, skills and confidence in the child development area. Even those practitioners who have a high degree of skill in identification of neurodevelopmental problems lack training in how best to communicate these findings to parents. Too often, parents are receiving false reassurance in response to their concerns rather than practical advice on how to address the issues.

*Continuity of care and care coordination* are very challenging areas for the child development field. Continuity of care with a designated person/provider is very important

when assessing developmental, behavioral and psychosocial issues in young children. Since current instruments are lack optimal precision, continuous observation by a skill evaluator can fill in the gaps and help to correctly interpret the nuances of developmental transitions and challenges. What is increasingly the national norm is for children to attend the same practice or clinic and see different providers at each well child visit. Even good place continuity may be unable to achieve the precision that good personal continuity with a skilled clinician can provide. ( If in fact only 1 in 4 clinicians actually has the skills to do good developmental assessments, it may behoove children to see a different provider at each visit in order to increase the odds that at least at one of the visits they encounter a provider with adequate knowledge and skills).

Some groups of at-risk children such as those in foster care are continually moved around between services, and many children are forced to change providers at age three when their intervention becomes the responsibility of the school district. Even where care coordination is provided, it is often within rather than across service sectors. Coordinators and case managers often have limited knowledge of services available outside of their own sector.

Ultimately the system must be judged by its *acceptability* to the population, and how far it meets the expectation of the client, community, providers and paying organizations. While some parents who have children identified early within the system and who are eligible for services are satisfied, in general there appears to be much room for improvement. Providers working in this area largely feel that their efforts are under-recognized and under-reimbursed. The community is not seeing the desired result of having all developmental and behavioral needs addressed and remediated as far as possible prior to school entry. The acceptability of the current system to payers is less clear, and developmental services is an area which has not received much attention from the insurance sector.

### *Gaps*

The significant gaps found in the system are largely predictable and are not unexpected. Although the overall performance of the service system at population level appears sub-optimal there are many innovative approaches in the county with enthusiastic stakeholders who have the desire and the expertise to change the existing system. As some of these programs have only been operating for a short time it is not possible to comment on their long-term effects.

### *Vision*

While a new vision for service delivery is emerging with different stakeholders starting to collaborate around shared issues these visions could diverge if they are not united under a common banner. A process is needed to help forge a more common vision between those stakeholders that embrace either a predominantly medically oriented or predominantly community oriented approach to the provision of developmental services.

### *Data*

Orange County needs more local data on the neurodevelopmental needs of its population, as without it, service planning must be based on incomplete national data. Without an

accurate baseline it is difficult to monitor the success of new innovative programs, or document the success of a new system. Quality monitoring and assessing the performance of the existing health system is challenging as traditional HEDIS measures do not include provision of developmental services. Therefore it will be necessary to consider how additional measures of the quality of these services can be obtained, and used to provide incentives for quality improvement. Greater academic leadership, personnel with expertise in study design, epidemiology and health services research, and funding for research are needed in this area. In this way, the Commission's investment in OCERS can be fully realized.

# Options

Given these findings regarding developmental services, Orange County has a number of options for courses of action. Each carries a different degree of costs, benefits and risks and should be carefully weighed during decision making.

**Option 1:**

The first option would be to continue to fund discrete programs such as CUIDAR, HABLA and For OC Kids and to let them evolve over time, forming connections in the process of their growth and evolution. The short-term risk of this approach is low, the option is clearly achievable, and the cost is predictable. The disadvantage of this approach is that many of these programs are not sustainable without continuous funding from the Commission unless broader policy changes affect insurance reimbursements for these types of services. Second, these programs themselves already suffer from the limitations and frustrations imposed by the care delivery systems in which they operate and significant barriers prevent them from developing on their own. This means that the population impact of these programs, even if they were to be expanded, is likely to be limited. Third, unless Commission funding is increased, or additional funding is identified, a meaningful evaluation of the effectiveness of these programs is not possible.

**Option 2:**

The second option would be to continue several of the existing programs and to choose either a geographic area of the county or a specific service sector and target either a place-based or a county-wide sector-specific initiative. This might include ensuring that all pediatric offices in an area become medical homes capable of providing high quality developmental services or that all pediatric offices across the county provide Reach Out and Read programs. This approach carries medium-risk, is more difficult to achieve and carries a higher cost.

- The problem with this kind of approach is that the results of our research in OC and research that we and others have conducted nationally, clearly indicate that pediatric offices experience great difficulty upgrading their ability to provide better quality developmental services unless they have better connections to appropriate diagnostic, intervention, and other specialized services.
- Pediatric offices need a full service delivery pathway that connects them with the community of child care and school readiness providers that have essential information about the child's development and that can be a great source of information and ongoing intervention.
    - Offices also need to be able to refer children for more complete diagnostic assessments and services.
    - If the pathway leading into the medical home and leading from the medical home into the world of more specialized diagnostic and treatment services is not functional then there are real disincentive (fiscal, organizational, and ethical) for upgrading the capacity and quality of the medical home.

