

Report

Hidden in Plain Sight:

California Children Using Long-Term Care Services



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Executive Summary

Long-term care—ongoing assistance with some of the most basic activities of daily life—is most often associated with senior citizens and nursing homes. In stark contrast to these images are between 100,000 and 300,000 California children who use a range of long-term care services that enable the majority of them to remain in their homes. Even a generation ago, many of these children who are now living into adulthood would not have survived infancy or early childhood, and those who did would have been consigned to institutions.

Hidden in Plain Sight places a spotlight on this largely invisible population of children with severe and enduring health problems and their families—who they are, the circumstances of their lives, and the policies that affect them. The report describes how historical developments and current policies contribute to the lack of a system of care to manage the often complex, multi-dimensional health needs of these children and leave families with an overwhelming burden of care.

A Large, Growing, and Invisible Population of Children and Families

The number of children needing long-term care services continues to grow as medical advances keep more seriously ill children alive. Their health problems include cognitive, physical, and mental health conditions; many have conditions that span two or even all three of these domains.

These children are among the groups with the highest health care costs and appear in five of the six most expensive Medicaid populations—premature infants, people with developmental or mental disabilities, children in foster care, and victims of spinal cord or traumatic brain injury.¹ Despite the growth in their numbers and the high cost of their care, children who use long-term care services are still only 5% of the users of long-term care services and thus do not command significant attention from policymakers. Due to their small numbers these children, their families, and the issues they face are also largely invisible to the general public.

Based on interviews with families and a review of existing literature and data, *Hidden in Plain Sight* highlights what is known about California children needing long-term care and their families. It focuses on the policies, programs, and funding sources that affect how these services hit the ground. It concludes with recommendations to improve the availability and quality of services for this population.

Fragmented Care

There is no single or integrated system to provide support to children needing long-term care services and the families caring for them. *Hidden in Plain Sight* describes four major government programs and multiple funding sources available to these children and their families. Each pathway to services and funding evolved for particular historical reasons for specific target populations. Consequently, each has its own eligibility criteria, unique array of services, and guidelines for how

¹ Calculated from figures presented in Kaye, H.S., Harrington, C. and LaPlante, M. (2010). Long-term care: Who gets it, who provides it, who pays, and how much? *Health Affairs* Vol. 29, No 1: 11-21, page 13.

the services are to be provided. For families whose children have needs that span multiple programs and funding streams—most children in long-term care—the result is severe fragmentation of care.

As a result of this kaleidoscopic fragmentation, few providers view or treat the whole child. Special medical care for the condition qualifying a child for long-term care services (LTCS) may cover just that condition, and families must find other providers for children's "regular" health care; physical and behavioral health are often not integrated; and children qualifying for multiple service systems may be denied services when agencies disagree about which is the funder of last resort.

The likelihood of fragmentation increases as children grow older. Their conditions may change very little, but their access to services changes dramatically at this highly vulnerable point in their developmental trajectories. Between the ages of 18 and 26, children using long-term care services lose eligibility for child-focused specialty health, mental health, and educational services, but face difficulties finding adult-oriented providers familiar with their conditions and willing to take on patients with their degree of medical complexity. Many important health benefits are more restricted for adults than they are for children, and long-term care for adults is oriented toward institutional care. Children's health insurance status may change as they enter adulthood, and they may face a loss of established professional relationships and comprehensive health coverage.

It falls upon families to navigate fragmentation across programs and funding sources as well as the chasms of care that emerge as children age. Even services designed to provide coordination often work only within one system, while children's needs cross multiple systems. One mother quoted in this report noted that her daughter had six different case managers at the same time, each assigned by different agencies to coordinate her care, yet each case manager worked only within one system. Securing access to services for their children is a challenge for even middle class and educated families and can be impossible for families who for linguistic, cultural or time reasons may not be able to advocate and coordinate care as successfully.

The capacity of families to care for children also changes over time as parents age. Even predictable changes in children's height and weight can have profound consequences for caregivers who lift and provide transportation for them. All of these changes require policies and services that take into consideration children's development and life course. And yet the fragmentation of services into multiple silos with limited responsibilities for discrete periods of time does not encourage taking this approach and creating integrated services.

High Costs to Families

Families caring for children who need LTCS bear enormous emotional and financial costs. Economic costs to families include both out-of-pocket payments and lost income or economic opportunity. Sixty-five percent of California families with children with complex health needs report cutting back work hours or stopping work altogether, and over half (57%) report the health conditions of their children cause financial problems for the family. The specific costs vary with the nature of the child's disability, the amount of funded services in place for the child, and even the income of the family; people who have more spend more, those without often do without. Out-of-pocket costs include co-pays and deductibles for medication covered by insurance and the cost of drugs and therapies that are not covered at all.

Many long-term care children must travel long distances to get the specialized care they need and families incur housing and travel costs, which may not be a covered benefit. Another cost to families is increased medical payments to in-home caregivers. Exhaustion, constant lifting, and stress take their toll on family members. Many have injuries, especially orthopedic-related (back, shoulder, and knee injuries are very common). Depression also is a major issue. As caregivers age, injuries are more frequent.

Non-economic costs can include isolation, loss of friends and family, loss of employment and any type of “normal” social life, whatever that may mean for a given family. In addition, when the child is initially diagnosed, whether at birth or later, the family suffers a significant emotional loss—the loss of a healthy child. While many families adjust their lives to lovingly meet the needs of the child, the emotional toll is high.

Significant Information Gaps

Significant information gaps exist regarding children needing long-term care services. Even arriving at the range of between 100,000 and 300,000 requires making inferences from multiple data sources. Despite the growing number of these children, their great vulnerability, and their high costs to families and insurers, there is no accurate count. Detailed information about the health conditions of these children is currently unknown but critical to guide policies about them. Other important but missing information includes demographic information such as race and ethnicity; patterns of caregiving and their cultural variations; and the geographic dispersion of children needing LTCS throughout the state.

Policy Implications and Recommendations

Hidden in Plain Sight concludes with policy recommendations that, if implemented, would provide starting points for improving conditions for this population of vulnerable children and their families. A synopsis of recommendations for policymakers includes:

1. Recognize that children using long-term care services and their families are an important, growing, and unique population that should be considered in policy discussions.
2. Create a coordinated or, ideally, integrated, system of care for children needing long-term care that takes advantage of the strengths of existing programs. Such a system would reduce the fragmentation that is currently a hallmark of services to this population of children.
3. Strengthen the infrastructure necessary for a system of care that includes a sufficient number of high-quality, well-trained personnel in all the disciplines needed to help them. Emphasis should be placed on improving Medi-Cal reimbursement rates, expanding training programs in shortage areas such as child psychiatry, and building stronger peer-to-peer information and support into the infrastructure of care.
4. Include families at all levels of care in policy setting and decision-making about children in long-term care. Families and the children they are caring for are the consumers of policies and systems of care, and experience first-hand the impact that decisions make. It is important that their voices contribute to policies and programs in a meaningful way at all levels of decision-making.

5. Develop an accurate profile of children and their families using long-term care services that includes such information as a current census, enumeration of children's health issues, the programs they are using—including enrollment in multiple programs—and information about the geographic, racial, ethnic, and linguistic distribution children use LTCS and how these characteristics affect care.

Implementing these recommendations would make an important difference to the highly vulnerable and nearly invisible children whose health conditions are severe and enduring enough to need long-term care services—and to the families who are struggling to support them.

I. Introduction

When Charlie Cleberg, Thomas Suen, and Maggie McDonald were born, doctors told their parents that given the severity of their health conditions, they would likely not live long. Now, at ages 15 and 10 respectively, Charlie and Thomas are living with their families, going to school, and pushing the limits of their disabilities. Maggie attended her senior prom, graduated from high school, and often amused her adoring family with a uniquely quirky sense of humor. She passed away unexpectedly at age 20 in spring 2014.

A conservative estimate is that between 100,000 and 300,000 California children have health conditions that, like Charlie's, Thomas's, and Maggie's, are serious and enduring enough to require long-term care services. Long-term care (LTC) refers to a broad range of services and supports that are provided at home or in institutions by paid or unpaid providers who assist people with limitations in their ability to care for themselves.^{2,3} As the capacity of medicine to save lives, including those of children with severe medical problems, increases, so do the numbers of children with unresolved, significant long-term medical, developmental, and or physical problems requiring long-term care services.

Up until the mid-20th century, the common practice for children with the most serious disabilities was institutionalization, and in 1965 more than 13,500 California children resided in state-run institutions.⁴ Since then, care has moved from institutions to the community. Today, Thomas, Charlie, Maggie, and their families are charting the territory that an increasing number of families enter as they care at home for children with severe and enduring health conditions requiring long-term care supports and services (LTCS).⁵

Despite their growing numbers, children requiring long-term care services are largely invisible in comparison with older adults. They and their families are faceless to the general public, and relatively voiceless in the policy arena.

In contrast, large numbers of aging baby boomers and the accelerating costs and expenditures for their institutional care have created a policy spotlight on seniors' long-term care and a springboard for innovation and reform for older Americans using long-term care services. Although children appear in five of the six most expensive Medicaid populations,⁶ policy and innovation focus almost entirely on adults, who constitute 95% of the long-term care population.⁷

There are important differences between children and seniors needing long-term care services. Most children using long-term care services live at home, compared to half of all adult long-term

2 Definition adapted from: The Scan Foundation. (November 2010). Long-Term Care Fundamentals. *Technical Brief Series* (Number 4). Retrieved from the Internet at http://thescanfoundation.org/sites/thescanfoundation.org/files/LTC_Fundamental_4_0.pdf

3 A list of supports and services frequently used by children needing long-term care services is included in Section IV.

4 History of the developmental disabilities system in California. Retrieved from the Internet at <http://arcanet.org/pdfs/HistoryOf-System.pdf>

5 Appendix 1 contains notes about language, including terms for long-term care, used in this report.

6 These five most expensive categories are: (1) children born prematurely, (2) people with mental illnesses, (3) people with intellectual disabilities, (4) children in foster care, and (5) victims of spinal cord and traumatic brain injury.

7 Calculated from figures presented in Kaye, H.S., Harrington, C. and LaPlante, M. (2010). Long-term care: Who gets it, who provides it, who pays, and how much? *Health Affairs* Vol. 29, No 1: 11-21, page 13.

care recipients who use institutional services.⁸ Parents are most often the primary caregivers, and there are costs associated with that role. The parents of Thomas, Charlie, and Maggie do not want to be characterized as heroic. They consider themselves regular families doing what any family would do under the circumstances. And yet their caregiving has required forgoing careers and income; vast amounts of personal time; countless nights of sleep; and years of emotional equilibrium.

Children requiring long-term care services also have conditions that are more diverse. Compared to adults in long-term care who fall primarily within six diagnostic categories, children's conditions spring from a wide variety of causes and therefore require a broader spectrum of care.⁹

Children needing long-term care are also different from adults because they mature, and their needs change over time. They develop from infants to toddlers and teens; their skills and capacities increase; education becomes an important activity; and they ultimately age out of children's services and must transition to adult systems of care. These developmental stages cause fault lines in the care children receive when even basic developmental changes such as in height and weight have profound consequences for caregivers who lift and provide transportation for them. The unique needs of developing children and a lifespan perspective should be integrated into policy considerations for children in long-term care.

Children needing long-term care services are provided care through a variety of programs and funding sources. Consequently, highlighting children using long-term care services and policy issues relevant to them is like looking into a kaleidoscope. Information is fragmented in many different systems and services that align in multiple, ever-changing configurations. This kaleidoscopic segmentation creates formidable hurdles for parents and caretakers to weld together the supports and services their children need. It also creates hurdles for research about them. Sketching out a foundation from which to understand and address this fragmentation will possibly serve as the basis from which more cohesion and attention can be created.

Currently there is no clear definition about which children are in the group requiring long-term care services, and information and data about them are fragmented among the many agencies and departments that have developed to address different aspects of their health. But this lack of clarity should not overshadow the major point that this is a large and growing group of children and families.

8 Kaiser Family Foundation. (2011). Medicaid's long-term care users: Spending patterns across institutional and community-based settings. An issue report prepared for the Kaiser Commission on Medicaid and the Uninsured. Page 2. Retrieved from the Internet at <http://kff.org/medicaid/issue-brief/medicaids-long-term-care-users-spending-patterns/>

9 Stein, R. (2001). Challenges in long-term health care for children. *Ambulatory Pediatrics*, Volume 1 (No. 5), pps. 280-288.

II. How Many California Children Use Long-Term Care Services and Who Are They?

Ten snapshots concerning children using LTCS and their health conditions are included below. These draw a general outline of this population and where additional information is needed.

1. Between 100,000 and 300,000 California children use long-term care services.

A review of multiple data sources including program participation rates and population surveys indicate that there are likely between 100,000 and 300,000 children needing some type of long-term care services. Appendix 2 details the analyses leading to this range. An important take-away from this exercise is that even the most basic descriptive information for children who need or use LTCS—a simple count—is unavailable. In addition to needing a clear definition and count, more descriptive information about these children is needed, for example, where they live, their demographic characteristics, and their access to services.

2. Three-quarters of children using LTCS are those whose health issues begin at birth.

H. Stephen Kaye, Professor at the University of California, San Francisco, reported to the President's 2013 Long-Term Care Commission that 76% of childhood disabilities have an onset at birth or in infancy and 24% are childhood onset.¹⁰

3. Three major constellations of disability describe children needing long-term care: physical health, cognitive/intellectual functioning, and mental health.

Children in long-term care may have conditions included in one, two, or all three of these constellations. Examples of conditions that may, but ordinarily do not, require LTCS include:

Physical health conditions such as:

- Children born with genetically handicapping conditions including
 - Hemophilia,
 - Sickle cell disease,
 - Hemophilia, and
 - Cystic fibrosis
- Other congenital problems including
 - Cerebral palsy (usually but not always congenital),

¹⁰ Kaye, H. (2103). Non-elderly people needing long-term services and supports: Who are they? What services do they get? What do they need? Slide deck presented to the Commission on Long-Term Care. Retrieved from the internet at <http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Kaye-LTC-Commission-7-17-13.pdf>

- Heart or lung conditions, and
- Spina bifida
- Severe and enduring diseases or conditions developed in childhood including
 - Traumatic brain injuries,
 - Cancer, and
 - Asthma

Intellectual and cognitive conditions such as:

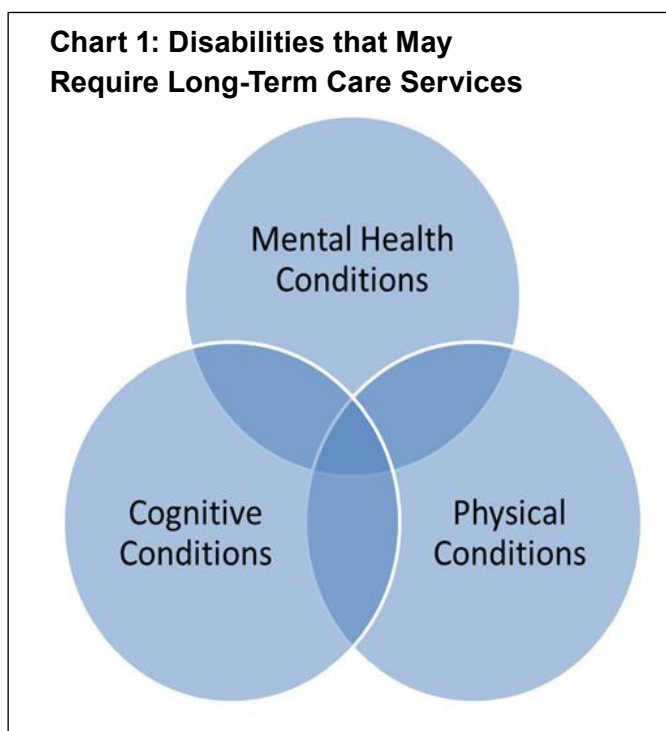
- Intellectual disabilities,¹¹
- Autism and autistic spectrum disorders, and
- Disabilities that do not always but may include cognitive and intellectual deficits such as cerebral palsy and epilepsy

Mental health conditions such as:

- Trauma,
- Anxiety, and
- Depression

4. Many children needing long-term care services have multiple conditions.

The relative sizes of the three circles in Chart 1 and their degree of overlap are important to better understand the population of children using and needing long-term care services. Social security data on child disability, which constrains diagnoses to one category, provides a clue about the relative sizes of the three circles with the largest number, 39%, diagnosed with intellectual/developmental disabilities, next largest at 28% with mental disabilities, and 23% with physical disabilities and 10% unknown. Another source reverses the second two categories, indicating that 41% of children using LTCS have cognitive issues, 38% physical problems, and 21% mental health concerns.¹²



¹¹ The term intellectual disabilities has replaced the appellation of mental retardation. The new designation does not include a component of functional abilities in its definition as mental retardation did, making it more challenging to know the numbers of children with intellectual disabilities who may need LTCS.

¹² Data presented to the 2013 President's Commission on Long-Term Care using National Health Interview data by Kaye, H. (2013). Ibid.

It is likely that many children needing LTCS come from areas of overlap in Chart 1. Appendix 2 cites one source of information that suggests 10% of children in long-term care have disabilities in more than one constellation of conditions, but knowledgeable observers believe the actual number is far higher.

