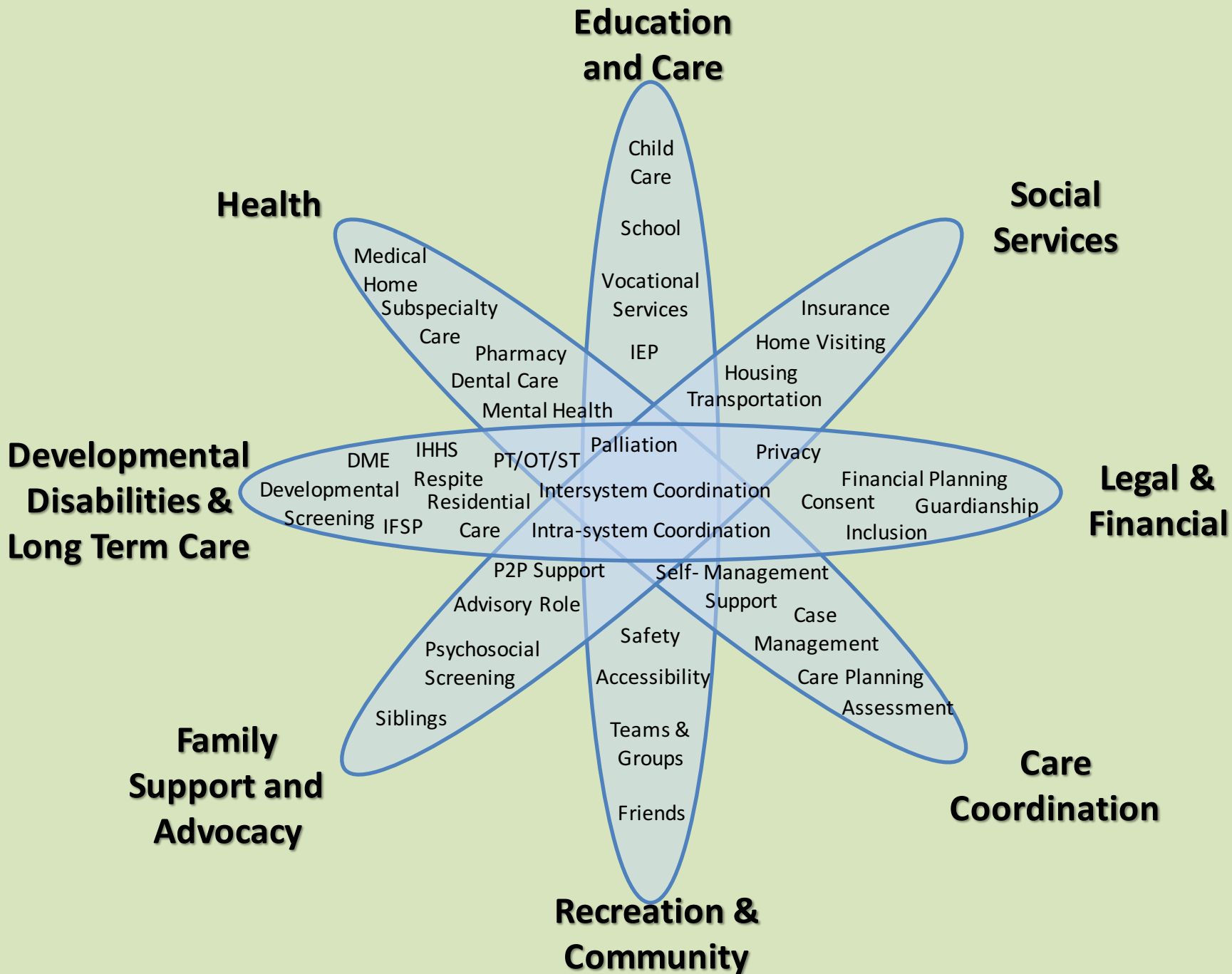


# **Systems for Children with Special Needs**

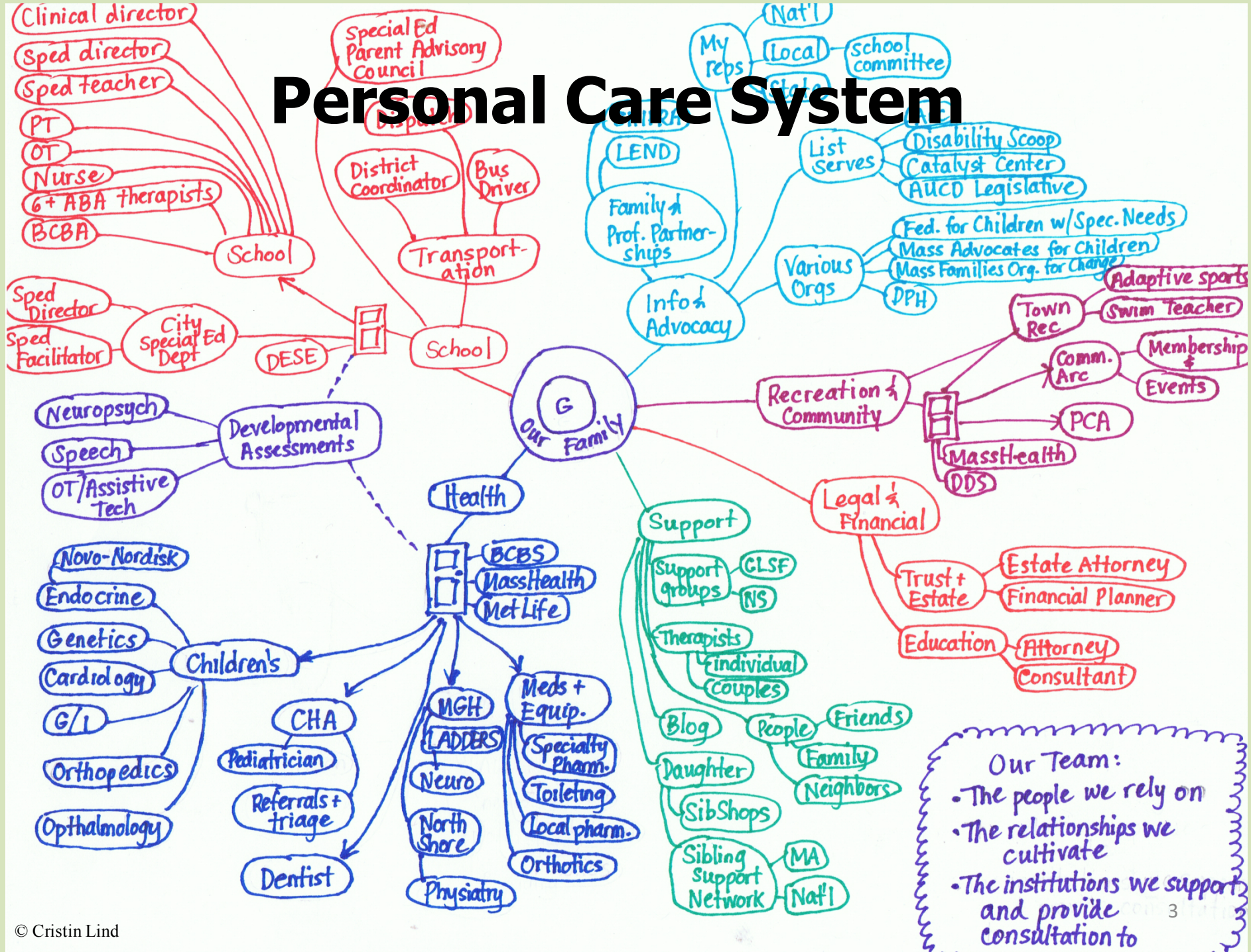
Edward L. Schor, MD

Lucile Packard Foundation for Children's Health

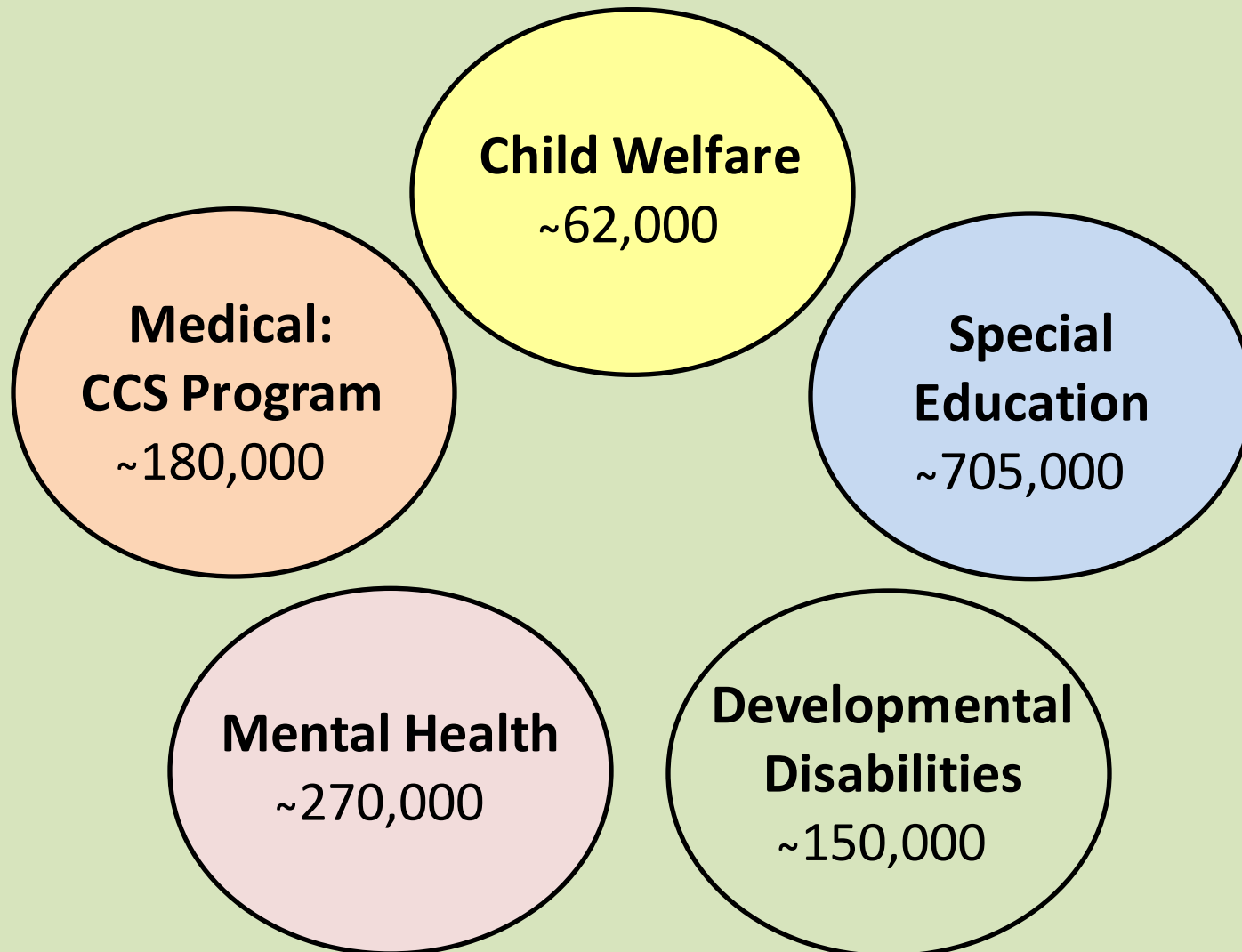
December 1, 2015



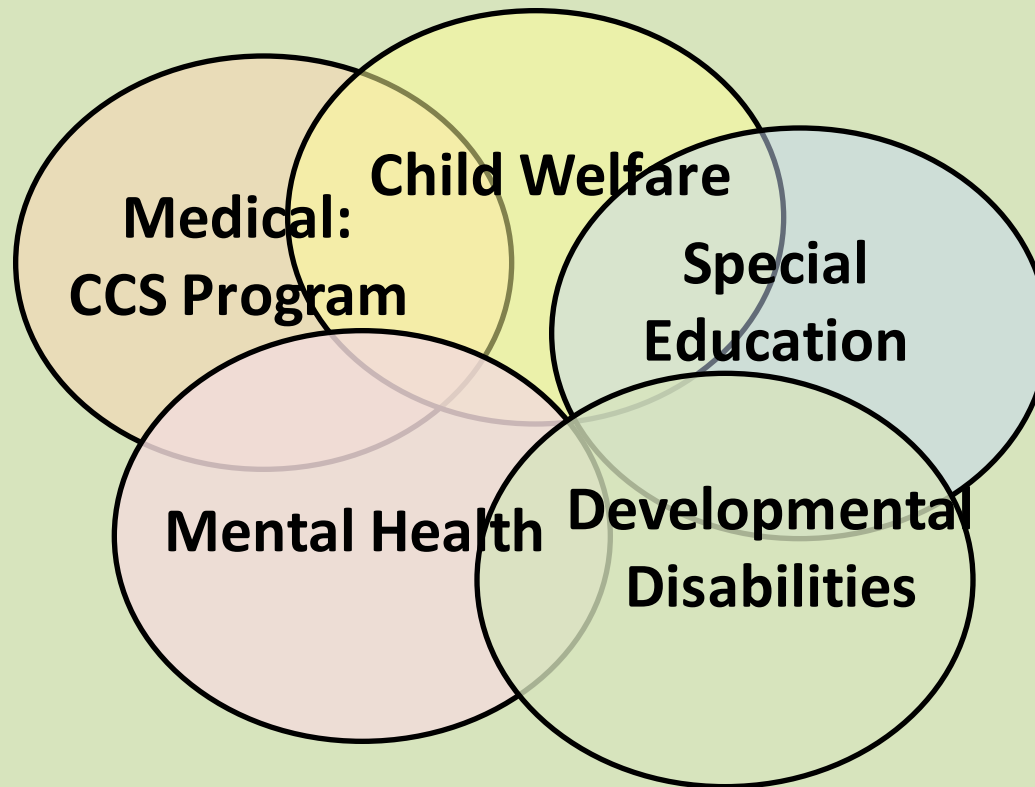
# Personal Care System



# California Programs for Children with Special Needs



# Overlapping Programs for Children with Special Needs



# Special Needs of Special Needs Children

**1. Readily available principle contact**

**2. Planned, accountable services**

**3. Multiple system involvement**

**4. Access to skilled professionals**

**5. Prevention of progression and comorbidities**

**6. Special accommodations**

**7. Family-centered services and supports**

**8. Readily available and shared records**

**9. Coordinated or integrated services**

# Key Components of a High Performance System for Special Needs Children

1. **Whole child, comprehensive coordinated services**
2. **Integrated service plans and information sharing**
3. **Meaningful family involvement**
4. **Adequate number of well-trained professionals**
5. **Equity of access to good quality services**
6. **Transparent monitoring to assure quality**