**Option 3:**

Because these other options would not achieve the Commission's stated aims, we propose that Orange County consider a third option, a more ambitious, comprehensive and integrated approach to creating a developmental services system. This system would, by definition, utilize an integrated, multi-disciplinary and multi-sector approach. While this approach would require taking advantage of every available opportunity and thwarting many existing challenges, we believe it is in fact the most desirable option as the other approaches will fall far short of reaching the desired result. In addition:

- Widespread system change is in keeping with the First 5 mission to create new and sustainable capacity to provide services, programs and systems that can ensure healthy development and school readiness for all children. It also represents a logical next step for the Commission to integrate the innovative programs and resources that it has created e.g. COPE/CUIDAR, HABLA, School Readiness Centers and others into more functional service pathways.
- The proposed new system represents an important step for the entire field of early childhood health and development.
    - Nationally the SECCS initiative is trying to get states to create early childhood systems that link health, early education, parenting and other developmental services together.
        - Upgrade the medical homes.
        - Create more effective community based developmental service systems.
        - Leverage existing funding and service into more functional systems that provide better quality developmental services- effective, efficient, accessible, acceptable, equitable etc.
- We believe that this option is feasible given certain fiscal, political and organizational considerations. In presenting our proposal we have addressed these considerations by suggesting a set of linked strategies that we believe can be utilized to create the optimum conditions for success.

# Proposal for Model Developmental Services System for Orange County

## Introduction

This report assesses the current status of the delivery of developmental services to children zero to five in Orange County. It also proposes creation of a county-wide developmental service system. This system would enable Orange County to be responsive to the:

- Estimated 40-50% of parents of preschool age children who have concerns about the development and behavior of their young children.
- 10-20% of preschool children who have unrecognized, undiagnosed, and potentially debilitating developmental disabilities.
- Substantial proportion of children who have a greater chance of reaching their developmental potential if their parents and other caregivers are provided information, guidance and customized developmentally targeted interventions.
- Needs of child care, school readiness, and other early education providers who are attempting to provide services to children who have undiagnosed and untreated developmental challenges, behavioral or mental health problems that would benefit from more timely diagnosis and treatment.
- Child health providers who face a number of organizational barriers and disincentives for screening and assessing children and who face significant barriers in connecting children and families to available diagnostic, treatment and intervention services.
- Community, civic, and business sectors that want to assure that all children in Orange County can experience optimal conditions for healthy development, so that they can be launched on an educational trajectory that gives them the potential to grow and develop into a healthy, productive, and competent work force.

The proposal is also strategic in that it:

- Takes advantage of state-of-the-art knowledge about the delivery of developmental services in community settings.
- Utilizes best practices, and new and emerging technology to enhance the capacity of the child health care system to improve the quality of the services they provide.
- Suggests specific sector strategies *(e.g., child care/school readiness; pediatric/child health care; health payers and insurers)* that can upgrade the quality of services provided within each of these sectors and create bridges across sectors for more effective delivery of services within the system.

- Calls for the introduction of several innovations in each one of these sectors and throughout the system; innovations that are necessary to improve functionality, take advantage of new technology, and also to achieve a tipping point momentum within and across the sectors and service providers involved.

- Responds to the unique needs and existing capacities of local communities by combining sector-based changes with place-based strategies.

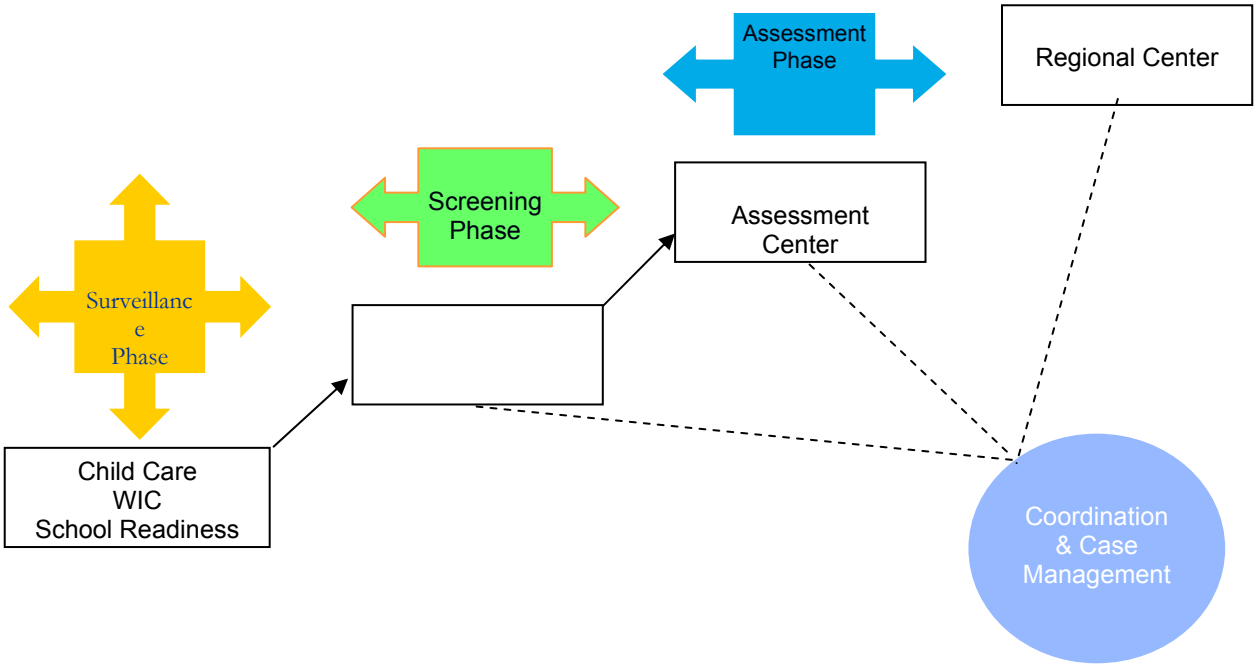
In this section of the report we will first provide an overview and basic design features of the developmental services system that OC should consider creating. We will then discuss the specific components of that system, the specification of those components, and how they are integrated together. We next discuss a package of linked strategies that can be employed to implement this ambitious re-design and re-engineering effort. Lastly we address other significant infrastructure, finance and training issues that also need to be addressed.