5. The status of children needing LTCS can be placed on a continuum of both severity and time.

Children's chronic conditions can be described on a continuum of severity, from mild to severe—or, for children with more than one type of condition, by their complexity. Children needing long-term care cluster on the severe end of these continuums. Children and their health conditions can also be thought of on a continuum of time. Some conditions resolve, either through improvement or, sadly, death. Children needing long-term care services are on the end of this time continuum, requiring services for years and, in many cases, their entire lifetimes. There is current lack of clarity about where to draw demarcation lines to designate children in long-term care, and it is likely that different agencies would draw the lines in different places. Clinical judgments, taking the child's context into consideration and the degree to which functioning is impaired, are key considerations.

6. Children using long-term care services are overrepresented in low-income populations:

There is an inverse relationship between socioeconomic status and health internationally,¹³ in the US population,¹⁴ for children with disabilities,¹⁵ for children with special health care needs,¹⁶ and for children with both special health care needs and disabilities.¹⁷ Income is strongly related to both the incidence of severe illness as well as access to resources for its treatment.

7. A significant information gap exists about cultural variations in the use of long-term care services for children.

Anecdotal information indicates that there are significant cultural differences in use of long-term care services for children. Accessing services can be challenging even for well-educated, middle-class parents, and is even more challenging for cultural and linguistic minorities. There are different cultural norms about using services, for example, the degree to which it is considered appropriate to allow strangers into one's home or to allow physical care to be provided by non-family members. Immigration documentation status is a major health access barrier affecting utilization of long-term care services for children. Anthropological studies about cultural variations in use of long-term care services for children would be an important starting point to gain information.

13 Marmot, M. and Wilkinson, R. (2003). Social determinants of health: The solid facts. Second edition. Report prepared for The World Health Organization. Retrieved from the Internet at http://www.euro.who.int/_data/assets/pdf_file/0005/98438/e81384.pdf

14 Evans, W., Wolfe, B., and Adler, N. The income-health gradient. Retrieved from the Internet at <http://www.irp.wisc.edu/publications/focus/pdfs/foc301b.pdf>

15 Halfon, N., Houtrow, A., Larson, K., and Newacheck, P. (2012). The changing landscape of disability in childhood. *The Future of Children*, Vol. 22, No. 1, page 24.

16 Bethell, C., Newacheck, P., Fine, A., Strickland, B., Antonelli, R., Cambria L., and Wilhelm, L. (2014) Optimizing health and health care systems for children with special health care needs using the life course perspective. *Journal of Maternal and Child Health*, Vol. 18, pps. 467–477. Retrieved from the Internet at <http://childhealthdata.org/docs/cshcn/cshcn-life-course-paper.pdf?Status=Master>

17 Houtrow, A., Okumura, M., Hilton, J. and Rehm, R. (2011). Profiling health and health-related services for children with special health care needs with and without disabilities. *Academic Pediatrics*, Vol. 11, pps. 508–516.

8. Children using LTCS are at high risk for out-of-home placement and as many as 25,000 are placed outside their homes. Approximately 10,000 children using LTCS are in foster care.

From 1965 when at least 13,500 Californians with developmental disabilities lived in four state hospitals,¹⁸ national and state policymakers have prioritized programs providing LTCS in family homes and other community settings, and a number of funding streams have been developed for that purpose. Yet many children requiring LTCS hover around an invisible line beyond which they cannot be cared for at home, and many are at home due to the extraordinary efforts by their families.

Children who cannot be cared for at home reside in different types of facilities that include hospitals, intermediate care facilities, sub-acute pediatric facilities, juvenile detention facilities, and residential treatment and care facilities.¹⁹ The most common form of placement is foster care. Different sources identified later in this report describe 531 children currently living in institutional health settings and an additional 4,052 minors from the Developmental Disabilities System and 22,000 from the mental health system living in different types of out-of-home care. The total of these, discounting for some duplicates, is over 25,000 children.

Foster care is the most common form of out-of-home care. When families cannot provide necessary care for children with serious health or mental health needs and their children do not require institutional care, they release their children, sometimes voluntarily and sometimes involuntarily, to the child welfare system. The Developmental Disabilities System reports involvement with 2,773 children in foster care and the mental health system with 7,777 children in foster care.²⁰ There is likely some overlap between these two categories. Many children with severe health problems whose families cannot manage their care are also in foster care, although that number is not available. This report therefore uses an estimate of 10,000 children needing long-term care who are in foster placements.

9. The number of children using long-term care services is increasing.

The overall number of children with disabling conditions is increasing due to rapid advances in technologies that keep very sick infants and children alive; more case finding; and changing patterns of diagnoses associated with childhood disabilities.²¹ Children with conditions of sufficient severity to cause limitations in school and play more than doubled between 1979 and 2009.²²

18 History of the developmental disabilities system in California. Retrieved from the Internet at <http://arcanet.org/pdfs/HistoryOf-System.pdf>

19 A thoughtful review and discussion of out-of-home placement for children from a national perspective is provided by Friedman, S. and Kalichman, A. (2014). Out-of-home placement for children and adolescents with disabilities. *Pediatrics*; 134;836. Retrieved from the Internet at <http://pediatrics.aappublications.org/content/134/4/836.abstract>

20 This number from the mental health system that relies on the number of children receiving services may seriously underestimate the number of children in the foster care system needing intensive, long-term mental health care. When a lawsuit (the Katie A lawsuit) required the Child Welfare System to estimate the number of children in foster care needing intensive, long-term services, the aggregated number from counties was 35,000.

21 Halfon, Neil, Houtrow, A., Larson, K., and Newacheck, P., (2012). Ibid.

22 Bethell, C., Newacheck, P., Fine, A., Strickland, B., Antonelli, R., Cambria L., and Wilhelm, L. (2014). Ibid.

10. Children using LTCS share significant legal protections promoting their integration in community settings.

The last half-century has witnessed major legislative advances securing the rights of people with disabilities, including children, to live in community settings with the goal of integrating them into mainstream social activities. Legal changes, both legislative and judicial, provide additional protections. The Americans with Disabilities Act of 1990 made discrimination against Americans with disabilities illegal, much as the Civil Rights Act of 1964 did for discrimination based on race. Other key legal decisions affecting children and their families using LTCS are included in Sections V and VI.

In summary, inference and extrapolation paint an approximate portrait of California children using LTCS. There are likely between 100,000 and 300,000 children with significant disabilities that require the intensive and enduring support of LTCS, three-quarters of them identifiable at birth or in infancy. Health problems of children using LTCS include physical, cognitive, and mental health disabilities, and many children have disabilities in more than one domain. Whereas there have been many advances moving children from institutional to community settings and a legal framework promoting this, an estimated 25,000 of these children do not live with their families. Children using LTCS are disproportionately low-income, and among the blind spots about this population is knowledge about racial and cultural variations in LTCS usage.

III. A Brief Introduction to Three Children Using Long-Term Care Services

Three children needing LTCS are introduced below whose families have generously agreed to share their experiences. They hope that more public knowledge about their children and the challenges they face may ultimately make it easier for other children and families. The children profiled here are middle class, not representative of all children using LTCS. Their experiences point out that if even these educated, middle class families experience the severe challenges they describe, lower-income and more culturally diverse families are likely to face issues that are all the more challenging.

Thomas Suen²³

Thomas Suen, 10, lives with his parents Ron Suen and Isabel Lydon and 8-year old brother, Jaspre, in a comfortable suburban ranch house that has been renovated to accommodate Thomas's wheelchair. Thomas's birth was normal, but at around four months he experienced clusters of seizures that led to a long hospitalization, batteries of grueling tests, and an ultimate diagnosis of a rare genetic condition. Due to his medical condition and the side effects from many strong drugs that have been part of his treatment, Thomas is non-verbal, non-ambulatory, and receives nourishment through a feeding tube. He goes to school where he is attended by a full-time nurse and also has nursing support at home to help with frequent suctioning to keep his lungs clear and provide the many other kinds of physical support he needs. Ron and Isabel point out that Thomas is happy and they can see the fruits of some of the therapies he has experienced. Thanks to a communicative assistive device and extensive therapy, for example, he was able to communicate when he felt a seizure coming on.

Charlie Cleberg²⁴

Charlie Cleberg is 14 and going into his sophomore year of high school in a San Francisco East Bay community. He has cerebral palsy, Tourette's syndrome, and a rare condition that leaves him with multiple physical deficits such as not being able to use his arms. Charlie is able to do many things with his feet—build Lego structures, work at the computer, and play the piano—but he cannot move his blankets at night, requiring help turning and parental vigilance to assure he is safe. His mother, who is a nurse, has resuscitated Charlie multiple times. Charlie is fine cognitively, and Kathryn lights up as she describes his irrepressible happiness, “He lives in a joie de vivre bubble. He once had a school assignment to write about a bad day, and he just couldn't do it.” At the same time, Charlie is aware of death. In spring 2014, Charlie was facing high-risk surgery necessary to keep his chest from caving in on his heart. If he were to stop breathing, his lungs could not support a tracheotomy, and if his heart were to stop, chest compressions that are typically life-saving would crush his chest. Charlie knows about palliative care, which he calls comfort care, and has signed a POLST²⁵ form that spells out the measures that he does and does not wish medical personnel to take

23 You can “meet” Thomas and his parents in a video created by the Lucile Packard Foundation for Children's Health at <https://www.youtube.com/watch?v=vZLay6t3g4k>

24 http://www.insidebayarea.com/news/ci_26093827/george-mark-childrens-house-offers-solace-families-terminally

25 POLST stands for Physician Orders for Life-Sustaining Treatment and refers to a form that individuals fill out to provide direction to health care teams about their treatment preferences in a life life-threatening situation.

in the event of life-challenging circumstances. Kathryn and her husband, Joseph, adopted Charlie when his birth parents, who see him several times a year, recognized that they were not able to manage his complex health condition.

Maggie McDonald²⁶

Maggie McDonald passed away unexpectedly in spring 2014 at age 20, likely from a sudden plug of her tracheotomy tube. Maggie was born with a genetic condition resulting in multiple internal physical anomalies requiring over 80 surgeries. She also had cerebral palsy and hydrocephalus and was medically fragile. Throughout life Maggie gained nourishment through a feeding tube and required catheterization, a wheelchair and multiple other assistive devices for communication and learning. She needed a trach from age 13 onward. Maggie had an active and full life, went to her junior prom, and graduated from high school. Maggie's innate intelligence, indomitable spirit, and irrepressible sense of humor shined through her physical conditions.

26 Maggie's mother kept a blog with many pictures of Maggie that can be accessed at www.sfmaggie.blogspot.com.

IV. What Services and Supports Do Children Using Long-Term Care Need?²⁷

Children needing long-term care services require a variety of services and supports to enable them to live at home. These are listed below. Sometimes living at home is not a possibility and children then require care in facilities, also listed in this section. Families are quick to point out that needing a service does not assure access to it, so this list does not imply the availability of these services to families. Discussions of access, quality, and coordination of services follow in Section VII.

Home and Community-Based Services

Health Services

- Ambulatory medical care: All children require medical care including preventive services, and many children needing LTCS require specialists and subspecialists.
- Therapies (help with mechanical interventions, speech, physical, psychological, and occupational therapies): These therapies can be provided in the home, hospital, or in community settings.
- Home health care: Children who need skilled nursing and other professional services may receive home health care from trained workers who visit the home to help with care needs. The services are provided by home health agencies licensed by the State.
- Emergency response system: Children with fragile health conditions require emergency services that can provide life-saving services and transport them to emergency rooms when necessary.
- Hospital care: Children using LTCS are likely to have many experiences in hospitals, where they require equipment and staff capable of understanding and managing complex conditions in neonatal intensive care units, pediatric intensive care units and regular inpatient wards.
- Palliative care: Children with serious, enduring health conditions benefit from palliative care for pain management and support for those making treatment decisions and providing care.

Educational Services and Child Care

- Special child care/day care: Children with health conditions that require close supervision may also require child care or day care provided either outside or inside the home. Finding quality child care is always challenging, more so when the providers need to have skills relevant to the child's health conditions and functional limitations.
- Day programs: Day programs include a focus on activities including: developing and maintaining self-help and self-care skills; developing the ability to interact with others; making one's needs known and responding to instructions; developing self-advocacy and employment skills; developing community integration skills such as accessing community services; behavior manage-

²⁷ This section draws heavily from The California HealthCare Foundation's Medi-Cal Policy Institute. (2001). Understanding Medi-Cal: Long-Term Care. Revised Edition. Retrieved from the Internet at <http://www.chcf.org/publications/2001/05/understanding-medical-long-term-care-revised-edition>

ment to help improve behaviors; and developing social and recreational skills. (These programs exist for infants, and often are integrated with school experiences for older children.)

- Special education: All school-age children (from 3 to 22) regardless of disability have the right to a free public education provided in the least restrictive and most mainstreamed settings possible.

Family Support Services

- Family support: Families under the stress of caregiving benefit from services that include helping with the tasks of everyday life such as preparing meals and doing housework. Because families can easily become isolated due to the stress of caregiving, friendly visitor/companion services are also valuable to them.
- Respite care: The wear and tear on families caused by caring for a child needing long-term care services results in the need for occasional breaks. Respite care enables families to take a breather by taking over care for the child temporarily. Respite care can be either intermittent or regularly scheduled temporary non-medical care and/or supervision. It is generally provided in a client's home and occasionally in licensed facilities.
- Personal care services: Children with disabilities who cannot manage activities of daily living such as dressing, eating or bathing benefit from personal care services. Workers, who may be family members, help children accomplish these activities by providing personal care services.
- Recreation: Children with serious and ongoing health conditions need opportunities for recreation. Families also need time to relax and spend time focused on activities that can divert their attention from the full-time work of health management.

Transportation

Children with disabilities often require specialized transportation such as vans or specially outfitted cars that can accommodate equipment needs such as wheelchairs. Car seats for larger children are often required.

Adaptive Equipment, Orthotics, and Other Supplies

- Many children require adaptive equipment such as wheelchairs, communication devices, and lifts to help compensate for physical limitations.
- Orthotics and prostheses are often important to compensate for physical disabilities and enhance positioning and mobility.
- Many children needing LTCS require many different supplies, including feeding tubes, various respiratory supplies, catheters, diapers, and other incontinence supplies, syringes, and bandages.

Institutional Care²⁸ with a Nursing Component

- Acute care hospitalization: Many children with severe and enduring health problems require multiple hospitalizations in acute care settings.
- Long-term nursing care/skilled nursing facilities (SNFs): Sometimes called nursing homes or convalescent hospitals, these facilities provide comprehensive nursing care for chronically ill or shorter-term residents of all ages, along with rehabilitation and specialized medical programs. There are few such facilities that accept children in California.
- Short-term, sub-acute: These specialized units are often a distinct part of a nursing facility. Sub-acute facilities focus on intensive rehabilitation, complex wound care, and post-surgical recovery for residents who no longer need the level of care found in a hospital. Such facilities that accept pediatric patients are also very rare in California.
- Intermediate-care facilities (ICFs): In addition to room and board, these facilities provide regular medical, nursing, social and rehabilitative services for people not capable of fully living independently. Again, these facilities are rare in California.
- Intermediate-care facilities for persons with development disabilities (ICFs/DD): These facilities provide services for people of all ages with developmental and intellectual disabilities. ICFs/DD-H (habilitative), ICFs/DD-CN (chronic nursing) and ICFs/DDN (nursing) have home-like settings with an average of six beds. ICFs/DD are larger homes with 16 or more beds. Reimbursement rates may vary depending upon the level of service.
- Institutes for mental health (SNF/STPs)—Designated in California as “special treatment programs,” these facilities provide extended treatment periods for people of all ages with mental health problems. Specialized staff serves clients in a secured environment.

Non-Medical 24-Hour Community Care Facilities²⁹

- Foster Family Homes (FFH) provide 24-hour care and supervision in a family setting in the licensee's family residence for no more than six children.
- Group Homes (GH) provide 24-hour non-medical care and supervision to children in a structured environment.
- Small Family Homes (SFH) provide 24-hour care in the licensee's family residence for six or fewer children who have emotional issues, are developmentally disabled or physically handicapped, and who require special care and supervision as a result of such disabilities.
- Community care facilities for children with developmental disabilities are licensed at Levels I through IV and, within IV, from 4A to 4I. The levels are associated with the type and amount of care needed by residents and the commensurate levels of staffing required to manage the different levels of disability.

²⁸ Definitions used in this section are drawn from those used by the California Association of Health Facilities.

²⁹ Descriptions of non-medical facilities are taken from the website of the California Department of Social Services (<http://www.cdss.ca.gov/cdssweb/PG66.htm>), which licenses these facilities.

Care Management and Advocacy Services

- Children and their families using long-term care services often have a need for help coordinating the many different types of support they need, as well as for advocacy.

Coordination

- The capacity to weave together services for families into a comprehensive net of safety and support is critical to children and families' survival and well-being.
- Information and referral: Families need a point of contact where they can bring questions and get information about resources that may be helpful to them.
- Life-long planning: Families with dependent children worry about what will happen to their children once they can no longer care for them. Planning for their children's futures is important for parents to assure that their children will continue to live with the care and support they need when families are no longer capable of providing this care.