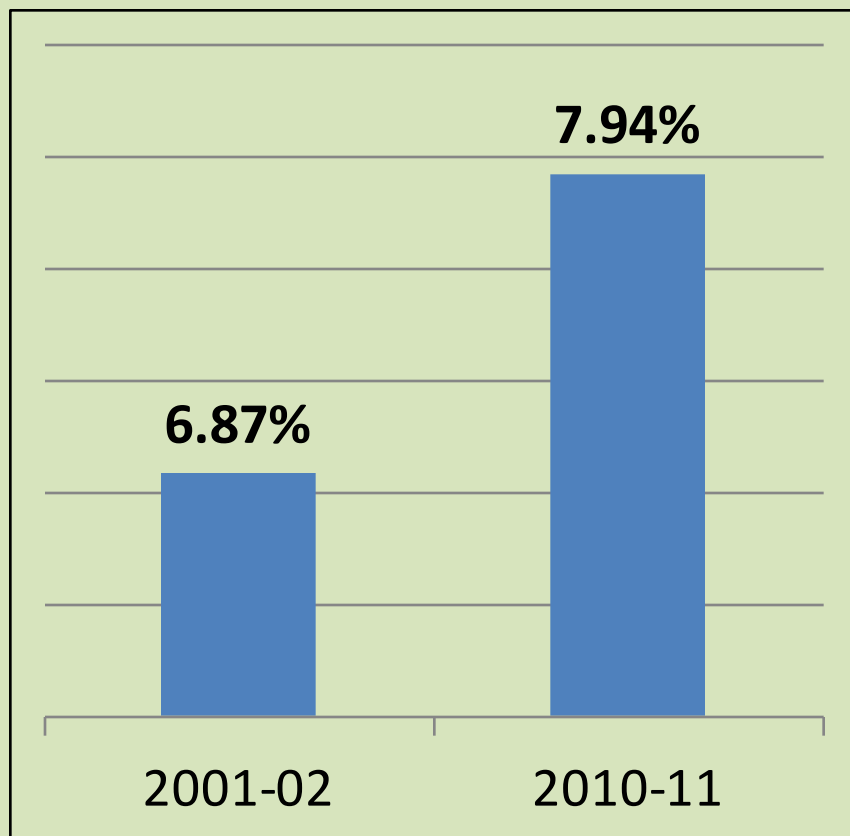
# Special Needs with Health Components

- **Child Welfare:** Mental illness, substance abuse, post-traumatic stress disorder, chronic illness
- **Special Education:** Prematurity, genetic and congenital disorders, mental illness, chronic illness
- **Developmental Disabilities:** Prematurity, genetic and congenital disorders, neurologic disorders