**The System**

As we presented earlier, there is a hierarchy of need for developmental services within the child population in Orange County. All parents require additional information and support in order to optimize their children's development and identify potential problems at the earliest possible juncture. In addition, all children require regular and periodic surveillance and screening to detect potential developmental disabilities and also to support optimum development. For a smaller proportion of children, additional diagnostic assessments will be necessary, as well as particular interventions to address specific problems and/or potential risks and deficits. For an even smaller proportion of children, there is a need for intensive services based on the level of neurodevelopmental disabilities. The pyramid in **Figure 8** describes this hierarchy in more detail.

Corresponding with this pyramid of need, we propose a comprehensive, community-based, and integrated system of developmental services (**Figure 1**). We propose the creation of a new system rather than a set of piecemeal projects and reforms, since many of the barriers to the delivery of developmental services are, in fact, systematic in nature. The research literature in this field clearly demonstrates that there are systematic financing, organizational, training, skill, and technology barriers that hamper the provision of effective service delivery pathways. Therefore, if those barriers are to be overcome in a strategic and systematic way, an overall system needs to be designed and developed.

**Figure 1: Model System of Developmental Services**




The system we propose has four basic levels, each corresponding to the four levels of the pyramid of need. The First Level is responsible for community-wide surveillance and provision of population-based developmental services. In this first tier of the system, the service providers include school readiness sites, child care centers, WIC sites, and other programs that have regular and continuous relationships with children zero to five and their families. This tier is responsible for providing essential information to parents to support their child rearing capacities, and conducting ongoing surveillance to detect developmental disabilities and/or identify risks that could interfere with the achievement of optimal developmental function.

Research that we conducted in Orange County showed that there already exist individuals within these service sectors who have expressed concerns about the late identification of child development problems and a willingness to form part of the solution. While additional training will be required to enhance expertise in this area, and the approach to discussion of child development issues with parents will need to be carefully planned, this initiative is feasible, and is in fact well aligned with national and international trends to develop community-based systems which support all parents.

Child care workers in Orange County have been asked by the State of California to implement "Desired Results for Children and Families" (California Department of Education 2003) and to determine whether children in their care are reaching designated milestones. Childcare professionals realize a need for increased training in this area if these approaches are to be successful, and there is a good opportunity for collaboration across health and education around this initiative. The Second Level of the system revolves around the provision of specific developmental screening and intervention services by pediatric providers in pediatric offices, clinics, and related institutions. The goal here is for these pediatric health care providers to be able to improve the quality of

the developmental services they provide, and to increase their ability to provide an effective and efficient developmental screening for children so as to provide appropriate developmental guidance and education, as well as interventions that are delivered in a pediatric office. This set of system design and reform specification are responsive to the American Academy of Pediatrics Medical Home and Bright Futures initiatives that seek to assure that all children have a medical home where care is accessible, family-centered, continuous, comprehensive, coordinated, comprehensive and culturally effective. Care should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. We believe that this initiative includes the provision of high quality pediatric care including developmental services.

Research conducted in Orange County confirms what has been found nationally; despite their best intentions, many pediatricians find it very difficult to provide developmental services because of systematic barriers. These include deficits in their own knowledge, inability to acquire the appropriate tools and techniques, problems with appropriate reimbursement, and lack of places to refer children for additional and more specific diagnostic assessments, such as hearing and speech.

Even though there are many barriers to the provision of developmental services, there has been a great deal of work nationally on developing a package of quality improvement that can be introduced into practices in a systematic way. These improvement kits have been shown to upgrade the ability of practices to provide these services and improve the quality of the services they deliver.

The Third Level is something that does not currently exist in the current health care system, and that is what we call a Mid-level Developmental Assessment Treatment and Coordination Center. This would be a community-based, multidisciplinary center capable of providing specific diagnostic assessments of developmental, behavioral, and mental health problems in children, as well as coordinating and case managing the services children and families may need. As our research showed, when children with suspected problems are seen by pediatricians, they are often sent to the regional centers for developmental assessments even though they may have relative moderate to minor developmental delay rather than the severe neurodevelopmental problems that the regional centers are designed to address. So at present the Orange County regional center (as is the case in all Regional Centers through out California) is flooded with children who basically need a formal developmental assessment. There is no other location where children who do not have clear neurodevelopmental problems, but have other developmental challenges and risk factors, can be assessed and/or be connected with the appropriate community-based services and parenting supports. Therefore, the need for such an assessment center is high.

Recently the cities of Hartford, Connecticut and Denver, Colorado have instituted such mid-level assessment centers with great success. Not only have these centers been able to provide needed services, but their presence has also enhanced the ability of pediatricians to provide surveillance and screening services since they now have some place to send the children who need to be assessed.

The Fourth Level would be the regional centers which are for children at the top of the pyramid who require specialized diagnostic treatment and long-term rehabilitation services.