Advocacy

- Peer-to-peer advocacy: Families run into roadblocks in their attempts to gain services for their children and it is important for them to have support from individuals and organizations that can help them through appeals processes and hearings to assure that their rights are honored. Families like those of Maggie, Thomas, and Charlie emphasize the value of advocacy organizations that are founded and run by families of children with disabilities.
- Advocacy from service and legal organizations: Many organizations also have an advocacy component or ombudsman service to help their clients, and these services can be invaluable. There are also legal service organizations that can provide critical information and help clients gain access to needed services.

In summary, children needing long-term care services require a broad range of supports and services spanning both institutional and community-based care.

On the Need for Advocacy

"Families are overtaxed in trying to secure services, many of which are routinely denied even though a family qualifies. The denials may be because the application is incorrect and needs to be redone, though that is infrequently explained. In a more jaded view of things, families often feel services are denied and agencies are hoping families will go away and stop asking for their services. Sadly, many do and go unserved. A denial in services requires an appeal up the chain of the department at issue. With several departments at play, this is incredibly tasking on families."

– Parent of a child using LTCS

V. Programs Serving California Children Using Long-Term Care Services

This section highlights the four government programs with primary responsibility for providing services to California children using long-term care services (LTCS). These systems are summarized in Chart 2. Many children, such as Thomas and Charlie, use multiple programs.

Chart 2 provides a thumbnail description of programs and highlights that there is both redundancy (of case management services, for example) and mismatch (such as different ages and terms of participation) between the systems. The following pages describe these programs and highlight policy issues they face.

Chart 2: At-a-Glance: California Programs for Children Using LTCS				
	California Children's Services	Developmental Disabilities (DD) System	Children's Mental Health	Special Education
Type of Service	Pediatric medical support services for qualifying condition; Medical Case Management ³⁰	Many therapeutic and support services; Case Management	Mental Health; Case Management	Educational Support, Mental Health, Case Management
Administration	State and Counties	State and 21 contract Regional Centers	State and Counties	State and County School Districts
Number of Children Served Annually	Approximately 150,000	Approximately 130,000	221,416 Children with Serious Mental Illness	Approximately 600,000 students
Is Eligibility Means Tested?	For most but not all services	No	Yes	No
Years of Eligibility	0-21	Lifetime	0-21	Through age 21

³⁰ Although "case management" is provided by many agencies, this term can mean many different things.

California Children's Services: Health Services for Children with Special Health Care Needs

California Children's Services (CCS) funds or provides direct health and therapeutic services to California children with special health care needs whose family incomes qualify them for these services. Because CCS funds children in neonatal intensive care units, it is often the first health agency to have contact with children who will need LTCS.

Current Issue

CCS has earned the reputation for upholding a high standard of health care that is perceived to have a positive ripple effect on all California children requiring subspecialty health care. Legislation authorizing CCS to be carved out from Medi-Cal managed care sunsets in 2016 and a planning process is ongoing to determine the future of this program. The stakes are high for children needing LTCS.

History and Legal Framework

Founded in 1927 in response to a polio epidemic, CCS is one of California's oldest children's health programs. National legislation followed eight years later mandating national health coverage for children with qualifying health conditions under Title V of the Social Security Act. Over 90 years later, California Children's Services still implements national Title V-mandated services for children with special health care needs (CSHCN). All of California's Title V CSHCN dollars go to CCS, which is not the case in all states.

Administration

The State and counties jointly manage the California Children's Services program. CCS is a Medicaid carve-out, an administrative status that allows CCS to bypass some Medicaid requirements³¹ and operate on a fee-for-service (as opposed to managed care) basis.³²

Eligibility

Eligibility for CCS is structured around qualifying conditions and income.

A complete list of qualifying conditions is available online.³³ Examples of CCS-eligible conditions include, but are not limited to, chronic medical conditions such as cystic fibrosis, hemophilia, cerebral palsy, heart disease, cancer, traumatic injuries, and infectious diseases producing major sequelae. The large number and wide range of eligible conditions contribute to the complexity of the program.³⁴

Children who meet Medi-Cal eligibility criteria, have medical expenses that surpass 20% of income, or are institutionally deemed, and thus eligible for Medi-Cal coverage while continuing to live in their parent's home, all qualify for CCS. The CCS Medical Therapy Program is open to

31 See more on carve-outs in Section VI on sources of funding.

32 Section VI contains more detail on fee-for-service versus managed care.

33 A complete list of conditions is available online at <http://www.dhcs.ca.gov/services/ccs/Pages/medicaleligibility.aspx>.

34 The California HealthCare Foundation, Medi-Cal Policy Institute. (2001). *Medi-Cal Facts*, Number 9, page 1.

all children with qualifying conditions irrespective of income. Children who meet the program's medical and financial criteria are eligible for CCS regardless of documentation status.

Medicaid Waiver Institutional Deeming (ID) is a process to obtain full-scope unrestricted Medi-Cal without a share of cost for developmentally disabled consumers under age 18. This program enables Regional Center eligible children ages 3 to 18 to receive full-scope Medi-Cal coverage while continuing to live in their parent's home.

An important characteristic of CCS is that it addresses a specific health condition and does not pay for other health care needed by the child. For example, if a child qualifies for CCS on the basis of cancer, CCS funding does not cover an ear infection or broken leg unless there is evidence that they are tied to the cancer. This implies that additional financing methods need to be in place to cover the rest of the child's health needs and that systematic coordination of these two (or more) funding mechanisms is required to avoid care that is fragmented and incomplete.

Funding and Costs

CCS is an approximately \$1.8 billion dollar program paid for by a combination of county, state, and federal funds.³⁵ A series of studies conducted by Stanford's Center for Programs, Outcomes, and Prevention that analyze CCS costs by age and diagnosis provides interesting cost detail including that a disproportionate share of costs is associated with the first year of life (newborn care accounts for 32% of CCS expenditures),³⁶ hospitalizations, and organ transplants.³⁷ Ten percent of CCS children account for 72% of the program's patient care expenditures.³⁸

Enrollment and Trends

Chart 3 describes enrollment in CCS over four years. The number of CCS participants not funded by Medi-Cal has declined in recent years from a high of 46,218 in FY2010-2011 to a projected 20,062 in 2013-2014 due to increases in the number of children covered by Medi-Cal.³⁹

35 A full breakdown of allocation among these three entities is provided at <http://www.dhcs.ca.gov/services/ccs/Pages/ProgramOverview.aspx#description>

36 Health Management Associates. (2009). Considerations for redesign of the California children's services program, p. 6. Retrieved from the Internet at <http://www.dhcs.ca.gov/provgovpart/Documents/Waiver%20Renewal/Considerations%20for%20Redesign%20of%20the%20CCS%20Program.pdf>

37 These can be found at <https://cpopstanford.wordpress.com/reports-and-policy-briefs/>.

38 The Center for Health Policy/Center for Primary Care and Outcomes Research. (2013). The cost of care for children enrolled in CCS. *Health Policy Facts*, Issue 1, Stanford University.

39 Washington, C. and Yoo, K. (2014). Ibid.

Chart 3: Enrollment in California Children's Services, 2009-2012

	Age	2009	2010	2011	2012
Medi-Cal	Under 1	12,073	12,446	4,545	6,784
	1-21	121,726	125,685	127,752	121,014
Not Medi-Cal	1-21	32,989	44,905	46,218	43,227
	Total	166,788	183,036	178,515	171,025

Children in Out-of-Home care

Information about the number of children enrolled in CCS who are placed in out-of-home care is not available. A national nursing home utilization data source indicates that 531 California children ages 0-20 resided in nursing homes for at least part of the year in 2011.⁴⁰

Services

The CCS program's list of covered health services include diagnostic services; specialty and subspecialty care; outpatient and inpatient care; occupational and physical therapies; pharmaceuticals and medical equipment supplies; and medical case management. Many CCS medical services are provided in special care centers located in academic medical centers and children's hospitals that provide interdisciplinary care to CCS-eligible children.

CCS is both a health insurer and a direct provider of some health services. The program authorizes and pays for services and assistive devices; certifies and maintains a provider network and hospital-based Special Care Units; and provides case management. CCS is also a direct provider of occupational therapy, physical therapy, and medical consultations to CCS patients through its Medical Therapy Program (MTP).

Program's Future

- The CCS carve-out may terminate in 2016, and some advocates believe that this will cause a major policy shift, possibly in advance of that deadline. A number of health policy analyses have identified different options for CCS administration in anticipation of 2016.⁴¹ These include that CCS assumes medical management of the whole child for children it serves rather than limiting its services to those associated with the qualifying condition. One way to accomplish this is to roll the CCS program into Medi-Cal managed care. Implications of the latter option are discussed in Section VII on "Access, Quality, and Coordination."
- Geographic inequities in access and quality exist in CCS services. CCS is administered at county or regional levels and there is room for interpretation about the severity of conditions and where eligibility lines should be drawn. There is also variation in how client needs assessments

40 Centers for Medicare and Medicaid Services. (2012). *Nursing Home Data Compendium, 2012 Edition*, page 156

41 For example: Health Management Associates. (2009). Ibid; Family Outcomes Project. (2010). Ibid.

are conducted and case management services are delivered throughout the state.⁴² There have been efforts to reduce some geographic variations and others remain.

- CCS has strong support from many parents of children needing LTCS and advocates who point out that, though not perfect, CCS has set the standard for health care excellence for all California children. At the same time, there may be something to learn from other states that include such things as funding for planning, care coordination, collaboration, and partnering with parents in their CCS budgets.

The Developmental Disability/Regional Center System: Providing Services to Children with Intellectual and Cognitive Disabilities

The California Department of Developmental Services (DDS) provides lifetime services and supports to individuals with developmental and intellectual disabilities through contracts with 21 nonprofit Regional Centers, community centers, and State-operated residential developmental centers.

Current Issue

Regional Centers' budgets have not kept pace with the growth in the number of clients they serve. Many of the Regional Centers' services are contracted from non-profits. Due to Regional Centers' stretched budgets, many find it difficult to find high-quality contractors able to work for the reimbursement rates they can provide. This problem is especially severe where there is a shortage of providers in some subspecialties such as pediatric dentistry and child psychiatry.

History and Legal Framework

Prior to 1969, 13,500 individuals with developmental disabilities, including children, were institutionalized and 3,000 remained on waiting lists.⁴³ By January 1, 2014, only 1,335 individuals lived in the five remaining State Developmental Centers (SDCs)⁴⁴ for the developmentally disabled including 23 children between the ages of 14 and 21.⁴⁵ Most were moved into community group homes.

Legislative milestones creating the architecture for the DD system include:

- **The Lanterman Act of 1969** assured that individuals with developmental disabilities have the right to receive services in the least restrictive environment, access to a continuum of services that support integration into the mainstream life of the community, and choice and empowerment in their life decisions. The intention of this legislation was to develop and provide community resources so people with developmental disabilities would not have to depend on institutional care.

42 Information on geographic variability is drawn from Lewis, V. (2009). Ibid. Page 6

43 The Scan Foundation. (2013). California's developmental disabilities service system. *Long-Term Care Fundamentals*, No. 12, page

4. Retrieved from the Internet at <http://www.thescanfoundation.org/californias-developmental-disabilities-service-system>

44 Dooley, D. (2014). Plan for the future of developmental centers in California. Retrieved from the Internet at <http://www.chhs.ca.gov/DCTFDocs/PlanfortheFutureofDevelopmentalCenters.pdf>

45 Department of Developmental Services Quarterly Consumer Report Index for the end of March 2014, page 26. Retrieved from the Internet at <http://itup.org/wp-content/uploads/2014/02/healthcare-financing.pdf>

- **The Association for Retarded Citizens v Department of Developmental Services** decision of 1985 established that DD services are entitlement services, as opposed to optional services. The implication is that if the need for services exists, their provision cannot be withheld even in times of severe budget constraints.
- The **Early Intervention Services Act of 1993** mandates services and supports for infants and toddlers from birth to 36 months who have or are at high risk for developmental delays. This Act has been implemented through the Early Start Program that screens and provides services to high-risk children up to three years of age.

Chart 4: Conditions of Developmental Disability System Members (Ages 0-21)

Condition	Rate
Autism	46%
Intellectual Disability (mild, moderate, severe, profound)	39%
Cerebral Palsy	11%
Epilepsy	10%
Vision Problems	8%
Hearing Problems	5%
Dual Diagnoses	6%
Behavioral Medication	9%
Medical Problems	15%
Special Health Care Requirements	13%
Notes: 1. Individual participants may appear in multiple categories. 2. Data compiled from State of California, Department of Developmental Services, Quarterly Consumer Characteristics Report Index for the end of March, 2014, Tables 44-48.	

Eligibility

Children and adults with disabilities including intellectual disability (IQ 70 or below), cerebral palsy, epilepsy, autism, and related conditions are eligible for services. Children at risk of developmental delays are also eligible through the Early Start program until they reach the age of 36 months, when children who meet criteria for DD enrollment are enrolled. The developmental disability that qualifies an individual for Regional Center services must “originate before the age

of 18, be expected to continue indefinitely and present a 'substantial disability' creating significant functional limitations in three or more areas of seven major life activities."⁴⁶

Enrollment and Trends

130,832 children ages 0-20 were enrolled in the Developmental Disability System as of February 2014.⁴⁷ The four most common diagnoses of children served through the Regional Centers (Chart 4) were autism, intellectual disabilities, cerebral palsy, and epilepsy.

The numbers of children with autism, which grew by 283% between 2000 and 2013,⁴⁸ has fueled enrollment in Regional Centers at a rate that far outpaces overall population growth. The prevalence of the other three major diagnoses of intellectual disability, cerebral palsy, and epilepsy has remained flat.⁴⁹

Chart 4 suggests levels of co-occurrence of other health conditions for children with developmental disabilities including mental health issues (5% dual diagnosis; 7% behavioral medication) and children with health conditions (14% with medical problems and 13% with special health care requirements).

Children in Out-of-Home Care

Among the 130,832 minors in the DD system in February 2014, 4,052 children were in out-of-home care. Most of these (2,773, 62%) were in foster care, community care facilities (695), intermediate care facilities (217), sub-acute pediatric facilities (116), and other health, mental health, and penal facilities.

Services Offered

Regional Centers provide or coordinate home and community-based services that include: day programs; education (augmenting education system offerings); work training and experience (habilitation); supported living services such as assistance moving into or maintaining a residence; independent living skill training; in-home supportive services; respite services (either in-home support to relieve families or short-term placement of children for family relief); and transportation that may include transportation vouchers, rehabbing or purchasing family cars suitable for transporting disabled clients.⁵⁰ Regional Centers rarely pay for direct health or dental services.

46 California Welfare & Institutions Code as quoted in Association of Regional Center Agencies. (2011). Federal funding in California's developmental services system: The role of regional centers, page 16. Retrieved from the Internet at <http://arcanet.org/pdfs/FFP%20Report%20-%20Final%203.11.pdf>

47 Because a very large number of 2-year-olds are enrolled as a result of the Early Start Prevention program, the number of 2-year-olds was adjusted downward by substituting the average number of enrollees for the years 0,1, and 3-10 for the inflated number of 2-year-olds. This reduced the number of 0-21-year-olds from 143,984 to 130,832.

48 The Scan Foundation. (2013). California's developmental disabilities service system. Ibid. p. 10.

49 Gans, D., Davis, A., Kinane, C., and Kominski, G. (2011). Challenges to sustaining California's developmental disability services system. *UCLA Center for Health Policy Research, Policy Note*. Retrieved from the Internet at <http://healthpolicy.ucla.edu/publications/Documents/PDF/Challenges%20to%20Sustaining%20California%E2%80%99s%20Developmental%20Disability%20Services%20System.pdf>

50 The Scan Foundation. (2013). Ibid. Page 5 presents a table from which these were drawn. Retrieved from the internet at <http://www.thescanfoundation.org/californias-developmental-disabilities-service-system>

Funding and Costs

The projected DDS budget for 2014-15 was \$5.2 billion. Of this, under half comes from the State general fund, \$2.7 billion from six different streams of Medicaid funding, and a series of other sources.^{51,52} Many Regional Center clients access services through Medicaid's Home and Community-Based Waiver (see Section VI for more detail on this waiver).

Current Issues

- Regional Center enrollment creates pressures on its budget allocation from the state. This pressure has resulted in cutbacks in some provider rates. Many providers are struggling nonprofits and low rates threaten their ability to continue providing services.
- Regional Centers are mandated to provide an array of services for their clients, yet there is an inadequate supply of providers for some services such as dental and mental health. Low reimbursement rates contribute to supply shortages. Inadequate numbers of specialists, especially those trained to work with developmentally disabled children, is another major challenge.
- Regional Centers' rapidly increasing enrollment of clients with autism has caused dramatic growth in the number of enrollees. While there were earlier indications that rates of increase had flattened, the CDC announced in 2014 that the incidence of autism has reached a high of one in sixty-eight or 147 per 1,000 individuals.⁵³ The decision in July 2014 by the federal Centers for Medicaid & Medicare (CMS) that Medicaid must cover comprehensive autism services may provide some budget relief.
- Many Regional Center clients use services in other systems, and there is a need for more coordination of care across systems. Some parents also point out that Regional Center staff can sometimes assume the role of gatekeeper rather than advocate for their children.