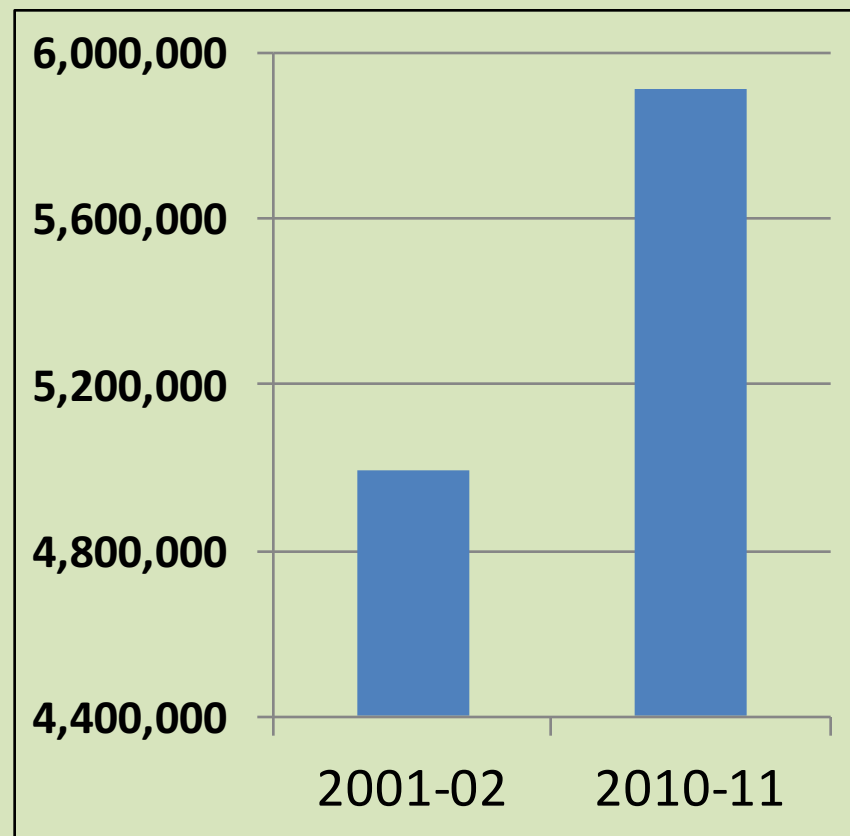


# Changing Trends in Childhood Disability (2001-2011)

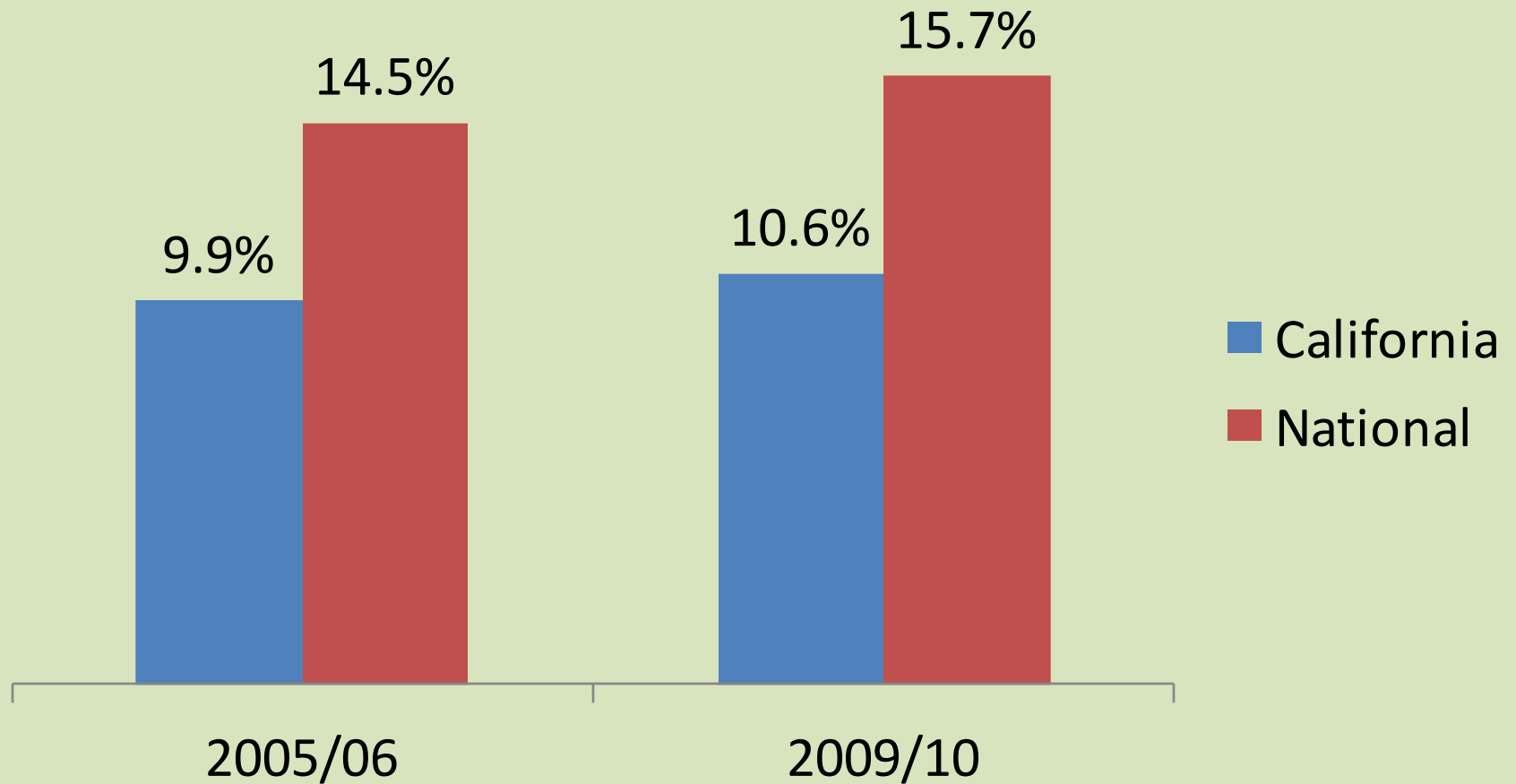
## Rates of Disability



## Number of Disabled Children



# Proportion of Children with Special Health Care Needs Ages 0-17



# California's Quality of Health Care for CSHCN: National Comparison

## National Ranking

- 50<sup>th</sup> in having at least one preventive care visit
- 46<sup>th</sup> for care coordination
- 50<sup>th</sup> in family-centered care
- 50<sup>th</sup> in proportion of parents with above average stress
- 45<sup>th</sup> in developmental screening
- 36<sup>th</sup> for transition to adult care
- 43<sup>rd</sup> in receiving needed mental health services

# Focus of Lucile Packard Foundation for Children's Health

1. Care Planning and Coordination
2. Family Participation and Advocacy
3. Self-Management Support
4. **Disparities in Quality of Care**

# Standards for Systems of Care for Children and Youth with Special Health Care Needs

A Product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project



# Core Domains for System Standards

1. Screening, assessment & referral
2. Eligibility and enrollment
3. Access to care
4. Medical home and care coordination
5. Community-based services
6. Family-professional partnerships
7. Transition to adulthood
8. Information technology
9. Quality assurance & improvement
10. Insurance & financing

# How State Agencies Can Use System Standards

1. Identify children with special needs as a special population in policy and programs
2. Identify and reference national system standards in system design
3. Monitor adherence to standards
4. Assess and compare performance
5. Guide technical assistance to improve performance
6. Create partnerships among all stakeholders to monitor access and quality

Edward.Schor@LPFCH.ORG

**[www.LPFCH.ORG/CSHCN](http://www.LPFCH.ORG/CSHCN)**