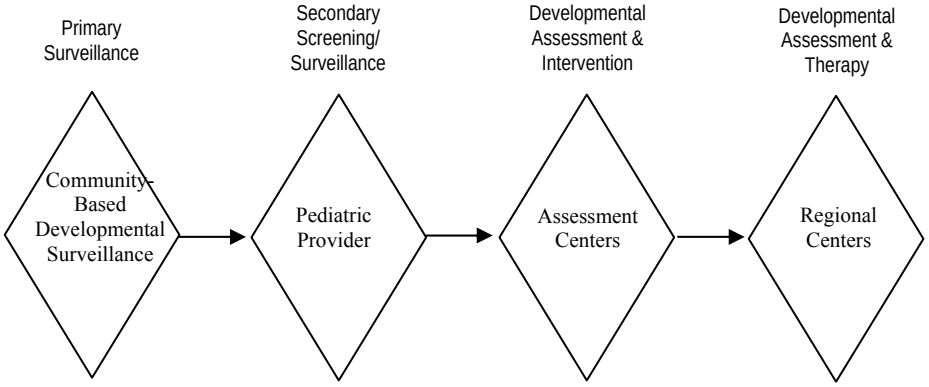
In addition to the specific components of the system, there is also the need for a coordination mechanism to provide a range of services, including connecting families in the First Level with pediatricians; children in pediatric offices with the assessment centers; and making sure that the pathways are functioning appropriately. The coordination center should also play a role in developing and securing services in communities.

**Components of the System:**

***First Level: Community-Based Surveillance and Supports***

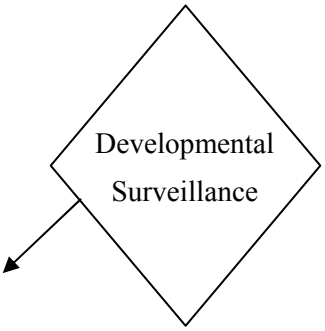
An effective system of developmental services requires population-wide support for optimal development, as well as a surveillance system that can identify children who have specific developmental problems or who are at risk for developing these problems. At present, Orange County has a growing capacity in their school readiness and child care sites to provide these functions. Nonetheless, there remain a number of challenges, as well as other opportunities, to provide these services. There are also good examples across the country where community-based child care and school readiness sites have upgraded their service delivery capacity and introduced specific innovative programs to increase their capacity to provide these types of services. **Figures 9-13** provide the specifications for the system and for the specific sites that will be necessary to move this process forward.

**Figure 9: Developmental Services Pathway**




Arrows represent flow of information and of clients across the four tiers of the system. The system will be flexible to allow for direct referral of children to regional center from any of the tiers when eligibility appears likely. Similarly, first tier providers can refer directly to a mid-level assessment centers when parents wish, with information about the referral being transmitted to the child's medical home as parents permit. *The system will need to be closely monitored for quality assurance to ensure that children do not become "stuck" inappropriately at one level when they should be moved on to the next.* If any of the levels appears to be providing an inappropriate or restrictive "gatekeeper role" then that sector of the model will need revision.

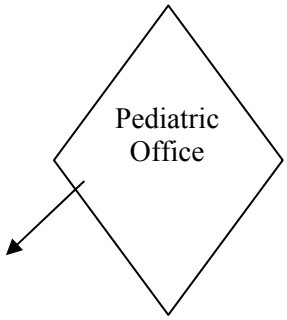
**Figure 10: Developmental Surveillance**




Developmental System Specifications

| | |
|---|---|
| Timing | • Flexible<br>• Continuous |
| Process | • Enhanced sensitivity to expressed parental concerns<br>• Enhanced recognition of developmental and behavioral problems<br>• Intermittent selective use of validated tools such as PEDS and ASQ |
| Facilities | • Childcare and family day care centers<br>• WIC centers<br>• Pediatric provider's office<br>• Preschools<br>• School Readiness Centers |
| Staff | • Childcare providers<br>• Pediatric healthcare providers<br>• Preschool teachers and nurses<br>• Public Health Nurses<br>• WIC Staff<br>• Mobile teams of developmental service providers |
| Staff Development and Training | • Training modules on child development and family-centered care<br>• Undergraduate and postgraduate courses and workshops<br>• Training on use of surveillance tools e.g. PEDS<br>• Training on talking to parents about child development issues |
| Service Relationships | • Develop relationships between community-based providers and medical home<br>• Community providers to work on an inter-disciplinary model of surveillance collaboratively with child development specialists. |
| Funding Resources | • EPSDT<br>• Commission Funding |
| Information flow | • Develop information pathways between community-based providers and medical homes<br>• Develop written tools to communicate surveillance findings to parents avoiding over-pathologizing |
| Quality monitoring and improvement | • Develop surveillance indicators.<br>• % children identified with problems or at-risk<br>• Parental perceptions of and satisfaction with the process<br>• % children receiving services at follow-up<br>• Outcomes on school readiness indicators e.g. language development |

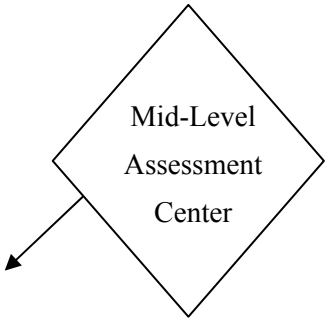
**Figure 11: Secondary Screening**




Developmental System Specifications

| | |
|---|---|
| Timing | • Flexible, Continuous surveillance<br>• Intermittent use of tools e.g. PEDS and ASQ<br>• Selective use of other tools, e.g. McCarthy Scales of Language, CBCL, PSC, and Denver II |
| Process | • Enhanced sensitivity to expressed parental concerns<br>• Enhanced recognition of developmental and behavioral problems<br>• Intermittent selective use of validated tools such as PEDS and ASQ<br>• Secondary screening of children referred from other providers |
| Facilities | • Pediatric Provider Offices |
| Staff | • Pediatricians<br>• Public Health Nurses<br>• Family Practitioners<br>• Pediatric Nurse Practitioners<br>• Developmental Specialists |
| Staff Development and Training | • Training modules on child development and family-centered care<br>• Undergraduate and postgraduate courses and workshops<br>• Training on use of surveillance tools, e.g. PEDS and ASQ<br>• Training on use of specialized tools, e.g. CBCL and McCarthy Scales<br>• Enhance provider knowledge of community-based services |
| Service Relationships | • Develop relationships between pediatric providers and assessment centers, community-based services |
| Funding Resources | • EPSDT, CHDP<br>• Medi-Cal, Managed Care, Third-Party Payers<br>• Commission Funding |
| Information flow | • Develop information pathways between medical homes, mid-level assessment centers, and community-based intervention services<br>• Develop written tools to communicate findings to parents, other professionals, assessment centers, and intervention services. |
| Quality monitoring and improvement | • Develop secondary screening indicators<br>• % children identified with problems or at-risk<br>• % children referred for mid-level assessments<br>• Parental perceptions of and satisfaction with the process<br>• % children receiving services at follow-up<br>• Outcomes on school readiness indicators e.g. language development |