The Mental Health System

California's public mental health programs provided mental health services to 250,196 children (0-20) in 2012 through county-based programs. The California Department of Mental Health was dissolved in 2011 and its responsibilities were disbursed among relevant departments in the California Department of Health Care Services.

Current Issue

There is compelling evidence that childhood mental health conditions are becoming more pervasive and severe over time and that mental health conditions experienced as a child can have life-long consequences. It does not appear that there is a commensurate public health response to this problem. This is especially important because, of all children's health problems that require LTCS, mental health conditions are the most potentially reversible.

51 Department of Developmental Services. (2014). Governor's Budget Highlights, page 8. Retrieved from the Internet at http://www.dds.ca.gov/Budget/Docs/2014_2015DDSBudgetHighlights.pdf

52 D. Gans, A. Davis, C. Kinane, and G. Kominski. (2011). Ibid.

53 Available on the CDC website at <http://www.cdc.gov/ncbddd/autism/data.html>

History and Legal Framework

Up until the 1960s many children with mental illness were cared for in state hospitals. Since that time, children have been cared for primarily at home, in smaller residential settings, and in foster homes. Only 1% of California children who used public mental health services were treated in a hospital inpatient setting in 2010.⁵⁴

- The **Short-Doyle Act of 1957** in California followed by the national **Community Mental Health Act of 1963** legislated shifts in philosophy and funding to prioritize mental health services delivered in communities over those provided in institutions.
- The **Children's Mental Health Services Act of 1992** established guidelines for mental health services to children in California emphasizing interagency systems of care and avoiding out-of-home placements.
- **Mental Health Realignment in 1991 and 2011** transferred funds and responsibilities from the state to counties to shape the current county-centric system in which counties have jurisdiction over 90% of mental health funds.
- The **Mental Health Services Act (MHSA) of 2004** implements Proposition 63 passed in November 2004 to expand and transform California's county mental health service systems with income from a 1 percent tax levied on the 51,000 Californians with annual incomes in excess of \$1 million. Most MHSA funds have focused on prevention and early intervention. Some have supported innovative treatments for children with serious mental disturbances and adults with serious mental illness.
- **AB114** (2011) transferred administration of many child and adolescent mental health services previously provided through county mental health agencies to the jurisdiction of Special Education.

Eligibility

Children eligible for Medi-Cal are treated in the public mental health system that has a focus on children with a serious emotional disturbance (SED). Criteria for a SED include that children:

- Have an identified mental disorder that results in age-inappropriate behavior;
- Are substantially impaired in at least two areas among self-care, school functioning, family relationships, and ability to function in the community; and/or
- Are at risk of removal from the home or have already been removed.⁵⁵

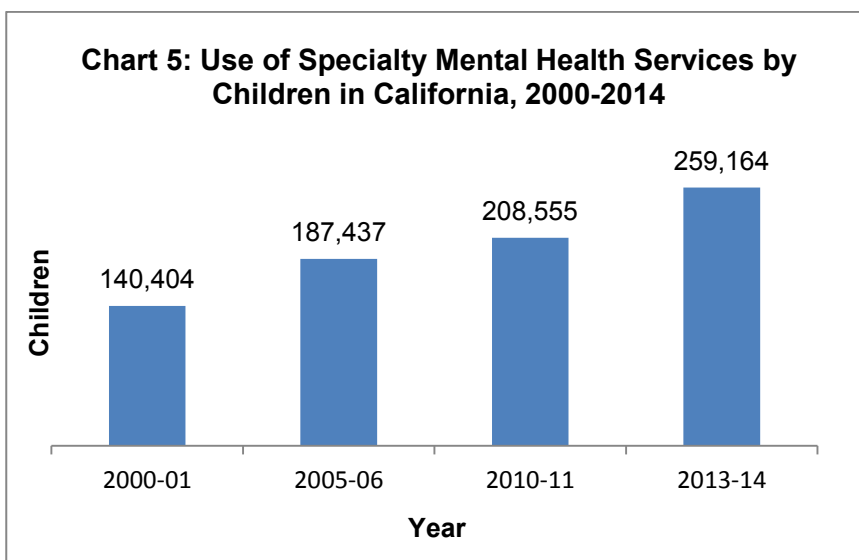
Of the total number of children served in 2012, 89% (222,674) were assessed to have a serious emotional disturbance. Of that number, over 22,000 were in out-of-home care, primarily in foster care (see Chart 5).

⁵⁴ Holt, W. and Adams, N. (2013). Mental health care in California: Painting a picture. Report prepared for the California HealthCare Foundation, page 36. Retrieved from the Internet at <http://www.chcf.org/publications/2013/07/mental-health-california>

⁵⁵ California Welfare and Institutions Code, §5600.3(a) as cited in Rehnquist, S. and Harbage, P. (2013). A complex case: Public mental health delivery and financing in California. A report prepared for the California HealthCare Foundation. Retrieved online at <http://www.chcf.org/publications/2013/07/complex-case-mental-health>

Funding

Medi-Cal funding for children's mental health services was \$1,394,890,000 in 2012-2013.⁵⁶ Although less than 10 percent of the overall Medicaid child population used mental health services, these services accounted for an estimated 38 percent of all Medicaid child expenditures and averaged \$4,200 per child (children 6-17 FY2011-2012).⁵⁷



Enrollment and Trends

Chart 5⁵⁸ depicts growth in the numbers of children using Medi-Cal Specialty Mental Health Services. This chart indicates that the numbers of children using these services have nearly doubled in the fourteen years included in the chart.

⁵⁶ Rehnquist, S. and Harbage, P. (2013). Ibid.

⁵⁷ Center for Health Care Strategies, Inc. (2013). Examining children's behavioral health service utilization and expenditures. *The Faces of Medicaid Series*. Retrieved online at http://www.chcs.org/media/Faces-of-Medicaid_Examining-Childrens-Behavioral-Health-Service-Utilization-and-ExpendituresI.pdf

⁵⁸ The chart is taken from "Children's Table of Approved Claim Costs and Unduplicated Client Counts, State Fiscal Years 2000-01 through 2015-16," available online at http://www.dhcs.ca.gov/services/MH/Documents/SMHSMay15_Est_Sup.pdf

More than 22,000 children receiving mental health services are not residing in the homes of their families of origin. As Chart 6 indicates, children in foster care account for slightly over one-third of children placed in out-of-home care and children in the juvenile justice system, 28%.⁵⁹

Chart 6: Out-of-Home Placements	
Children (Ages 0-17) Served by the State Mental Health Authority	
Foster Home	7,777
Residential Care	2,720
Residential treatment center	521
Institutional setting	23
Jail	6,130
Homeless shelters	381
Other	4,602
Total	22,154

Services Offered

The range of mental health services offered by counties includes outpatient mental health services, crisis intervention, psychiatry and medication management, short- and long-term inpatient mental health, as well as rehabilitative and supportive services. Of particular relevance to children using long-term care services, some behavioral health interventions have the specific aim of avoiding out-of-home placements. These interventions include intensive care coordination (ICC), therapeutic behavioral services (TBS), intensive home-based services (IHBS) as well as wrap-around services.⁶⁰

Current Issues

- Spending varies considerably by county, from Modoc County at the low end spending approximately \$1,877 per child, to Santa Cruz that spends \$10,216.⁶¹ This likely reflects variation in access and quality.
- Under the Affordable Care Act, responsibility for mental health treatment for children enrolled in Medi-Cal is divided between county plans that treat children with mild to moderate mental health services and programs and providers under the Specialty Mental Health Services Medicaid carve-out (see Section VI for more discussion of this carve-out) which serve children with SED. Counties are currently grappling with how to create this two-stream process yet make

⁵⁹ From the 2012 CMHS UNIFORM REPORTING SYSTEM (URS) OUTPUT TABLES

⁶⁰ These services are described in Core Practice Model Guide and Medi-Cal Manual for ICC, IHBS & TFC. (Updated August 13, 2013). Retrieved online at <http://www.dhcs.ca.gov/Documents/FAQs%20updated%20August%2013.vr.2.pdf>

⁶¹ Rehnquist, S. and Harbage, P. (2013). Ibid. Page 23

services feel seamless to families. These challenges are exacerbated by the shortage of child providers specializing in mental health.

- There is a severe shortage of child psychiatrists.⁶² More than 60% of all psychiatrists in California are clustered in San Francisco and Los Angeles and child psychiatrists likely follow this same distribution. The result is that primary care providers without training in mental health provide behavioral health services and medications to children—if the children are treated at all—in many parts of the state.
- There is currently no system to capture data about California children receiving mental health services across different systems of care such as in education and the juvenile justice system. Although building such a system is in process, there is an important information gap in the meantime.⁶³
- A review of childhood health with trends and consequences over the life course concludes there is compelling evidence that childhood mental health conditions are becoming more pervasive and severe over time and mental health conditions experienced as a child have life-long consequences.⁶⁴ It does not appear that there is a commensurate public or private health insurance response to this problem.

The Special Education System⁶⁵

The Special Education System provides educational support to 11% of California's approximately six million K-12 students.

Current Issue

California ranks close to the bottom of all states on a number of performance measures including identifying students with disabilities (sixth from bottom); placing children in least restrictive settings (defined as participating in regular education classrooms 80% or more of the time), and the number of Special Education children in grades 4-8 with low scores in reading and arithmetic (fourth from bottom).⁶⁶

History and Legal Framework

Prior to 1975 only one in five children with disabilities attended public schools, and many states explicitly excluded children with certain types of disabilities including those who were blind or deaf, and children labeled as emotionally disturbed or mentally retarded. Three laws overturned these discriminatory practices:

62 McRae, T., Dower, C., Briggance, B., Vance, J., Keane, D., and O'Neill, E. (2003). The mental health workforce: Who is meeting California's need? Publication prepared for the California Health Workforce Initiative of the California HealthCare Foundation and the California Endowment. Retrieved from the Internet at http://www.futurehealth.ucsf.edu/Content/29/200302_The_Mental_Health_Workforce_Executive_Summary.pdf

63 Personal communication from Jennifer Taylor, Section Chief, Mental Health Services Division, Fiscal Management and Outcomes Reporting Branch, May 1, 2014

64 Delaney, L. and Smith, J. (2012). Childhood health: Trends and consequences over the life course. *The Future of Children*, Vol. 22, page 59

65 Information for this section was drawn from two key sources: Parrish, T. (2012). Special Education Expenditures, Revenues, and Provision in California. American Institutes for Research as Partner in the California Comprehensive Center at WestEd. Retrieved from the Internet at http://cacompcenter.org/wp-content/uploads/2013/02/CA_CC_Special_Education_2012.pdf and Laudan, A. and Loprest, P. (2012). Disability and the Education System, *The Future of Children*, Vol. 22, No. 1, pps. 97-122. Retrieved from the Internet at <http://www.princeton.edu/futureofchildren/publications/journals/article/index.xml?journalid=77&articleid=562>

66 Statistics from Parrish, T. (2012). Ibid.

- The **Rehabilitation Act of 1973** challenged the assumption that disadvantages faced by people with disabilities, such as low educational attainment, result from the disability itself rather than from societal barriers and prejudices. This law declared it illegal for recipients of federal funds to discriminate against people with disabilities.
- The **Individuals with Disabilities Education Act (IDEA) of 1975** established the right for children with disabilities to attend public schools, to receive services designed to meet their needs free of charge and, to the greatest extent possible, receive instruction in regular classrooms alongside nondisabled children.

Part C of IDEA, passed in 1986, provides funds to states for children ages 0 through 2 who have or may have disabilities, in order to prevent future need for special education and other services where possible. In California, Part C is implemented through the California Early Intervention Services Act “to provide a statewide system of coordinated, comprehensive, family-centered, multidisciplinary, interagency programs, responsible for providing appropriate early intervention services and support to all eligible infants and toddlers and their families.” [California Government Code (Cal. Gov. Code) Sec. 95002.]⁶⁷ Children’s service plans are specified in Individualized Family Service Plans (IFSPs). Children may be eligible for services provided by both the Department of Education and the Department of Developmental Services (DDS); DDS has been designated as the lead agency responsible for the administration and coordination of the statewide service delivery system.

- In California, **AB114** (2011) dramatically changed responsibilities for providing mental health services to children with Individual Education Plans (IEPs) by shifting this role from county mental health services to the education system. These responsibilities include placing children in out-of-home care if that is deemed desirable to improve the child’s opportunities for school success.

Eligibility

Children ages birth-22 with a diagnosed disability that impedes their ability to learn are eligible for special education services. This is true even if it is not obvious that students can benefit from educational exposure. Eligibility for services is based on an IEP (Individual Educational Plan) developed by a committee consisting of school administrators, special education staff, parents, and others whose input may be relevant. A critical and sometimes controversial factor in eligibility determinations is the eligibility criterion that the disability must interfere with learning. A child with a severe stutter, for example, may not qualify because the stutter doesn’t necessarily impede learning, although it may impede successful progress in life.

⁶⁷ Quoted from Disability Rights California. (Undated). Special education rights and responsibilities, Chapter 12, pps. 12-22. Retrieved from the Internet at <http://www.disabilityrightsca.org/pubs/504001Ch12.pdf>

Chart 7: Disabilities of California Children Ages Birth-22 Enrolled in Special Education	
Disability	Rate
Specific Learning Disability	40%
Speech or Language Impairment	23%
Autism	12%
Other Health Impairment	10%
Intellectual Disability	6%
Emotional Disturbance	3%
Hard of Hearing/Deaf	2%
Orthopedic Impairment	2%
Multiple Disabilities	1%
Visual Impairment	1%
Traumatic Brain Injury	0%
Deaf-Blindness	0%
Source: December 2013 data downloaded from the Department of Education's DataQuest system	

Enrollment and Trends

Enrollment in special education as a percent of total students has only minimally increased over the past 15 years, growing from 10% of the overall student population to about 11% by 2010. Chart 7 describes the disabilities of children in Special Education in December 2013.

Funding

Special Education is funded through a complex mix of federal, state, and local funds. California spent \$10.7 billion on special education in FY 2011. Special Education expenditures have grown as a percentage of total education expenditures from 22% in FY 2003 to 32% in FY 2013. A study based on 2010 data places California fifth from the bottom of all states in Special Education per pupil expenditures. The Department of Education's projected budget for mental health services in FY 2012-2013 was \$420 million, of which \$60 million was federal.

Services Offered

Chart 8 lists services covered under IDEA.

Chart 8: IDEA Covered Services: Examples	
Related Services	Early Intervention Services
<ul style="list-style-type: none"> ● Speech-language pathology ● Physical and occupational therapy ● Audiology ● Psychological services ● Social work and counseling services ● Orientation and mobility services ● School health and school nurse services, and; ● Medical services for diagnostic and evaluation purposes only ● Transportation ● Vision services 	<ul style="list-style-type: none"> ● Speech-language pathology ● Physical and occupational therapy ● Assistive technology ● Vision services ● Family training and counseling ● Psychological services ● Family training and counseling ● Medical services for diagnostic and evaluation purposes only ● Health services necessary to enable the infant or toddler to benefit from the other early intervention services ● Special instruction ● Service coordination

Children can access a continuum of services, and participate in general education classrooms where special education coaches work with students needing extra help, in special day classes taught by special education teachers, in schools designed for students with significant disabilities, and, for very ill children, at home or in institutional settings. Education provided at home is generally only a very few hours per week.

Summary for the Four Systems

Each of these four systems—California Children's Services, the Developmental Disabilities System, Mental Health, and Special Education—has evolved to address a particular population and purpose, from meeting the demands created by an epidemic to providing lifelong services for people with intellectual challenges. There are many duplicative services among these providers as well as differences, for example, in eligibility criteria and the duration of time services can be accessed. And three of the systems (IDEA, mental health, and DDS) all fund parent advocacy services but CCS does not.

To return to the metaphor of the kaleidoscope, each service is a unique frame in the kaleidoscope of services needed by children using LTCS and the frames are overlaid upon each other. Some counties have made deliberate efforts to coordinate services among the four systems. More often, responsibility for navigating the complex systems to gain access to services falls on the shoulders of the parents of children needing LTCS. This is especially challenging when each system wants to be the provider of last resort. This and related access challenges are discussed in Section VII.

VI. Sources of Funding for Children Using Long-Term Care Services

Children needing LTCS require flexible services, medical and non-medical, that shift over time according to children’s developmental and life stages and their changing capacities and health conditions. In this section we review four different sources of funding for children’s long-term care with an emphasis on programs developed specifically to promote care in home and community settings.

Private Insurance

Approximately 46% (4.5 million) of California children are covered by private insurance through their parents’ employers⁶⁸ and an additional 453,000 families purchase policies on the open market.⁶⁹ The Affordable Care Act of 2010 extends the age through which children can be covered under their parents’ plans to age 26 and makes it illegal to deny coverage for pre-existing conditions. The last decade has seen a trend of decreasing coverage by private insurers (from 65% to 55% over a decade that was studied from the mid-1990s to the mid-2000s)⁷⁰ and increasing use of public sources. This trend is projected to continue as a result of increased eligibility for public subsidies under the Affordable Care Act of 2010.

The quality and availability of services available through private insurance companies varies with the company and the plan. Private insurers often control access to care for high-end users of services such as children needing LTCS through a case or care manager who may know little about the child’s health condition. In general, there are more complaints against private health insurers for denying services than against public health plans.⁷¹

Medicaid and Medi-Cal

Medicaid is the nation’s largest purchaser of health and long-term care services, financing almost 40% of the country’s long-term care services.⁷² It was created in 1965 as an entitlement program under Title XIX of the Social Security Act to assure health coverage for needy Americans. Most Medicaid programs are administered by states and require a match to obtain federal funds. Medicaid funds are administered in California as Medi-Cal. States do not all receive the same reimbursement rates, and California has among the lowest state:federal ratio and low provider reimbursement rates. The following section looks first at the overall disbursement of Medicaid dollars in the state and then at particular Medi-Cal programs and exceptions that are important for children needing LTCS.

68 Coleman, C. (2014). Children’s health insurance under the ACA. Report prepared by the Insure the Uninsured Project for the Lucile Packard Foundation for Children’s Health. Retrieved from the Internet at <http://itup.org/wp-content/uploads/2014/01/Executive-Summary-Childrens-Health.pdf>

69 Coleman, C. (2014). Ibid

70 Coleman, C. (2014). Ibid

71 Thank you to Laurie Soman, who has analyzed these complaints, for this observation.

72 Quoted in The Scan Foundation. (2011). Medicaid-funded home and community based services. *Long-term care fundamentals, Technical Brief Series #9*. Retrieved from the Internet at <http://thescanfoundation.org/medicaid-funded-home-and-community-based-services>

Once Medicaid funds reach California they are distributed to multiple agencies and departments responsible for their administration. As pictured in Chart 9, the distribution includes funding streams that go to the California Department of Health Care Services (including Medi-Cal health insurance, the largest pipeline of funds); the Department of Developmental Services; Mental Health Services; California Children's Services; Early Periodic Screening, Detection, and Treatment; the Genetically Handicapped Persons Program; the California Department of Social Services (In-Home Supportive Services; foster care), and the Department of Education (Special Education). As a result of this fanning out process, individual children needing long-term care services may access Medicaid dollars through nine or more funding streams.

Medi-Cal provided health insurance to 4.1 million California children in 2011-2012, approximately 45% of the total child population.⁷³ As a result of the Affordable Care Act that number has increased to 50%.⁷⁴ A challenge for the Medi-Cal insurance program, exacerbated by its expansion under health reform, is its ability to recruit and retain providers willing to work for its relatively low reimbursement rates. This is captured in the accompanying quote from the Los Angeles Times. Low Medi-Cal reimbursement rates, already very low, were recently cut by 10%.

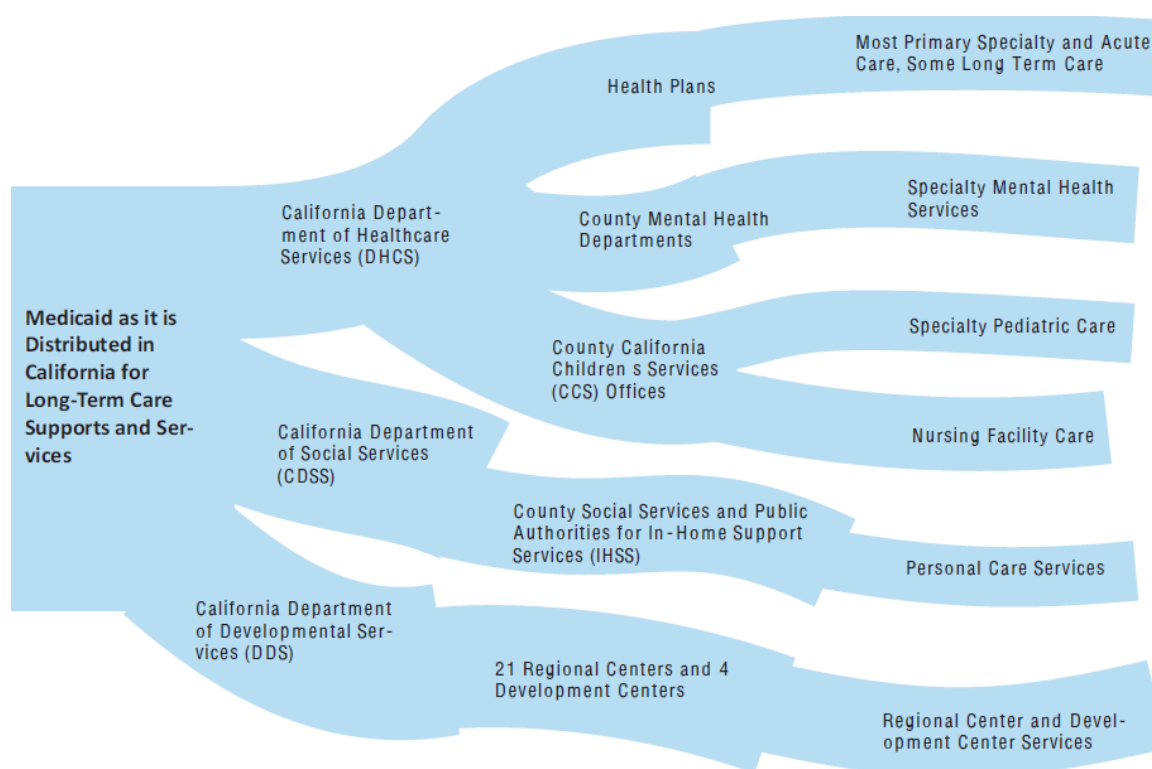
"California is coming face to face with the reality of one of its biggest Obamacare successes: the explosion in Medi-Cal enrollment. The numbers—2.2 million enrollees since January 2014—surprised health care experts and created unforeseen challenges for state officials. Altogether, there are now about 11 million Medi-Cal beneficiaries, constituting nearly 30% of the state's population. That has pushed the public insurance program into the spotlight, after nearly 50 years as a quiet mainstay of the state's health care system, and it has raised concerns about California's ability to meet the increased demand for healthcare."

– Anna Gorman, Los Angeles Times Editorial, August 13, 2014

Family income is the primary qualifying criterion for Medi-Cal. Enrollment in other income-based health programs including California Children's Services (CCS), the Genetically Handicapped Person's Program, Medicare, and Social Security—which have already been described or are described below—also qualifies children for Medi-Cal.

⁷³ Coleman, C. (2014). Ibid

⁷⁴ How Are Children Faring as A Result of the Affordable Care Act? Data presented by the Children's Defense Fund, California. 2015. Retrieved from the Internet at <http://www.cdfca.org/library/publications/2015/aca-anniversary-factsheet.pdf>

Chart 9: California Sources of Funding for Children's Long-Term Care Services

Full-Scope Medi-Cal

Depending upon their families' levels of income, children can be qualified as "full-scope Medi-Cal" or "zero cost of share Medi-Cal" which means that they have access to all Medi-Cal services free of charge. "Share of cost" Medi-Cal requires that families make a contribution to the overall cost of care.⁷⁵

Institutional Deeming: This exception to Medi-Cal's income requirements is important to children using LTCS. Children are "institutionally deemed" when they have a disability or other health condition of such severity that they are at high risk of institutionalization. Institutionally deemed children are granted full-scope Medi-Cal status, a gatekeeper for many services and payments that are often essential in families' ability to keep their children at home. Both Maggie and Thomas were institutionally deemed, which, according to their parents, made a night and day difference in their ability to gain access to services, especially home nursing, that was pivotal to their ability to care for their children at home.

Medicaid Waivers:⁷⁶ Some Medicaid programs have been created with the specific aim of bypassing (waiving) certain Medicaid rules and regulations to create programs that promote caring

⁷⁵ Disability Rights California. (2013). 2013 zero share of cost Medi-Cal program for children with disabilities. Retrieved online from <http://www.disabilityrightscalifornia.org/pubs/524401.pdf>

⁷⁶ The websites of the California Department of Health Care Services and Disability Rights California have excellent information about waivers.

at home and in communities for children and adults needing long-term care services. Especially relevant waivers include:

Home and Community-Based Services or HCBS waivers (Section 1915(C) waivers) allow states to provide long-term care services in community settings. Services include a combination of standard medical services and non-medical services and allow some services not ordinarily available under the regular Medi-Cal program for people living at home, such as transportation and targeted case management.

- The Home and Community-Based Services Waiver for People with Developmental Disabilities (HCBS-DD) provides services to enable people with developmental disabilities who might otherwise be housed in a facility (ICF/DD) to live at home. This waiver affects 92,000 individuals.⁷⁷
- The Developmentally Disabled Continuous Nursing Care Waiver (DD-CNC) provides continuous nursing care to medically fragile Medi-Cal beneficiaries with developmental disabilities in a small home-like community setting. This waiver served fewer than 50 people in fiscal year 2010-2011.⁷⁸
- The Pediatric Palliative Care waiver allows eligible children and their families to receive palliative care services during the course of the child's illness, while concurrently pursuing curative treatment for the child's life limiting or life-threatening medical condition. The goal is to improve quality of life as well as reduce hospital stays, medical transports and emergency room visits. Palliative care services include care coordination, family training, respite, expressive therapies, and family bereavement counseling. This program is in an early start-up and an evaluation based on the first 123 enrolled patients reports high levels of satisfaction and savings that average \$1,677 per patient per month, an overall 11% reduction in costs.⁷⁹

Managed care waivers (Section 1915(B)) allow states to bypass federal requirements that consumers must have choice of providers by limiting access to a panel of providers identified by a health plan.

- The Specialty Mental Health Services (SMHS) Act allows counties to operate county plans with designated providers of mental health services. This waiver affects 425,000 people including children and is authorized through June 2015. This program for Medi-Cal beneficiaries with severe mental illness includes a range of intensive inpatient and outpatient services provided through County Mental Health Plans.

77 A full list of services provided under this waiver is available online at <http://www.dhcs.ca.gov/services/medi-cal/Pages/HCBSD-DMediCalWaiver.aspx#>

78 The Scan Foundation. (2011). Ibid, page 7

79 Gans, D., Kominski, G., Roby, D., Diamant, A., Chen, X, Lin, W. and Hohe, N. (2012) Better outcomes, lower costs: Palliative care program reduces stress, costs of care for children with life-threatening conditions. *A Policy Brief of the UCLA Center for Health Policy Research*. Retrieved online at: <http://healthpolicy.ucla.edu/publications/search/pages/detail.aspx?PubID=1087>

Medicaid Optional and Specialized Programs

In addition to federally mandated Medicaid programs, others are left to the discretion of states and counties. Several of these that are critically important to families caring for children needing long-term care services include:

- **The In-Home Supportive Services (IHSS) Program** enables personal care workers to provide a variety of services, primarily based in the home. Because family members can be certified and paid to be providers, this program is a vital support to families who forgo income to care for their children needing LTCS at home. The State Department of Social Services and county departments of social services administer this program. Eligibility is determined at the county level and is based on income and level of disability. Personal assistance services include help with such activities as bathing, dressing, transferring, and domestic assistance tasks such as meal preparation, shopping, heavy house cleaning, and protective supervision.

Enrollment for 2014-2015 is projected to be 447,702 individuals of all ages.⁸⁰ In February 2014 enrollment of children ages 0-20 was approximately 30,000,⁸¹ accounting for approximately 6.7% of all IHSS users. An analysis of FY 2011 Medi-Cal expenditures for long-term care shows that personal care services (IHSS) account for 40% of all long-term care costs, slightly behind nursing facility and other institutional care that, at 42%, accounts for the largest share of Medi-Cal spending on long-term care.⁸²

During the recent recession, IHSS funding was reduced, which made it difficult to find qualified workers for in-home support to families. Funding for durable medical equipment was also reduced to the point that some vendors refused to participate. There is also controversy about whether workers providing in-home support can be paid overtime and a case to determine this is currently pending.

- **Early and Periodic Screening, Detection and Treatment (EPSDT):** In addition to screening and diagnostic services, EPSDT provides mental health and supplemental long-term care services such as in-home skilled nursing services, pediatric day health services for medically fragile children, and transportation. Although EPSDT was first enacted in 1967 with an emphasis on prevention, the federal Omnibus Budget Reconciliation Act (OBRA) of 1989 expanded and more precisely defined this entitlement to emphasize treatment for conditions identified through screening and detection. In California this resulted in a major expansion of services starting in 1995. The Clebergs, McDonalds, and Suens believe that the in-home skilled nursing services provided by EPSDT have been absolutely critical to their ability to continue to care for their children at home. Services covered under EPSDT include all mandatory and optional services that states can cover under Medicaid. Examples of covered services are included in Chart 10.

⁸⁰ Governor's Budget Summary 2014-2015. Ibid. p. 45.

⁸¹ Many thanks to Ernie Ruoff and other staff of IHSS in the Department of Health Care Services who provided a spreadsheet of users.

⁸² California HealthCare Foundation. (2013). Health Care Almanac, Medi-Cal Facts and Figures: A Program Transforms, p. 31. Retrieved from the Internet at <http://www.chcf.org/publications/2013/05/medical-facts-figures>

Chart 10: EPSDT Services: Examples

- Physical and occupational therapy
- Speech-language pathology
- Psychological services
- Personal care services
- Private duty nursing
- Durable medical equipment (e.g., wheelchairs, crutches, communication devices)
- Transportation

- Combined 2011 county and federal spending on EPSDT mental health services totaled \$1.25 billion, a tenfold increase from the \$100 million spent in 1995. The average amount per beneficiary was \$5,600. There is controversy about whether EPSDT is a capped benefit or is an entitlement that can be used to the extent that it is needed. Under mental health realignment, counties bear the burden for EPSDT spending in excess of their allotments from the State, which makes county allotments a “soft cap” for spending.
- **Genetically Handicapped Persons Program (GHPP):** GHPP provides health coverage for both adults and children not eligible for CCS who have specific genetic diseases. These include diseases of the blood such as hemophilia and sickle cell disease; cystic fibrosis; diseases of the brain and nerves such as Huntington’s disease and Friedrich’s ataxia; diseases of protein metabolism such as phenylketonuria; diseases of carbohydrates metabolism such as galactosemia; the disease of copper metabolism; and Von Hippel-Lindau disease.⁸³ Families with incomes over 200 percent of the federal poverty level pay fees based on a sliding scale. The program is administered statewide through the GHPP office in Sacramento.
- **Medi-Cal Managed Care:** California counties administer Medi-Cal as either a fee-for-service program that reimburses providers for each service they deliver or in a managed care plan that pays provider groups prospectively for negotiated estimates of what they believe their enrolled patients will cost. Increasing numbers of Medi-Cal participants have been enrolled in managed care plans over the past 20 years; currently 69 percent of Medi-Cal members are enrolled in managed care.⁸⁴

Parents and advocates for children with special health care needs believe that managed care may not meet the needs of their children. Central to their concerns is that all Medi-Cal recipients will soon be required to enroll in managed care, but the limited provider networks of managed care plans may not include the specialists and subspecialists that their children need to treat their complex, often rare conditions. If mandated to enroll in managed care, they believe that they could lose access to the providers and specialists they have found to provide the best care for their children. Their concerns are echoed in a meta-review of studies about managed care for children with special health care needs that concludes that the record of managed care for

⁸³ A complete list is available on the California Department of Health Care Services website at <http://www.dhcs.ca.gov/services/ghpp/Pages/MedicalEligibility.aspx>

⁸⁴ Coleman, C. (2014). Ibid, p 2

children with special health care needs is mixed and that caution should be exercised in implementing managed care programs for this population.⁸⁵

A recent Medi-Cal policy shift required seniors and persons with disabilities (referred to as SPDs) who had previously been exempt from managed care to move into managed care plans. Research conducted on this shift reported that among those least satisfied were participants with the most serious and complex health conditions.⁸⁶ Because children needing LTCS may parallel this “serious and complex” adult group, these findings have important implications for children whose conditions are also serious and complex.

Medical Homes

Another trend in Medi-Cal management is to move participants into “medical homes” that assure access to a regular source of care that assumes primary responsibility for coordinating among service providers. Although there are many different definitions and interpretations of what medical homes are, they generally aim to provide multi-disciplinary health care that includes both preventive and treatment services to panel members. Medical homes may focus on a general population or a subgroup of individuals such as homeless patients or children with special health care needs. In many areas medical homes have taken on the meaning of practices in which primary medical care and behavioral health care are coordinated and sometimes co-located; these are sometimes referred to as health homes. Medicaid has a special initiative to encourage this coordination for patients with at least one chronic medical condition and a behavioral health condition.

California children with special health care needs are less likely to receive services in a medical home if their conditions are considered “more complex” (35.1% in California and 29.2% nationally compared to those that are “less complex” (55.9 nationally, 54.2% in California).⁸⁷ Medical homes, like managed care, have the potential to be beneficial if they help families manage and integrate their care.

Blended Private and Public Insurance through Covered California and the California Health Exchange

California’s Health Exchange administers a range of insurance products, subsidized and unsubsidized, made available through California’s implementation of the Affordable Care Act of 2010 to individuals with incomes up to 400% of poverty.

Current Issue

A current issue of great importance to children needing LTCS is whether Health Exchange policies will cover durable medical equipment such as wheelchairs. Advocate organizations are seeking clarification.