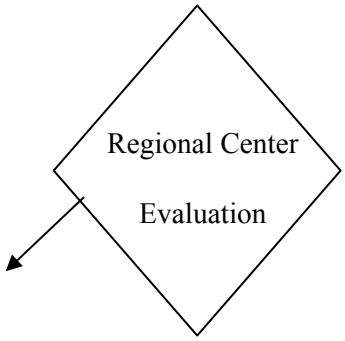
**Figure 12: Mid Level Assessment**




Developmental System Specifications

| | |
|---|---|
| Timing | • On referral from community providers, pediatric healthcare providers and directly from parents |
| Process | • Inter-disciplinary developmental assessment based on Zero to Three Guidelines for comprehensive assessment in motor, language, cognitive and social-emotional domains |
| Facilities | • Centers located throughout Orange County<br>• Ability for Mobile Team to travel to other locations for assessments.<br>• Provision of low-cost interventions on-site, e.g. parent groups and language stimulation classes |
| Staff | • Developmental Pediatrician<br>• Psychologist (cognitive testing)<br>• Psychologist (Mental Health)<br>• Speech Pathologist (Language Assessment)<br>• Occupational Therapist<br>• Administrative Staff |
| Staff Development and Training | • Training on Interdisciplinary Collaboration<br>• Training on Assessment Methods<br>• Improved knowledge base of therapy and intervention options<br>• Training on communicating findings to parents |
| Service Relationships | • Develop relationships between assessment center, community based surveillance, screening staff and medical homes.<br>• Develop relationships with early intervention providers |
| Funding Resources | • EPSDT<br>• Commission Funding<br>• Medi-Cal and Third Party |
| Information flow | • Develop information pathways between medical homes, regional center, intervention services and assessment center<br>• Develop written tools to communicate surveillance findings to parents |
| Quality monitoring and improvement | • Develop assessment indicators<br>• % children identified with problems<br>• % referred to regional center or for other services<br>• Parental perceptions of and satisfaction with the process<br>• % children receiving services at follow-up<br>• Outcomes on school readiness indicators e.g. language development |

**Figure 13: Regional Center Assessment**




Developmental System Specifications

| | |
|---|---|
| Timing | • On referral from community providers, pediatric healthcare providers and directly from parents |
| Process | • Inter-disciplinary developmental assessment based on Zero to Three Guidelines for comprehensive assessment in motor, language, cognitive and social-emotional domains<br>• Therapy provision and case coordination |
| Facilities | • Regional center plus satellite sites |
| Staff | • Developmental Pediatrician<br>• Psychologist (Cognitive testing)<br>• Psychologist (Mental Health)<br>• Speech Pathologist (Language Assessment)<br>• Occupational Therapist/Physiotherapist<br>• Administrative Staff |
| Staff Development and Training | • Training on Interdisciplinary Collaboration<br>• Training on Assessment Methods<br>• Improved knowledge base of therapy and intervention options<br>• Training on communicating findings to parents and providers |
| Service Relationships | • Develop relationships with community based surveillance/screening staff and medical homes<br>• Expand relationships with early intervention and special education providers |
| Funding Resources | • IDEA-Part C Funding |
| Information flow | • Develop information pathways between regional center and medical homes, community providers and mid-level assessment center<br>• Enhance written tools to communicate surveillance findings to parents and providers |
| Quality monitoring and improvement | • Develop assessment indicators<br>• % children identified with problems<br>• % referred for therapy<br>• Parental perceptions of and satisfaction with the process<br>• % children receiving services at follow-up<br>• Outcomes on school readiness indicators e.g. language development and need for special education |

### *Second Level: Secondary Screening and Surveillance*

Pediatricians are in a good position to provide second-tier services for children identified as at-risk or as having developmental problems by the community-based surveillance system. Some offices, such as those in the Healthy Steps model, have achieved this by stationing a developmental specialist in the provider's office. This model can be expensive, but might be appropriate for those practices that can and wish to provide it. Alternatively the skills of the general pediatricians can be upgraded through additional training to allow them to play this role.

### *Third Level: Mid-Level Developmental Assessment, Treatment and Coordination Center*

More than one center will need to be developed in Orange County to serve the likely volume of referrals from active surveillance and secondary screening. One of the centers at least should have capacity to perform mobile assessments, traveling to parts of the county where transportation issues preclude client attendance at one of the centers. These centers could be co-located with existing Commission programs such as EDAC, For OC Kids, COPE/CUIDAR and at School Readiness Sites, or could be located in separate facilities. The sites could also have capacity for the delivery of low-cost interventions such as parent education groups, Mommy and Me classes, language stimulation groups, and parent training classes on redirecting children's behavior and fostering longer attention spans. Some of the most challenging aspects of providing developmental services could be addressed through a dedicated care coordination unit, that might include call center and a web-based resource list associated with these mid-level centers, modeled after the Connecticut Help Me Grow program. The success of the Connecticut model and the importance in overcoming the difficulty in linking services, and coordinating services that make up a functional delivery pathways makes this a high priority strategy.