85 Houtrow, A., Okumura, M., Hilton, J., and Rehm, R. (2010) Profiling health and health-related services for children with special health care needs with and without disabilities. *Academic Pediatrics*, 10:48-55

86 California HealthCare Foundation. (2014) In transition: seniors and persons with disabilities reflect on their move to managed care. Retrieved from the Internet at <http://www.chcf.org/publications/2014/04/transition-spds-move-mmc>

87 Bethell, C. (2013). Children with special health care needs in California: A profile of key issues. Report prepared for the Lucile Packard Foundation for Children’s Health by the Child & Adolescent Health Measure Initiative. Retrieved from the Internet at <http://lpfch-cshcn.org/publications/research-reports/children-with-special-health-care-needs-in-california-a-profile-of-key-issues/>

Enrollment began in fall 2013 and coverage commenced January 1, 2014. Pre-implementation forecasts anticipated that 1.8 million individuals previously without health insurance would enroll in private health insurance, of which 1.7 million would be subsidized coverage. As of April 15, 2014, 1.4 million people had registered for private plans through the Exchange.^{88,89} It is still too early to present a breakdown of subsidized and unsubsidized policies. A full range of health and preventive services are offered through Health Exchange plans but coverage for some areas important to children needing LTCS need clarification.

Supplemental Security Income (SSI)

This federal program is the only cash assistance program to help families meet some expenses related to disabilities. In December 2013, 119,647 California children ages 0-17 were enrolled in SSI.⁹⁰ Eligibility is based on financial need and an assessment of whether the child has a physical or mental impairment, including emotional or learning problems, which result in functional limitations. The impairment must last for at least 12 months or be expected to result in death.

Medicare

Medicare is a health benefit primarily for seniors, with the exception of children who have had a kidney transplant and/or require dialysis for kidney disease. Only 306 California children are dually eligible for Medicaid and Medicare.⁹¹

Children with No Insurance and Inadequate Insurance

Are there children in long-term care without insurance? Overall, approximately 5% of California children are uninsured.⁹² A review of coverage for children with special health care needs concludes that large numbers of children with disabilities are uninsured or inadequately insured, especially among older and lower-income children and minority children.⁹³ This number is being reduced with implementation of the ACA and it remains to be seen what the residual uninsured will be. An important group ineligible for Medi-Cal (except for emergencies and some exceptions) that covers health and mental health services is undocumented children, who are also not able to access insurance through Covered California. California Children's Services and services offered through the Department of Developmental Services do not have documentation requirements.

Even having insurance coverage does not assure that all costs of LTCS are paid for by insurance, and Section VIII on costs of care describes out-of-pocket costs carried by many families caring at home for children needing long-term care supports and services.

88 Levey, N. and Terhune, C. (2014). Eight million people signed up for health care, Obama announces, *The Los Angeles Times*.

89 Diamond, D. (2014). From 0 to 3.3 Million sign-ups: How California 'won' the Obamacare race. *Kaiser Health News*. Retrieved from the Internet at <http://www.wall-street.com/2014/04/29/from-zero-to-3-3-million-sign-ups-how-california-won-the-obamacare-race/>

90 Table for 2013 California SSI recipients available at http://www.ssa.gov/policy/docs/statcomps/ssi_sc/2013/ca.html

91 California Department of Health Care Services.(2014). Medi-Cal's dual eligible population demographics, health characteristics, and costs of health coverage, executive summary. Retrieved from the Internet at <http://www.dhcs.ca.gov/provgovpart/Documents/Dual%20Eligibles%20Summary%20California%20Data.pdf>

92 Coleman, C. (2014). Ibid, p 1

93 Szilagyi, P. (2012). Health insurance and children with disabilities. *The Future of Children*, Vol. 22, No. 1, p 126

VII. Access, Quality, and Coordination of Children's Long-Term Care Services

Ideally, families caring for children needing LTCS are supported by a system of care that creates access, maintains a high level of quality, and assures coordination. The parents of Maggie, Thomas, and Charlie reported that despite many well-meaning and conscientious individuals working in programs they have encountered, there is no system of care for their children. This leaves parents at the helm, navigating a kaleidoscope of programs and funding sources with multiple, sometimes conflicting, conditions and requirements.

The Current State of Systems of Care

This section draws on information based on analyses of survey data about children with special health care needs (CSHCN). As discussed in Section II, it is likely that there is considerable overlap between CSHCN with complex health needs and children using LTCS due to similarly high levels of severity.

Access

More than 40% of CSHCN in California with complex health needs have difficulty accessing community-based services, compared to 20% with less complex needs.⁹⁴

Many factors influence access to services, for example, whether the service or providers exist, whether they are close enough geographically to use, whether the service is affordable and culturally appropriate, and whether it is reasonably easy to schedule appointments.

When the McDonalds left the hospital with their baby daughter with significant disabilities, a social worker told them they would not qualify for services because their family income was too high. This information was not correct, but it was not until Maggie was admitted to a different hospital six months later for hydrocephalus that the McDonalds started to learn about services that could help them manage Maggie's care.

Knowledge about services is the starting point for access, and this alone can be challenging. Charlie's, Maggie's, and Thomas's parents found that other families with disabled children and nonprofits run by families with disabled children were their best sources of information about services. Hospital NICUs are required to have high-risk infant follow-up programs, but families report that hospital-based nurses and social worker services often do not have comprehensive knowledge of community resources. Even a simple pamphlet with key telephone numbers for families of disabled newborns leaving the hospital is one resource that families suggested could provide some immediate relief and support.

94 This and other statistical references in this section are from: Bethell, J.C. (2013). Ibid. Pages 9-19

There is great variability in the accessibility of services across California. Generally, urban areas provide better access than rural areas. Some specialty and subspecialty medical services are scarce throughout the state, especially in rural areas.⁹⁵ Many children using LTCS have complicated conditions for which there may only be a few specialists in the state. Even living within an urban metropolitan area, Charlie sees seven different specialists at a hospital about forty-five minutes from his home. Because the clinics he needs are on different days, it is rare that he is able to double up on appointments. So although he does have access to the specialists he needs, the opportunity cost of seeing them is very high.

“The services themselves are not intuitive. Parents of a child with special needs cannot simply look up ‘disabled children’ and find what they need. It is a confusing set of systems that sometimes overlap and often leaves gaping holes in the services needed for any given child. Each program has a different name and any of several different agencies may sponsor them.

– Parent of a child using LTCS

Access is closely tied to service coordination for children using LTCS because their service needs cross multiple jurisdictional boundaries. In the case of multiple service systems providing similar services, each system is financially motivated to have the other system provide the service and tries to position itself as the payer of last resort. This places families in the position of needing to negotiate between or among the systems before they are able to gain access to the help they need, a process that can require time and energy and cause frustration.

Quality

California ranked last in the country in the percentage of CSHCN whose care met a set of minimum quality standards. Publicly insured children fare worse on this measure than do those with private insurance.

Quality of care is an issue for all families with children with special health care needs, and complexity of health problems intensifies the challenge. Families of disabled children stress that good communication and strong partnerships between parents and providers are key to high-quality care.

The Suens, for example, learned they had to be confrontational with providers in an intensive care unit in order to convince them that Thomas could not tolerate the number of calories they were feeding him. The providers were intent on providing the calorie count for a typical child of Thomas' height and weight, without understanding the signs of his distress that his parents could perceive, and without knowing what was typical for him. Maggie's mother, Sally, recounts that she learned to explain diplomatically to specialists that they were experts in medical science yet she was a specialist in her daughter, so the two “experts” should pool their knowledge.

⁹⁵ Gans, D., Battistelli, M., Ramirez, M., Cabezas, L., and Pourat, N. (2013) Assuring children's access to subspecialty care in California. *UCLA Center for Health Policy Research Policy Note*. Retrieved online at <http://healthpolicy.ucla.edu/publications/Documents/PDF/psepn-apr2013.pdf>

California ranks 46th in the nation in providing family-centered care that supports the family's relationship with the child's health care providers and recognizes the importance of the family's customs and values in the child's care. Again, children with more complex health care needs score worse on this measure.

Even parents cannot be good monitors for quality when they do not know what to look for. When the Suens first gained access to home nursing care for Thomas, the nurses generally sat by his bedside when not involved with a specific procedure. It was not until the Suens moved to another county and used nurses trained by a different home health agency that they realized they should have expected more. The new nurses actively engaged Thomas by talking and reading to him and checked frequently with supervising physicians when they had questions and concerns.

Coordination

Nearly half of California children with special health care needs do not receive effective care coordination. The state ranks 46th in the nation on this measure. Children with more complex health needs fare worse in California than children with less complex needs for all measures of care coordination. Forty-six percent of children with complex special health care needs received effective care coordination compared to 70.1% for children with less complex health needs. This difference remains constant for different types of coordination, including help with coordinating care, communication among doctors and specialists, and communication between doctors and school programs.

For the McDonalds, Suens, and Clebergs, managing care is a full-time activity. Isabella Suen, for example, spends at least 10 hours a week simply coordinating Thomas's care. This includes scheduling appointments with his physician specialists; ordering and monitoring medical supplies such as diapers, trach, G-tube, and medications; coordinating therapies such as occupational, physical, and communication; and managing the schedules of nurses providing home nursing. Forty-four percent of California parents caring for children with complex health care needs report spending 11 or more hours per week managing their care.⁹⁶ A simple but revealing example of failure to coordinate was when Thomas's school-based communication specialist and home-based speech therapist taught him communication skills with different assistive devices. This was confusing for Thomas and it fell to his parents to work with the two systems so that Thomas was learning communication skills using just one device.

Maggie MacDonald had six different case managers at the same time, all mandated to help access services and coordinate care. Each of the case managers worked within a system (private insurance, hospital, Medi-Cal, CCS, DDS, Special Ed), but the role of coordinating among and between the systems falls on families. The case managers did not talk to each other, so sharing information among them fell on Maggie's mother's shoulders.

⁹⁶ Data are from the 2009/10 National Survey of Children with Special Health Care Needs. The reported number is based on children meeting four or more screening criteria for special health care needs. Retrieved from the Internet at <http://www.childhealth-data.org/browse/survey>

Chart 11: Sources of Family Support in California

	Early Start Family Resource Centers (ESFRC) 47 statewide	Family Empowerment Centers (FEC) 14 statewide	Family Voices of California (FVCA) 10 Statewide	Federally Funded Parent Centers: Parent Training & Information Centers (PTI) and Community Parent Resource Centers (CPRC)
Population Served	Ages 0-3 Focus on families of infants/ toddlers at risk of or with developmental delays and disabilities	Ages 3-22 Focus on children with disabilities who require special education services	No age limit Focus on children with special health care needs	Ages 0-26 Focus on children with education needs
Services Provided	Supports families of children with disabilities, special health care needs, and those at risk of developmental delays in every California county. ESFRCs offer parent-to-parent support, information and referral, public awareness, family professional collaborations and transition assistance when the child is approaching age three. In addition, many ESFRCs offer services to families of children over the age of three.	Assists families of children with disabilities in the area of educational needs. The FECs work collaboratively through the California Association of Family Empowerment Centers to advocate for educational improvement on a statewide level.	Seeks to improve the lives of children with special health care needs by improving policies and systems of care for children with special health care needs, providing information and education to families and professionals regarding health care for children with special health care needs, promoting family-centered, culturally competent, community-based coordination, and quality of care for children with special health care needs, and developing family and professional partnerships.	The eight <i>Parent Training and Information Centers</i> (PTIs) and six <i>Community Parent Resource Centers</i> (CPRCs) provide training and information to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children. This assistance helps parents to participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. The Parent Centers work to improve educational outcomes for children and youth with all disabilities (emotional, learning, mental, and physical). Community Parent Resource Centers focus on underserved populations such as the Vietnamese Parents of Disabled Children and Parents of Watts.

Family and Peer Support

Families find peer-to-peer support among the most helpful types of aid as they navigate services for their children needing LTCS. There is some government support for these services summarized in Chart 11.⁹⁷ The California Department of Developmental Services funds Family Resource Centers, the California Department of Education funds family empowerment centers, federal Maternal and Child Health dollars support Family Voices and federal education funds support Parent Centers. Funding for these services is not always ample. The Maternal and Child Health Bureau, for example, provides \$95,000 per state for Family to Family Health Information Centers. Thus California receives the same amount as Rhode Island.

Standards of Care and Models of Care Coordination

Recognizing the problems of access, quality, and coordination that many parents of children with special health care needs face, different initiatives have specified the components of an ideal system that can serve as a template for assessing and improving care systems. A report from the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs⁹⁸ provides an excellent framework for standards of care emphasizing:

- Access to care
- Cultural competence
- Family-centered care
- Transitions (among and between systems)
- Information technology and safeguards including Electronic Health Records

Family-centered care refers to an important set of principles that places families front and center in the care of children. It is gaining traction as a set of best practices in the care of children with special health care needs. A review of the literature⁹⁹ spells out some of the generally accepted principles of family-centered care:

- People are treated with dignity and respect;
- Health care providers communicate and share information with patients and families that is affirming and useful;
- Individuals and families build on their strengths by participating in experiences that enhance feelings of control and independence; and
- Collaboration among patient, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.¹⁰⁰

97 Provided by Juno Duenas, Executive Director of Support for Families of Children with Disabilities in San Francisco

98 Association of Maternal and Child Health Programs. (2014). Developing structure and process standards of systems of care serving children and youth with special health care needs: A background white paper. Published online by the Lucile Packard Foundation for Children's Health. Retrieved from the Internet at <http://lpfch-cshcn.org/publications/research-reports/developing-structure-and-process-standards-for-systems-of-care-serving-children-and-youth-with-special-health-care-needs/>

99 Hughes, D. (2014) A review of the literature of family-centered care as it pertains to children with special health care needs. Report prepared for the Lucile Packard Foundation for Children's Health. Retrieved from the Internet at <http://lpfch-cshcn.org/publications/research-reports/a-review-of-the-literature-pertaining-to-family-centered-care-for-children-with-special-health-care-needs/>

100 Johnson, B.H. (2000). Family-centered care: Four decades of progress. *Families, Systems & Health*. 18(2):137-156 as cited in Hughes, D. (2014). Ibid.

Evaluations of family-centered care point to the importance of family-provider partnerships in creating satisfaction¹⁰¹ and improved performance on a number of outcome measures including access, communication, family functioning and family impact/cost.¹⁰²

Coordination across systems managed at the state level is especially difficult to achieve. The National Academy for State Health Policy has created a useful primer for care coordination across state systems¹⁰³ and the Lucile Packard Foundation for Children's Health has published recommendations for care coordination for California's CSHCN based on practices in other states¹⁰⁴ and a practical guide to creating a shared plan for caring for children and youth with special health care needs.¹⁰⁵ One framework for care coordination especially relevant for children needing LTCS makes an important distinction by proposing models of care coordination adjusted according to whether the intensity of services is basic, moderate, or extensive.¹⁰⁶

Putting Standards and Models into Practice

Although there are excellent standards and models to draw from to develop family-centered care coordination for children using LTCS, challenges to implementing them include that care coordination for these children:

- Requires coordinating resources among multiple independent systems;
- Must include a focus on the whole child to include resources that are medical in nature and those that promote independent living in communities;
- Means working closely with families;
- Is highly individualized.

Medi-Cal managed care and medical homes are two approaches to care coordination driven by funding streams. The fear for families with children needing LTCS is that these methods of care coordination may have the unintended consequence of limiting their children's access to the specialists and subspecialists that they have found work most effectively with their children. Thus it is important that system change maintains access and continuity of care and does not achieve efficiencies at the expense of servicing children appropriately.

101 Kenney, M.K., Denoba, D., Strickland, B., and Newacheck, P. (2011). Assessing family-provider partnerships and satisfaction with care among US children with special health care needs. *Academic Pediatrics*, 11:144-151.

102 Kuhlthau, K., Bloom, S., Van Cleave, J., Knapp, A., Romm, D., Klatka, K., Homer, C., Newacheck, P., and Perrin, T. (2011). Evidence for family-centered care for children with special health care needs: A Systematic Review. *Academic Pediatrics*, 11:136-143.

103 Henderson, M. and Kaye, N. (2012) Policies for care coordination across systems: Lessons from ABCD III. Report prepared for National Academy for State Health Policy. Retrieved from the Internet at: <http://www.lpfch.org/programs/cshcn/Policies%20for%20Care%20Coordination%20Across%20Systems.pdf>

104 Silow-Carroll, S., Ehrenpreis, B., and Rosenstein, S. (2014). Care coordination for California's children and youth with special health care needs: Building blocks from other states. Report prepared for the Lucile Packard Foundation for Children's Health. Retrieved online at: <http://lpfch-cshcn.org/publications/research-reports/care-coordination-for-californias-children-and-youth-with-special-health-care-needs-building-blocks-from-other-states/>

105 McAllister, J. (2014). Achieving a shared plan of care with children and youth with special health care needs. Report prepared for the Lucile Packard Foundation for Children's Health. Retrieved from the Internet at: <http://lpfch-cshcn.org/publications/research-reports/achieving-a-shared-plan-of-care-with-children-and-youth-with-special-health-care-needs/>

106 Antonelli, R., McAllister, J., and Popp, J. (2009). Making care coordination a critical component of the pediatric health system: A multidisciplinary framework. A report prepared for the Commonwealth Foundation. Retrieved from the Internet at <http://www.commonwealthfund.org/publications/fund-reports/2009/may/making-care-coordination-a-critical-component-of-the-pediatric-health-system>

There are certainly possibilities for comprehensive care management within existing systems. CCS, for example, plays a critical role for most children using LTCS and has well-developed relationships with many of the medical and rehabilitative providers important for their health. Yet CCS, with its sole focus on the child's qualifying medical condition, has a limited focus.

Each of these agencies operates vertically, that is, they report up the chain in their own departments, and rarely work with each other—or horizontally. Because they don't work horizontally with each other, families become the central communication points, and often end up mediating among the different departments.

– Parent of a child using LTCS

DDS has the asset of providing lifelong services to its clients and thus taking a lifetime perspective. Yet without a formal role regarding the services they do not provide, such as medical and educational care, DDS does not have a position from which they can coordinate the full needs of children with complex health needs. Families find voluntary organizations run by families with children like theirs to be most effective in communicating information about the services available and helping them secure those services. Yet these groups are often stymied because they do not have a formal role with the major systems, which leaves them without leverage in many situations. They are also chronically underfunded.

In short, there is no easy or immediately obvious path for creating comprehensive care coordination for children needing LTCS, and it is an important area where innovation is needed. Previous opportunities for addressing this issue through California's Section 1115 Medicaid Waiver did not materialize. Activities intended to redesign the CCS program offer a new opportunity to address the need for better care coordination.

In summary, creating a system of care that assures access, quality, and coordination is a particular challenge for children needing LTCS. Their needs are complex and require participation from multiple systems that are hierarchically organized, yet there is no entity that has cross-system jurisdiction or purview. There is a clear need for innovation and working closely with families to test models of care to create cross-jurisdictional systems that can assure access, quality, and coordination of services for children and families.

VIII. Costs of Care

Caring for children who use long-term care services is expensive and enduring. This is true when viewed from the vantage point of various public payers as well as from the point of view of families who experience not only financial outlays for uncovered services but also the opportunity and emotional costs of caring for a child using LTCS.

Monetary Costs

The following statistics provide different perspectives on the cost of children using long-term care services:

The Cost of Long-Term Care

- Nearly half the US Medicaid budget goes to long-term care.¹⁰⁷

The Cost of Children with Disabilities

- From all insurance sources combined, public and private, an insurance authority estimates that a nickel of every health care dollar is spent on children with disabilities.¹⁰⁸
- 26% of the costs for children with disabilities is spent on children using long-term care services. This is just under two cents (1.9 cents) of every health care dollar.¹⁰⁹
- Children with disabilities were only 2% of the Medi-Cal population in 2011, but accounted for 8% of expenditures.¹¹⁰

Medi-Cal High-Cost Beneficiaries

- A study of Medi-Cal high-cost beneficiaries¹¹¹ reports that more than half (55 percent) of the 1,000 most costly beneficiaries are under age 21, compared to only 15 percent of all high-cost beneficiaries. The 1,000 most costly beneficiaries are more likely than high-cost beneficiaries to have three or more conditions and a large portion have co-occurring mental illness. The highest costs for the 1,000 most expensive beneficiaries include inpatient hospital care (42% or an average of \$211,037 per person) and prescription drugs (31% of spending, an average of \$157,613 per person). The 1,000 most costly are likely to incur large expenditures for multiple years: 70 percent of those in the top 1,000 in FY 2006 also appear among the top 1,000 in both of the following years.

107 Kaiser Commission. Ibid.

108 Szilagyi. Ibid, p. 138

109 California HealthCare Foundation. (2013). Medi-Cal Almanac. Ibid. P. 37

110 California HealthCare Foundation. (2013). Medi-Cal Almanac. Ibid. P. 36

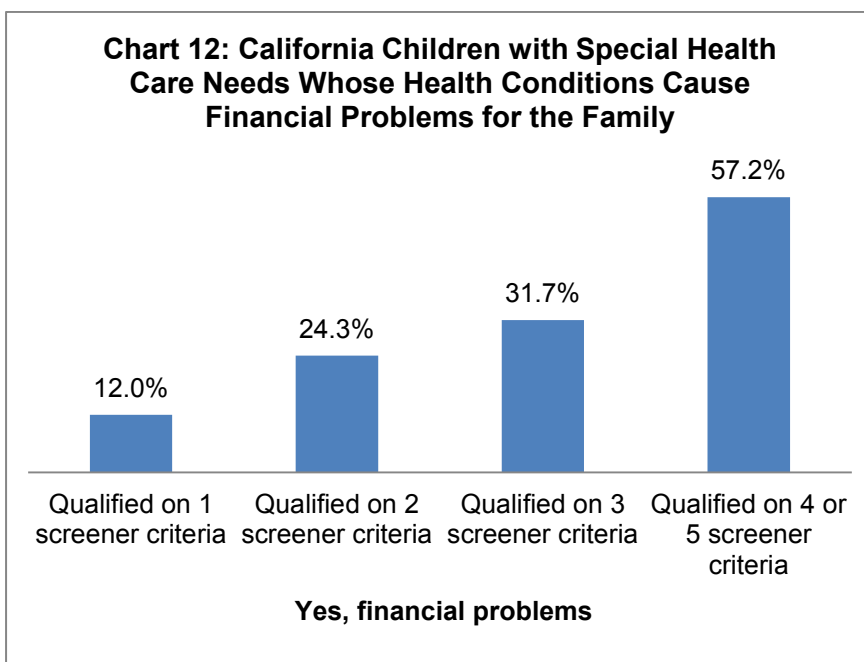
111 The Lewin Group and Ingenix Government Solutions. (2010). Where the money goes: Understanding Medi-Cal's high-cost beneficiaries. Report prepared for the California HealthCare Foundation. Retrieved from the Internet at <http://www.chcf.org/publications/2010/07/where-the-money-goes-understanding-medicals-high-cost-beneficiaries>

Costs to Families

The cost to the families of children using LTCS is considerable. The specific costs vary with the nature of the child's disability, the amount of funded services in place for the child and even the income of the family; people who have more spend more, those without often do without. The non-economic costs, such as social and emotional costs, are harder to measure but very high.

Out-of-Pocket Costs

The out-of-pocket costs vary depending on the family's circumstances and the needs of the particular child. There are costs of uncovered medical supplies and equipment, which includes everything from extra diapers to wheelchairs. There are also transportation costs. Many LTC children cannot ride in a typical car or ride a public bus, if indeed one is available in their area. Vouchers are available but never in a sufficient amount to meet all transportation needs. Regional Centers will assist a family with an adapted wheelchair van, for example, but only with the modifications to the vehicle. The family is expected to provide a brand new van, which is beyond the means of many families. Of course this is only for those children who are eligible for Regional Center services, and whose family has the tenacity to procure an adapted van.



Other out-of-pocket costs include co-pays and deductibles for medication for those children not covered by Medi-Cal and costs of drugs and therapies that are not covered by Medi-Cal at all. Many LTC children have to travel long distances to get the specialized care they need and incur housing and travel costs, which can be extremely costly when they are not a covered benefit.¹¹² As Chart 12 indicates, 57% of families caring for children with complex medical problems report their child's health problems cause financial problems.¹¹³

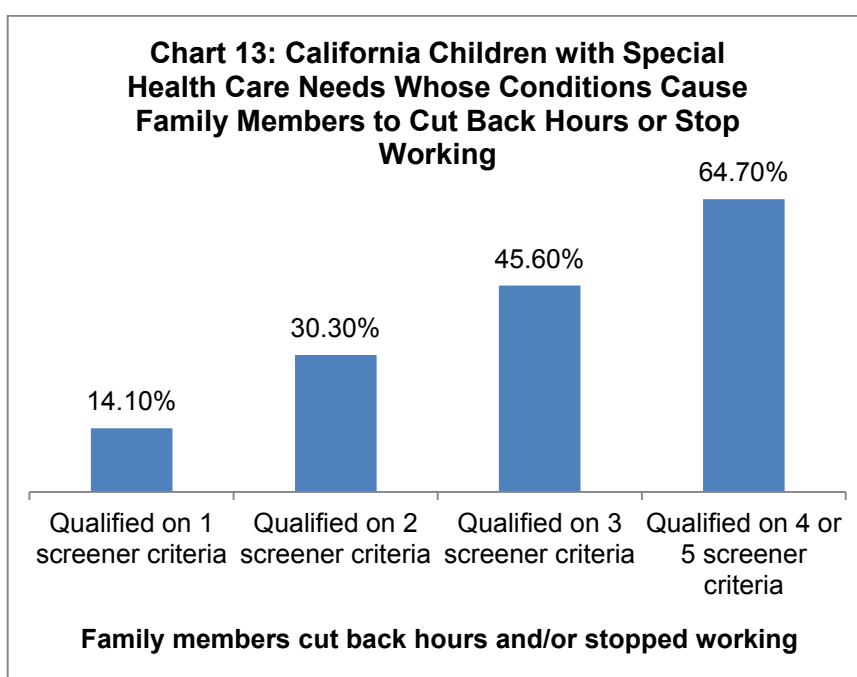
¹¹² For those who qualify for CCS, reimbursement is available for some but not all travel costs, and reimbursement policies vary from county to county. EPSDT also covers some travel costs for eligible families.

¹¹³ Data are from the 2009/10 National Survey of Children with Special Health Care Needs. The reported number is based on children meeting four or more screening criteria for special health care needs. Retrieved from the Internet at <http://www.childhealth-data.org/browse/survey>

Families also often have to incur remodeling costs on their home to accommodate the needs of the child. These are rarely compensated unless families receive help from a nonprofit organization such as Habitat for Humanity. Those who do not own their homes cannot make those changes.

Another cost to families is increased medical costs for the caregivers. Exhaustion, constant lifting and stress take their toll on family members. Many family members have injuries, especially orthopedic-related (back, shoulder, and knee injuries are common). Depression is also a major issue. As the caregivers age, these injuries are more frequent. When the caregiver is injured, there are not only medical costs, but the increased cost of finding someone to care for the LTC child while the main caregiver recovers.

Opportunity Costs



Though out-of-pocket costs are a huge burden on families, they are only part of the economic story. An exhaustive amount of time must be invested to simply secure and manage services. Given the current lack of an integrated system of care, there is very little possibility of a two-parent working family. One parent sacrifices some or all of their salary to meet the needs of the child needing LTC. In the case of single parent families, the challenges and costs are even greater because there is no second income to assist, and unless there is support from extended families they are completely reliant on and limited to government programs. Getting to and maintaining services from those programs has incredible costs of the most precious commodity of all—time. Families are never compensated for this part of the picture. As Chart 13 indicates, 65 percent of families caring for children with complex medical needs report cutting back work hours or stopping working to care for their children.¹¹⁴

¹¹⁴ Data are from the 2009/10 National Survey of Children with Special Health Care Needs. The reported number is based on children meeting four or more screening criteria for special health care needs. Retrieved from the Internet at <http://www.childhealth-data.org/browse/survey>

In economic terms, then, families have forgone at least one income (and maybe the sole income), and spend an inordinate amount of uncompensated time accessing and maintaining services, which often still fall short of meeting the child's needs. The unmet needs, whether due to the complexity of the child's condition or the inability to access the available services, become the out-of-pocket costs.

Emotional Costs

The non-economic costs include social and emotional costs, which are impossible to accurately measure or convey.

The social costs include isolation, loss of friends and family, loss of employment, and the loss of their previous "normal" social life, whatever that may mean for a given family. It may be difficult to go anywhere with a child who has LTC needs because of transportation limitation or immobility of medical equipment. Something as simple as a graduation or a family birthday party may be too difficult to attend. The caregiver and the LTC child stay home while others go out. Even in those cases where bringing the child is possible, the child is often unwelcome at the event because of their care needs, behaviors, equipment, sounds, etc.

Further, not infrequently peers may slowly disappear from the lives of families of children with LTC needs—especially those with typically developing children. This can be particularly devastating for parents of young children with LTC needs as they do not have the natural support of other young parents. In many cases they cannot turn to their own families for support either because the extended family is not in the area or because the extended family does not know what to do to provide the needed support.

Theoretically there are respite hours available to parents/caregivers through the Regional Center, for those children who are Regional Center clients, but respite is particularly difficult to get, especially for younger children. In difficult budget times it is the first benefit to be cut. Even for those few who can get it, families are often expected to find their own respite providers and complete onerous amounts of paperwork.

Social costs are aggravated by the demands on the caregivers' time. Caregivers are expected to take part or be present at everything their children are involved in other than the school day (and many caregivers become the educational aides for their children as well.) This includes every therapy, medical appointment, delivery of supplies, etc. The recreational opportunities for children with LTC needs are practically nonexistent, and those that do exist require a family member to be involved.

In addition to the social and economic costs are the often-ignored emotional costs to the families and caregivers of LTC children. When the child is initially diagnosed, whether at birth or later, the family suffers a significant loss—the loss of a healthy child. While many families adjust their lives to lovingly meet the needs of the child, the emotional toll is high. Moreover, the emotional difficulties are often exacerbated with every missed milestone or birthday that for normal children would celebrate their development. Because families are so busy doing, managing or accessing the care the child needs, these emotional hits are not "valued" or resolved in any way. This is a very large cost to families of LTC children.

IX. Transition to Adulthood and a Life Course Perspective

Between the ages of 18 and 21, depending on the program and service, children age out of most services and programs that have been available to them as children.¹¹⁵ Even some programs such as Medi-Cal that have the same name before and after age 21 offer different benefits for children and adults. The transition to adulthood presents challenges on all fronts—medical, educational, home, and social.

Transitions in Medical Care

- Children covered by Medicaid lose access to EPSDT at age 21 when they transfer to adult Medicaid. EPSDT provides a federally mandated comprehensive broad range of services appropriate for children with fragile health conditions. Adult services provided by Medicaid vary by states and do not assure a similarly broad or comprehensive range of services.¹¹⁶ Some children eligible for Medicaid are no longer eligible as adults.¹¹⁷
- On a positive note, the ACA-mandated ability to carry children on parents' health insurance policies until age 26 has extended the period of time that children needing LTCS have access to parental health insurance.
- CCS coverage stops at age 21.
- It becomes no longer appropriate for adults to see the pediatricians and pediatric subspecialists who have come to know and manage their conditions the best, yet many specialists in the adult world are unfamiliar with the conditions that are often limited to childhood.
- Many but not all children needing LTCS will continue to need a parent or other advocate to assist them in the medical world. This is not the norm for adult medicine as it is in pediatrics.
- Privacy issues can prevent communication to family members without formal legal permission in the form of a power of attorney or conservatorship. These are expensive and time-consuming legal documents to draw up, and can have the unintended and unwelcome consequence of stripping young adults of some of their civil rights. Simple agreements to document needs, goals, and responsibilities that are not overly legalistic can be helpful and are often overlooked.

Transitions in Education

- Children are eligible for special education through age 21. Going to school is often a major activity for children needing LTCS and provides social and intellectual stimulation. There is nothing comparable for young adults. Although there are adult day health programs for adults needing LTCS, these programs are primarily geared to older adults and often are not able to take young clients with the most severe disabilities.

¹¹⁵ The Developmental Disabilities System is the only system that provides services across the life span of its members.

¹¹⁶ Williams, B. and Tolbert, J. (2007). Aging out of EPSDT: Issues for young adults with disabilities. A report prepared for the Kaiser Commission on Medicaid and the Uninsured. Retrieved online at https://www.aucd.org/docs/policy/aging/aging_out_of_epsdt.pdf

¹¹⁷ Williams and Tolbert. (2007). Ibid.

Transitions in Residence

- Parents age with their children and cannot indefinitely manage their children's care, especially when children are immobile and require heavy lifting.
- The adult long-term care system has much greater reliance on institutional care than for children using LTCS, yet nursing homes are not appropriate and are largely unavailable to young people.
- Self-care and self-management become critically important for young people whose health permits them to move away from the families, as do the physicians who have helped them manage their care. Children with cystic fibrosis, for example, must be responsible for spending hours every day on procedures that, if they do not do them, place their lives at risk. This happens at an age when all children are risk-takers and push limits.

The chasm facing children with serious and enduring health conditions as they become young adults¹¹⁸ is gaining recognition, as are thoughtful approaches to reduce the negative impacts of this transition on children and families.¹¹⁹ The movement overall to consider maternal and child health from a life course framework rather than an exclusive focus on childhood years¹²⁰ is particularly appropriate for children and families needing LTCS. Future planning is an important activity that would come into play using a life course perspective.

118 Okamura, M. (2009). Growing up and getting old(er) with childhood-onset chronic diseases: Paving the way to better chronic illness care worldwide. *Journal of Adolescent Health* 45: 541–542

119 Bensen, R., Steidtmann, D., and Vaks, Y. (2014) *A triple aim approach to transition from pediatric to adult health care for youth with special health care needs*. An Issue Brief prepared for the Lucile Packard Foundation for Children's Health. Retrieved from the Internet at <http://lpfch-cshcn.org/publications/issue-briefs/a-triple-aim-approach-to-transition-from-pediatric-to-adult-health-care-for-youth-with-special-health-care-needs/>

120 Fine, A. and Kotelchuck, M. (2010) *Rethinking maternal and child health: The life course model as an organizing framework: A concept report*. Report prepared for the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Version 1.1. Retrieved from the Internet at <http://mchb.hrsa.gov/lifecourse/rethinkingmchlifecourse.pdf>

X. Conclusions and Recommendations

Increasing numbers of children with a wide variety of severe health problems survive the perils of infancy and young childhood to live and grow up at home, not in the institutions commonplace in mid-century United States. Yet approaches to adequately care at home and in communities for children needing ongoing medical and social attention have not kept pace with the medical advances that have assured their survival. *Hidden in Plain Sight* has explored the landscape of caring for these children, the programs that are in place and what is missing.