### *Fourth Level: Regional Center*

Regional Center will continue to determine eligibility for and deliver IDEA Part C Services. Relationships and communication with pediatric healthcare providers, community surveillance sites and mid-level assessment centers will need to be developed and strengthened. While the proposed system changes should result in earlier identification of children needing services, the referrals to regional center should be much more appropriate given the increased system capacity for detection and management of more minor developmental problems, and so should prevent flooding of this service.

### **Strategies:**

In order to be strategic and responsive to parents, child care and pediatric providers, and communities, we suggest a set of strategies to create, roll out, and implement the system. Inevitably, existing services and agencies will be concerned about their potential roles within this new system. It is envisaged that existing services will all be incorporated into the new model, but with enhanced connectivity, capacity and functioning. This should result in greater efficiency and effectiveness of individual services and enhanced staff satisfaction for providers.

***Time and Phasing:***

Since it will take at least 5 years to get this new system fully operational, a time and phasing strategy is important. To facilitate this phase-in process, we recommend that the commission develop specific strategic and business plans for each tier of the system and the specific sectors involved. These strategic and business plans should provide a detailed set of considerations and plans for the five-year period with the expectation that refinement and improvement of the system will require a 10-year horizon. The plans should include:

- A vision for that tier or sector with specific short- and long-term goals and objectives;
- A communications strategy with key messages targeting key audiences in order to advance the strategy within that tier or sector;
- A leadership strategy for the development of leadership within that sector or tier, as well as for nurturing appropriate cross-sector and tier relationships;
- A strategy for the leveraged and sustainable funding of services provided in that tier or sector;
- A strategy for monitoring the delivery of services and improvement of services over time.

***Sector Strategy:***

Because of the level of service delivery change and the introduction of important innovations, it will be important for peer-to-peer training, quality improvements, and funding to develop sector-specific strategies. Sectors include pediatric health care, child care and early education centers, and school readiness sites. Since each of these sectors has a different culture, vocabulary, service delivery, and funding, sector-specific strategies are going to be necessary in order to drive the re-engineering that is essential to move each sector forward, in order to accomplish the goals and objectives of the overall system delivery. Since current financing options tend to be somewhat sector specific ( Health care uses Medi-Cal, Healthy Families, EPSDT and CHDP, developmental disabilities uses CCS and IDEA funding), it will be necessary to develop finance strategies that are sustainable within each sector. In addition, since each sector will take advantage of unique innovations, having well organized and sector-specific plans will:

- Encourage collaborative learning and system change strategies within a specific sector in order to assure the adoption and spread of the specific innovation.
- Take advantage of the sector specific cultural and organization strength and allow for specific strategies that leverage entire institutions within those sectors.
    - For example in the health care sector it might be possible to leverage the participation of birth hospitals to create developmental service delivery platforms within family resource centers based on the very successful and sustainable model of the Hope Street Family Center in Los Angeles.

- Allow for the overall initiative to approach foundations and federal and other funding sources for the support of sector-specific innovations.

    - For example, within the childcare sector we might decide that it is important to introduce a Reach Out and Read program within the child care sector. To make this happen, we could approach specific foundations and agencies interested in early literacy to support a multi-center trial within child care centers in Orange County.

***Innovation Strategy:***

Much of the work to enhance developmental services across the country has focused on the introduction of a number of innovations into traditional practice and service sectors. For example, one of the great innovations in helping pediatric providers focuses more on early literacy and cognitive development has been the Reach Out and Reach program. This program has been shown to be highly effective in augmenting parents' early literacy behaviors and improving the development of children's vocabulary. In order for the entire service system to develop, and for different service providers and sectors to redesign and re-engineer current service offerings and connections, there are a number of innovations that will be necessary to enhance the capacity of pediatric providers, child care providers, and school readiness sites to perform the services that they will need to in order to make the service system work. Again, by creating a set of strategies to foster innovations, it will be possible to prioritize these and approach required technical assistance and funding partners in order to realize the potential within each of these strategies. This might include the development of sector specific innovations teams that are responsible for considering how to develop innovations within a specific sector.

Similarly there could be place based innovation teams that want to consider how they can foster the adoption of innovations like Reach Out and Read in all the pediatric practices and child care centers in their communities. In the financing section below we also suggest the development of an endowed innovation fund that can be administered and managed to foster innovations and draw down available matching and research funding to support this process. This set of innovation strategies can be marketed as a way of keeping OC at the forefront of this emerging field and in a place to draw down available dollars that will be used to foster innovation nationally.

***Place-based Strategies:***

Since different communities in Orange County have different existing capacities and different levels of need, if the overall system is to be optimally successful, it is very important to make sure that each tier is functional within these varied community and geographic units. Therefore, we recommend specific strategies for, e.g. Anaheim, Westminster, Santa Ana, and/or specific communities. This way we can assure that community-level and city-level leadership is developed to support all components of the system within their respective realms.

***Collaborative Strategies:***

Each of these strategies lends itself to the development of collaborative learning and rapid reengineering strategies. By using sector strategies, we would be able to work across the child care sector and help them introduce new surveillance tools into child care

settings so that they can upgrade their ability to provide these services across that sector. Similarly, collaborative strategies can be used in the pediatric sector to help pediatricians upgrade their ability to perform screenings and specific interventions like Reach Out and Read. Not only can collaborations be done within a sector but they can be done across sectors within a community. For example, Anaheim, Westminster, Newport Beach, and Santa Ana could be part of a community-based collaborative where these geographic areas implement all components of the system. From our standpoint, this ability to initiate collaborations within sectors and across communities has the highest likelihood of reengineering services into the kinds of systems and pathways that are necessary to achieve the goals of this initiative.