Key Findings

1. Children in long-term care are an important, growing, and expensive population of children, currently largely invisible to the policy world.
 - Inferences from different sources of statistics suggest that there are between 100,000 and 300,000 such children in California.
 - There are important information gaps about these children. These include more detailed knowledge of their health conditions, geographic dispersion, and socio-economic characteristics including racial, linguistic, ethnic and cultural backgrounds and how these factors affect their care.
2. Sources of support for children with serious and long-term health conditions are fragmented among many different programs and funding sources.
 - As a result of the depth and complexity of their needs, children needing long-term care services are eligible for many different service programs and funding streams.
 - Because of their eligibility for multiple programs and funding sources, children are treated in a fragmented, kaleidoscopic fashion that loses sight of the whole child. Even when services are assembled to meet a child's needs, each new point in their developmental trajectories—gaining mobility, reaching school-age, becoming larger and heavier—creates necessary realignments in the services that they use. Each of these steps causes stress.
 - A particular developmental point of stress occurs when children become young adults and age out of the services that have been available to them as children. Although their health conditions do not change, the services available to them are dramatically reduced.
3. The fragmentation of services adds to the already strenuous demands of family caregivers to create tremendous pressures on those who care for children needing long-term care services.
 - Families spend extensive amounts of time not only providing care, but also even negotiating for coverage among programs and funders and coordinating services.
 - The physical, financial, and emotional costs to families of caring for their children and managing their complicated care are very high.

- These highly stressed families have no systematic ways of gaining access to the information they need about supports and services available to their children. It is often through a process of trial and error that they slowly learn about help available to them and how to gain access to it.
4. There is a crucial need for advocacy for children who need long-term care services and their caregivers. This advocacy includes support for individuals to gain access to existing services, and advocacy to improve services and the coordination among them.
- Each of the funding streams and service systems that are primary providers to children needing LTCS faces important challenges and policy changes in their own right that may have profound implications for these families and children, and yet;
 - There is no systematic way for these families, whose time is engulfed by caretaking, to participate in dialogues about policies affecting funding streams and services programs, even when the outcomes could profoundly affect them, and;
 - As a result, children needing long-term care services live in a policy blind spot within the world of long-term care policy, innovation, and change.
5. Organizations run by other families with children with disabilities are highly valued as sources of information and support for navigating relevant systems and advocating for improvements. Yet these organizations have no formal role or leverage with the service organizations mandated to serve children and their families. These organizations also exist on low and uncertain funding.

These findings lead to some recommendations.

Recommendations

1. Recognize that children in long-term care and their families are a unique and growing population that is important from the perspective of both human rights and economics, and the many systems of care on which they depend should be a focus of policy discussions and reform efforts.

2. Create a system of care, real or virtual, for children needing long-term care services that is based on a single set of principles addressing access and quality.

One of the factors that makes this population unique is that their serious and enduring health conditions ordinarily involve multiple systems among which coordination is poor.

Primary oversight and accountability for services for children in long-term care should be assigned to the agency or system whose mission and resources most closely matches each child's constellation of needs. The principles guiding these activities should be universal among the various agencies and programs and should be strongly informed by the families and youth they serve.

In the process of designing a system of care for children needing long-term care services it will be important to draw upon and accentuate strengths of existing systems and target weaknesses. Some general design principles include developing:

- A clear understanding of what currently works well within and among current programs;
- An equally clear understanding of those aspects of programs and their coordination that need improvement;
- A transparent articulation of change strategies that build on strengths and improve shortcoming of existing services; and
- Testing and evaluating proposed changes before they are implemented wholesale to avoid any unanticipated negative consequences.

A well-designed system of care should take an integrated, developmental, and lifespan perspective on the health and development of the whole child in the context of the strengths and limitations of his or her family and their socio-economic and cultural context.

3. Strengthen the infrastructure necessary for creating a system of care. Currently, a shortage of trained personnel to provide services to children needing long-term care services, especially in the public sector, is a limiting factor in California's ability to appropriately serve these children.

California's Medi-Cal reimbursement rates are among the lowest in the country and are a significant disincentive to providers who might otherwise serve California children enrolled in Medi-Cal. These rates need to be raised to assure that there are adequate numbers of providers and thus adequate access to services.

There are also personnel shortages in some subspecialties and in some geographic areas that go beyond what even higher reimbursement rates could remediate. The shortage of mental health providers trained to care for children is well known, as is the misdistribution of a variety of pediatric subspecialists. The state should identify all shortage areas and consider strategies for increasing the supply of providers, such as by developing training programs, providing loans and loan forgiveness programs, and other such incentives.

Many families with children needing long-term care services have found that their most valuable information and support comes from other families. It is important for peer-to-peer information and support to be built into the basic infrastructure for a system of care. Current federal support for such resources is far from adequate.

4. Include families at all levels of care in policy setting and decision-making about children in long-term care. Families and the children they are caring for most acutely feel the shortcomings of public policies and experience first-hand the impact that decisions make. It is important that their voices are welcomed and amplified in forums where policies are made and programs are implemented.

5. More and better data are needed to create an accurate profile of these children and their families and to monitor the effectiveness of existing and newly created programs and services. This includes such information as:

- How many children are using long-term care services?
- What are their disabilities?
- Which service systems do they use?
- How many children are enrolled in multiple service systems? Which systems?
- What are the important subcategories of children using LTCS?
- What is the geographic, racial, ethnic, and linguistic distribution of families whose children use LTCS?
- How do these characteristics affect care?

Implementing these recommendations will substantially improve the efficiency and effectiveness of LTCS for children and youth in California and thus improve their health and the quality of life they and their families experience.

Appendix 1:

A Note about Terminology and Acronyms

Some words, concepts, definitions and acronyms used frequently in this report are called out here to clarify meaning and assumptions.

Children: This generic term for children and youth ages 0-20 is used throughout the report. This term admittedly hides many important distinctions within these years—distinctions between infants, toddlers, school-age children, teens, early adolescents, and late adolescents. Yet it is a term of convenience used with apologies to the many age-related distinctions of childhood not acknowledged under this generic umbrella. Not all data are available for using the 0-20 definition of children across all types of information in this report so when necessary other age spans, often 0-17, are reported.

Long-term care or LTC: This term refers to a category of services that includes a broad range of interventions, services and supports provided by paid or unpaid providers that assist people—children and adults—with limitations in their ability to care for themselves. A frequently heard colloquialism is that someone is “in” long-term care, referring to adults residing in long-term care facilities such as nursing homes, which is only a fraction of adults using long-term care services. There is no one service for children—except perhaps nursing home residence for the very small number of children to whom this pertains—signifying that they are “in” long-term care. We consequently use the phrase “use long-term care services.”

Long-term care services or LTCS: This term refers to the services that children and others need when they cannot manage activities of daily life or self-care appropriate for children their age. This term is sometimes called long-term care services and supports (LTCSS) to incorporate a full range of interventions. In this report we simply use LTCS to refer to all services and supports.

The difference between needing and using LTC: Both terms are used in this report. The distinction is an important one because all children needing long-term care services do not use them. Some methods of estimating the numbers of children using long-term care rely on estimates of need and others are based on counting children actually using specified services.

Appendix 2: How Many Children Need and Use Long-Term Care Services?

This Appendix examines different data sources to estimate the number of children in California who use and/or need long-term care services. There are two main methods of developing estimates: using information about the number of children *participating in programs* associated with long-term care use and using *population surveys* that ask questions about health in the population at large. Estimates based on these two methods are presented below.

Estimates Based on Program Participation

Chart 14 provides estimates of California children using long-term care services based on program participation. The drawback to program participation data is that not all children who need long-term care services enroll in programs that provide these services. Factors affecting enrollment include knowledge of the programs, and eligibility criteria such as income and immigration status.

Note that the last three categories (California Children's Services, DDS, and Mental Health) include children with specific types of health problems. Many children needing long-term care services use more than one of these three programs.

Chart 14: Estimates of California Children Using Long-Term Care Services Based on Program Participation		
Data Source	Ages Included	Estimate
Medicaid data (children using long-term care services)	0 to 18	50,000 to 60,000
SSI 2013 data (children with disabilities)	0 to 18	117,885
California Children's Services (health issues) (average 2009-2012)	0 to 18	70,000
Regional Centers (cognitive and intellectual issues) February 2013	0 to 21	124,290
Mental Health (2012 data) seriously mentally disturbed (SED)	0 to 21	112,719

Medicaid Data

An extrapolation to California from a national study of participation in LTCSS¹²¹ based on 2007 Medicaid data results in an estimate of 52,119 California children 0-17 using LTCSS. Eligibility for Medicaid is based primarily on income.¹²² An advantage of Medicaid data is that Medicaid codes include information about both diagnosis and treatment; a disadvantage is that, because it is primarily income-based, not all higher income families needing long-term care are included in Medicaid data.

Social Security Income (SSI) Data

Social Security provides funding to low-income families of children who qualify for SSI on the basis of the child's serious disability. 119,743 California children ages 0-17 received disability SSI in December 2013.¹²³ SSI is an income-based benefit and therefore does not include most higher-income families. Although the disability needs to be "serious" to qualify for SSI, it is not clear what percentage of SSI disabilities are permanent or long-lasting and therefore requires LTCS. Most children on SSI have a developmental or mental health disorder; inclusion for primarily medical problems is much less common with the exception of diseases of the nervous system and sense organs. Single parent households are disproportionately represented.

California Children's Services Data

This program described in Section V provides services to California children with special health care needs. How many CCS children need long-term care services? There are various estimates:

- A 2001 California HealthCare Foundation report states that half of CCS enrollees receive long-term care services.¹²⁴
- Dr. Rita Mangione-Smith at Seattle Children's Hospital has developed an algorithm for analyzing Medicaid claims data to identify different levels of illness severity. Vandana Sundaram, MPH, of Stanford's Center for Policy, Outcomes, and Prevention applied the Rita Mangione-Smith metric for "chronic complex," the metric that measures the most serious health conditions, to California CCS data and found that 45% of CCS children meet those criteria.¹²⁵
- Dr. Stephen Hayashida, who heads the San Francisco CCS office, estimates that 25% of CCS enrollees need long-term care services.¹²⁶

The estimate included in Chart 14 is based on averaging the above three estimates (40%) and applying it to the average CCS population between 2009 and 2012 (175,000 children per year). This results in 70,000 children participating in CCS needing long-term care services.

121 Kaiser Family Foundation. (2011). Medicaid's Long-Term Care Users, Spending Patterns Across Institutional and Community-Based Settings. *Kaiser Commission on Medicaid and the Uninsured*. Page 3. Retrieved from <http://kff.org/medicaid/issue-brief/medicaids-long-term-care-users-spending-patterns/>

122 Medicaid includes an income disregard provision called "institutional deeming" for children whose health conditions, without Medicaid, would cause them to be placed in an institution. As a result, some higher income families whose children use long-term care services are included in Medicaid data. More information on institutional deeming is included in Section VI.

123 Social Security Administration. (2013). SSI Annual Statistical Report. Retrieved from: http://www.ssa.gov/policy/docs/stat-comps/ssi_asr/2013/ssi_asr13.pdf

124 California HealthCare Foundation, Medi-Cal Policy Institute, Understanding Medi-Cal: Long-Term Care, September 2001, page 20.

125 Personal communication from Vandana Sundaram.

126 Personal communication, Dr. Stephen Hayashida, January 2014.

Regional Center Data

By definition, children enrolled in Regional Centers after age 3 have a substantial disability due to eligibility criteria that “qualifying disabilities originate before the age of 18, are expected to continue indefinitely and present a ‘substantial disability’ creating significant functional limitations in three or more areas of seven major life activities.”¹²⁷ It is reasonable to expect that all but a small percentage of Regional Center participants will require some kind of LTCS. Assuming that 5% might not need LTCS, this would result in 124,290 children enrolled in DDS in February 2014 needing LTCS. There is no formal validation for this assumption.

Mental Health Data

Among the 250,196 children treated by the public mental health system in 2012 nearly 90% or 221,417 are considered seriously emotionally disturbed (SED). There is no available information about mental health diagnoses among children not enrolled in Medi-Cal. It is challenging to know how many SED children served by Medi-Cal need LTCS because:

- Many children needing mental health services are untreated.
- Mental health diagnoses are not always accurate. Differential mental health diagnosis is difficult for all practitioners, and many diagnosticians of children in publicly funded programs have little training and experience in diagnosis.
- Mental health conditions are highly conflated with environmental stress.
- Most mental health conditions children experience are responsive to effective treatment, rendering the link between diagnosis and prognosis weak.¹²⁸

These challenges of estimation are especially frustrating because there is evidence that the lifelong consequences of childhood mental health problems are much greater than for many other childhood illnesses.¹²⁹ Lacking any better method of estimating the number of California children diagnosed with SED who use LTCS, we suggest 50% or 110,709 children.

Estimates Based on Cumulative CCS, DD, and Mental Health Program Participation Data

Children may be enrolled in one, two, or three of the California programs making it impossible to sum estimates across the three programs to arrive at an unduplicated estimate of children needing LTCS. There are only hints about the percentages of overlap. Kaye presented data to President Obama’s Long-Term Care Commission in 2013 that suggest there may be 10% overlap among DD, mental health, and physical health categories.¹³⁰ The duplicated total for children in the three Cali-

127 California Welfare & Institutions Code as quoted in Federal Funding in California’s Developmental Services System: The Role of Regional Centers (2011) published by the Association of Regional Center Agencies. Page 16. Retrieved from the Internet at <http://arcanet.org/pdfs/FFP%20Report%20-%20Final%203.11.pdf>

128 Onset of schizophrenia and bipolar disease starts in the mid- to late teenage years but numbers are still small among the 0-20 population. Increasing emphasis is placed on preventive treatment in the prodromal phases, which would include more mid to late teens.

129 Delaney, L. and Smith, J., Childhood Health: Trends and Consequences over the Life Course. (2012). *The Future of Children*, Vol. 22. Page 43

130 10% is based on a figure provided in the President’s Commission on Long-Term Care Report to Congress (2013) on page 3 showing 600,000 children using LTCS (retrieved from the Internet at <http://ltccommission.org/>) and data on a slide presentation (retrieved from the Internet at <http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Kaye-LTC-Commission-7-17-13>).

California systems who may need LTCSS is 300,000. Reduced by a potential 10% overlap, the number using LTCS is 270,000. Knowledgeable observers believe the overlap is likely much higher than 10%. Assuming that 30% of children are enrolled in multiple programs, the child LTCS population would be reduced to 210,000 and even assuming 50% overlap would leave 150,000 children using long-term care services.

Estimates Based on Population Surveys

This method uses surveys of the general population to assess those who use need and/or use long-term care services. A strong point of population surveys is that they reach beyond those enrolled in programs to the entire population. A potential weakness is that questions used to determine whether long-term care services are needed may miss important detail and are subject to respondent bias. The American Community Survey, for example, only asks parents of children younger than 5 about visual and auditory disabilities, thereby missing other kinds of disabilities.

Chart 15: Estimates of California Children Needing Long-Term Care Based on Population Surveys		
Data Source	Ages Included	Estimate
American Community Survey 2013 data ¹³²	0 to 18	82,956 California children have two or more disabilities ¹³³
	5 to 18	55,063 California children have a self-care difficulty
Children with Special Health Care Needs Survey ¹³⁴	0 to 18	126,000 California children have four or more health conditions

The American Community Survey is the assessment instrument used by the U.S. Census Bureau for decennial census counts and many interim surveys focused on specific aspects of American life. The Children with Special Health Care Needs Survey assesses many aspects of life and health care for the population of children with special health care needs every five years. Both surveys are online and have data browsing capabilities.

Summary

From the different sources of information reviewed above, it is safe to infer a range of between 100,000 and 300,000 children need long-term care services. An important take-away is that this most basic descriptive information about children who need or use LTCS, a simple count, is unavailable. Knowing this number and having more information about these children such as where they live, their demographic characteristics, and their degree of access to services would be a helpful starting point for improving their care.

pdf) to this commission using the same data source indicating a cumulative 660,000 children using LTCS as a result of cognitive, physical health, and mental health conditions. The difference is 60,000 children, a 10% overlap.

131 Both figures retrieved from the Internet at factfinder2.census.gov

132 For children under 5 only disabilities of sight and hearing are included in this figure.

133 Bethell, C. (2014). Children with special health care needs in California: A profile of key issues. Report prepared for the Lucile Packard Foundation for Children's Health by the Child and Adolescent Health Measure Initiative. Page 9. Retrieved from <http://www.lpfch.org/publication/children-special-health-care-needs-california-profile-key-issues>

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