***Funding Strategy:***

There are a number of financing considerations that this proposed system must address. First, funding will need to be made available for the process of system creation and redesign. Funding will be needed for the development and design of specific components of the system, as well as for the innovation strategies, system accountability, information and improvement and related system infrastructure. At present, there are a number of federal and state funding streams that are available to fund many of the services and system development characteristics we propose. In fact, a large proportion of the services being proposed are potentially fundable under the current federal Medicaid and EPSDT guidelines. But in order to secure such funding and make this system operational, it will require redirecting funds that are currently coming to Orange County and specific institutions.

In order to create and redesign the current system, the Commission will need to reallocate funds to create the strategic and business plans that are appropriate for this venture. It will also need to support:

- Funding for strategic communications within sectors, across sectors, and to key audiences.

- Identification of targets of opportunity, to enhance funding for specific innovations and specific federal programs.

It will also be important to develop a financing strategy that considers all existing federal, state, and local public dollars and how those dollars could be redirected, pooled, integrated, or leveraged in order to accomplish the goals of the system.

It would be highly desirable for the Commission to consider also how it will build research and development capacity to support this initiative. Both UCI and Children's Hospital of Orange County, as well as the AAP, have enormous existing capacity that could be leveraged by providing additional funds to build the academic research and training infrastructure that is necessary to support this initiative. This would include an endowed research fund that was allocated towards the development of better service delivery. Such and endowed fund might be initially created using First 5 Commission funds on a matching basis, with a targeted fundraising campaign organized and coordinated by UCI and CHOC to raise the matching dollars from corporate sector in OC. This is distinct from additional funds that might be necessary to develop new clinical programs. Building the pediatric and child health service research capacity within CHOC

and UCI would support this process. In addition, the Commission could consider how it might leverage its monies within those institutions to garner endowed research funds and endowed professorships that would attract additional world-class faculty and research capacity to leverage millions of additional dollars from the National Institutes of Health and other related funding organizations.

### *Governance*

In order for this system to come into being, it is going to require a governance structure that can both be strategic and responsive to the needs of the First 5 Commission and its strategic goals for Orange County. We suggest that you set up a steering committee of key stakeholders, as well as a subcommittee structure. Subcommittees should include groups looking at the development of innovative programs; sector-specific strategies, including pediatric, child care, and school readiness sectors; community-based, place-based system development; and the development of infrastructure, financing, and other pathway support.

### *Training*

There is going to be a significant multidisciplinary and long-term set of training and education needs. This includes:

- Educational information, materials, and social marketing focused on parents and a range of different providers.

- Training of service providers, including existing child care, school readiness, WIC, and other service providers – as well as training individuals who will be assuming positions in those organizations.

- Training of pediatricians and, specifically, developmental pediatricians and enhancing the capacity of current training programs in Orange County and Long Beach to provide enhanced training in this area.

- Workshops for providers from different disciplines to meet and form personal contacts across service sectors.

This might be best accomplished through the development of a training consortium that includes UCI, Children's Hospital, Cal State Fullerton, and various community colleges and other institutions. Similar training consortiums that have been quite effective have been developed in other areas.

## Feasibility and Sustainability

The feasibility of creating and sustaining the continuous improvement of a comprehensive and integrated developmental services system will require additional consideration. This can be better assessed after considering a more detailed strategic and business plan, where both cost and potential revenue can be more fully assessed. While we have suggested a range of potential funding approaches, each one of these must be evaluated in more detail.

**Phase 1 Implementation Outline**

Given the necessity for a staged phase-in of the model system we propose the following next steps to initiate the process during the initial 1-2 years.

1. ***Place-based Strategy*:** All four service levels of the model-community surveillance, secondary screening, assessment and intervention should be established in two communities in Orange County. This process will involve training of all the relevant providers in those two areas – pediatric healthcare providers, teachers, childcare workers, preschool staff, WIC staff and all who are in regular contact with young children 0-5. Providers will need to come together and explore new ways of working together to ensure an efficient comprehensive approach to developmental services.

An integral component of the new model will be open communication and a closer collaboration between different professional groups, requiring a cultural shift to a more collaborative family-centered service. This will require training in both communication and cultural competence possibly initiated in a series of workshops aimed at developing relationships across organization and disciplines, examining belief systems and cultures, and forging new ways of interacting across services. This would build on the work done in Australia in the Platforms model (see p 61), and will form the underpinning of the "Community-Ready" aspect of program initiation. A parent education component will be initiated in the two communities. Parents have the greatest knowledge of their children and are often the first to suspect a problem. It is essential that they know how to voice their concerns and where to go for help about developmental and behavioral issues. Parent satisfaction levels and measures of family-centeredness will be important indicators of the new developmental services model.

The two communities chosen as pilot sites for implementation of the full model should ideally already have proven ability to build capacity, and have strong leadership in place at the local level, with pediatric practices willing to be involved. The way in which each local community embraces and responds to the new model will be pivotal to its success. The mechanisms for achieving community-building at these local levels will need to be more clearly articulated as the model is developed, but could include training on family-centered care, and working with the communities to help them to develop ways of monitoring their own progress towards goals, as has been piloted in the Australian Platforms model.

2. ***Sector-based Strategy*:** At the same time as the place-based strategy is initiated in two communities, a series of sector-specific strategies will be implemented. For pediatric practices the initial focus will be on the implementation of developmental surveillance activities using a validated tool, the PEDS. A series of pilot sites will be chosen by the Commission and the AAP to pilot this initiative. This process lends itself to a collaborative learning strategy such as use of the Breakthrough series to re-engineer practices and ensure the smooth incorporation of the PEDS as a developmental surveillance tool into office practice. Continuous "Plan, Do, Study, Act" Cycles will be used to inform office practice change and achieve developmental services aims. This process will be evaluated to document levels of developmental surveillance achieved. Following use of "Breakthrough Series" type of activity, it is envisaged that best

practices will spread to other pediatric providers in the county so that the momentum of the new initiative is maintained.

Pediatric office-based surveillance strategies will only be successful if there is also enhanced communication and linkage with other "levels" of the developmental services pyramid. Consequently, preliminary linkages will be initiated between physician offices and childcare providers to deliver a more collaborative approach to developmental monitoring. The possibility of developmental surveillance being performed in childcare settings will be explored. Some initiatives will be implemented across entire service sectors in the county e.g. Reach Out and Read in all pediatric practices, with consideration of a new "Reach Out and Read" in childcare and family day care centers.

3. ***Establishment of Mid-Level Assessment Center*:** A planning process will begin, led by the CHOC-UCI Collaborative, for the development of a mid-level assessment center in the county focused on delivering assessment services to children with developmental and behavioral problems which fall short of eligibility criteria for regional center. The location of the center should be decided in collaboration with the geographic focus of the place-based strategy. Financing and sustainability of the center will be key issues and a sound fiscal plan using multiple potential funding sources will be created. As the center develops, it is envisaged that it will offer low-cost interventions for common childhood developmental issues, while developing its role as a community resource for education on child development. Care coordination could be provided through a call-center or web-based resource.

4. ***Establish a Care Coordination Program*:** Care coordination could be provided through a call-center similar to the center that is operated by Help Me Grow in Connecticut. This call center would provide a resource for community based surveillance sites that are attempting to create better connections with pediatric providers, and other service providers. The call center/coordination program would also play an essential role in linking pediatric provider with the mid-level assessment center, and to other resources for children identified as needing other community based services and referrals. Using a range of new technologies the call center/coordination program could also provide web based resources to parents, community child care and school readiness partners, pediatricians and other early childhood developmental service providers..

5. ***Develop a Short and Long Term Funding Strategy*:** This will be pivotal to the success of the program. All available federal, state and local funding sources will need to be explored to ensure the viability and sustainability of each component of the system and the system as a whole. A range of local, state and federal funding strategies should be considered that could provide funding during different phases of implementation, and to cover service, evaluation, and infrastructure development costs. Where needed services that lack a currently identifiable funding source are identified, alternatives in the Orange County Community will be sought e.g. donations from private foundations, individuals and corporations.

## Summary

Orange County has built a series of promising and innovative programs in the developmental services arena. Impressive degrees of multi-disciplinary collaboration are emerging. While the challenges are formidable, the combination of effective strong leadership within key sectors, a willingness to collaborate and to look at existing systems in new ways, and the tremendous progress which has been made in recent years within the CHOC-UCI collaborative, now place the county in an excellent position to move forward with implementation of the new system. The Commission needs to play a leadership role in developing a strong financial underpinning for this endeavor. The Orange County Model proposed in this report has great potential for true innovation in the field of developmental services. Both implementation and evaluation of the new model will be of national and international interest.

# Appendix A

**Acronyms**

| | |
|---|---|
| AAP | American Academy of Pediatrics |
| ADHD | Attention-Deficit/Hyperactivity Disorder |
| ASQ | Ages and Stages Questionnaire |
| CAHPS | Consumer Assessment of Health Plans Survey |
| CBCL | Child Behavior Checklist |
| CCS | California Children's Services |
| CHDP | Child Health Disability Prevention |
| CHIS | California Health Interview Survey |
| COPE | Community Parent Education |
| CUIDAR | CHOC/UCI Initiative for the Development of Attention and Readiness |
| DCFS | Department of Children and Family Services |
| DDS | Developmental Disability Services |
| ECENA | Early Childhood and Educational Needs Assessment |
| EDAC | Early Development and Assessment Center |
| EPSDT | Early and Periodic Screening, Diagnosis, and Treatment |
| FACT | Families and Communities Together |
| FAPE | Free Appropriate Public Education |
| FOPE II | Future of Pediatrics II |
| FRC | Family Resource Center |
| FSN | Family Support Network |
| HABLA | Home-based Activities Building Language Acquisition |
| HEDIS | Health Plan Employer Data and Information Set |
| HRSA | Health Resources and Services Administration |
| IDEA | Individuals with Disabilities and Education Act |
| IOM | Institute of Medicine |
| IRB | Institutional Review Board |
| MCHB | Maternal and Child Health Bureau |
| N2N | Neurons to Neighborhoods |
| NEGP | National Education Goals Panel |
| NSECH | National Survey on Early Childhood Health |
| OCERS | Outcome Collection, Evaluation and Reporting Services |
| OCHNA | Orange County Health Needs Assessment |
| PEDS | Parents' Evaluation of Developmental Stages |
| POMS | Performance Outcomes Measurement System |
| PSC | Pediatric Symptom Checklist |
| ROAR | Reach Out And Read |
| RCOC | Regional Center of Orange County |
| SECCS | State Early Childhood Comprehensive Systems |
| SED | Serious Emotional Disturbance |
| SES | Socio-Economic Status |
| SELPA | Special Education Local Planning Areas |
| WIC | Woman, Infants and Children |

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