



# Section 1000

## Mission and Philosophy

### Contents

1100	Introduction .....	2
1200	The International Perspective .....	2
1300	The National Perspective.....	2
1310	A National Goal .....	2
1320	Title V Maternal and Child Health Block Grant .....	3
1330	Omnibus Budget and Reconciliation Act of 1989 .....	4
1340	Individuals with Disabilities Education Act (Formerly PL 99-457).....	5
1350	The American with Disabilities Act.....	5
1360	National MCH Objectives for the Year 2020 .....	6
1370	Institute of Medicine Report: The Future of Public Health .....	7
1380	Early Intervention Services .....	7
1400	Washington State Perspective.....	8
1440	Organizational and Program Descriptions.....	8
1441	Washington State Board of Health.....	8
1442	Department of Health.....	8
1443	Prevention and Community Health Division.....	9
1444	Office of Family and Community Health Improvement .....	9
1445	Access, Systems and Care Coordination.....	9
1446	Healthy Starts and Transitions.....	9
1447	Children and Youth with Special Health Care Needs Program.....	9



**Alert!** Each section listed in this table of contents has been created with a built-in link to take you directly to it— simply hover over the line item and Ctrl and Click to go directly to the page.

## 1100 Introduction

*This section uses a number of acronyms that are listed in the Appendices.*

In recent years, there has been a movement to reform the delivery of services to children and families. An increasing number of initiatives have been directed at the reorganization and restructuring of these services. Federal legislation has led to major federal and state initiatives to improve maternal and child health and to support the development of service delivery systems for infants and children, including those with special health care needs and their families.

The purpose of this section is to provide information about some of these activities and a philosophical framework for services for children, including those with special health care needs, from international, national, state, and agency perspectives.

## 1200 The International Perspective

In 1989, the United Nations adopted the Convention of the Rights of the Child, which is the first comprehensive international law for children. Each country can choose to ratify the convention and make it a part of their national law. The Convention protects children's rights by setting standards in health care, education, and legal, civil and social services. In 2002, two protocols were adopted to strengthen provisions for children in armed conflict.

Under the Convention the following Rights of the Child will be protected:

- **The Right to Survival** through the provision of primary health care, adequate food, clean water and shelter.
- **The Right to Protection** from abuse, neglect and exploitation, including the right to special protection in times of war, and
- **The Right to Develop** in a safe environment through formal education, constructive play, advanced health care and the opportunity to participate in the family social, economic, religious and political life of their culture, free from discrimination.

## 1300 The National Perspective

### 1310 A National Goal

In June of 1987, the Surgeon General of the United States called for the promotion of family-centered, community-based, coordinated care for children and youth with special health care needs and their families. With the issuance of the Surgeon General's report, *Children With Special Health Care Needs: Campaign '87*, the creation, expansion, and improvement of community-based service systems for children and youth with special health care needs became a national goal.

Currently, health care reform is driving improvements in clinical care and chronic disease prevention. In 2011, federal Chronic Disease Prevention and Health Promotion Program Grant funding was directed toward building and strengthening capacity to prevent chronic disease and promote health. The primary requirement is to build a single statewide plan in coordination with partners to improve health. National priorities include:

- **The National Prevention Strategy** – a comprehensive plan to increase the number of Americans that are healthy at every stage of life.
- **Rethinking Maternal and Child Health** – combines health equity, social determinants, biology and environment in a *life course model*. The life course theory addresses these interactions in an understanding of health development over a lifespan and generations.
- **National Quality Strategy** – aims at making health care accessible, safe, and patient centered.
- **Healthy People 2020** – establishes goals for the prevention of chronic disease and measures the health of the nation.
- **The Triple Aim** – a framework developed by the Institute for Healthcare Improvement (IHI) that describes an approach to optimizing health system performance. It is IHI’s belief that new designs must be developed to simultaneously pursue three dimensions, called the “Triple Aim”. These three aims are as follows:
  - Aim 1.** Improving the patient experience of care (including quality and satisfaction);
  - Aim 2.** Improving the health of populations; and
  - Aim 3.** Reducing the per capita cost of health care.
- **Affordable Care Act** – On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (ACA). Along with the Health Care and Education Reconciliation Act of 2010, the law put in place comprehensive health insurance reforms. The law makes preventive care—including family planning and related care—more accessible and affordable for many Americans. For additional information, go to <http://www.hhs.gov/healthcare/about-the-law/read-the-law/>
- **National Standards for Systems of Care for Children and Youth with Special Health Care Needs.** This white paper, **Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs** (March 13, 2014), along with the standards, outlines in detail the structures and processes needed for a high-quality, coordinated system of care for children and youth with special health care needs. The report is unique in that it represents the consensus of a consortium of public and private organizations, and is the first-ever national, collective effort to detail the components of a high quality system. <http://www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs>

1320 Title V Maternal and Child Health Block Grant

Title V of the Social Security Act has authorized Maternal and Child Health (MCH) Services Programs since 1935. The Title V Federal-State partnership continues to provide a dynamic program to improve the health of all mothers and children including children and youth with special health care needs. Significant amendments to the program were made in 1981 when seven categorical programs, the largest being the Maternal and Child Health Services and Crippled Children's Services programs, were consolidated into a single Maternal and Child Health Block Grant (MCHBG), allowing states discretion in use of federal funds to achieve goals consistent with identified state needs and the purpose of the enabling legislation.

Effective in 1986, programs for Crippled Children were re-designated as programs for Children and Youth with Special Health Care Needs (CYSHCN) and new provisions relating to children's services were introduced. Title V was amended by the Omnibus Budget Reconciliation Act of 1989 (OBRA '89), Public Law 101-239 and a minimum of 30 percent of the block grant funding was/is earmarked for children and youth with special health care needs and their families. In 1993, the Government Performance and Results Act, Public Law 103-62, required Federal agencies to establish measurable goals, and for the first time, funding decisions were linked directly with performance.

The purpose of Title V is to improve the health of all mothers and children consistent with the applicable health status goals and the Healthy People National Health Objectives, established under the Public Health Service Act.

Healthy People 2020 builds on initiatives pursued over the past two decades and challenges individuals, communities and professionals to take specific steps to ensure that good health, as well as long life, are enjoyed by all.

Funds allocated to the states by formula under the Block Grant, along with required matching state funds, enable states to:

- Assure mothers and children access to quality maternal and child health services;
- Reduce infant mortality, the incidence of preventable diseases and handicapping conditions, and the need for inpatient and long-term care services;
- Increase the number of children appropriately immunized against disease.
- Increase the number of low income children receiving health assessments and follow-up diagnostic and treatment services;
- Promote the health of mothers and infants by providing prenatal, delivery, and postpartum care for low-income, at-risk pregnant women,
- Promote the health of children by providing preventive and primary care services for low-income children;
- Provide rehabilitation services for blind and disabled individuals under the age of 16 receiving benefits under Title XVI (of the Social Security Act) to the extent medical assistance for such services is not provided under Title XIX;
- Promote family-centered, community-based, coordinated care (including care coordination services); and
- Facilitate the development of community-based systems of services for children and youth with special health care needs and their families.

In 2015, the MCH Bureau transformed the MCHBG. This resulted in a change to different performance measures and proposed activities. For the Title V program, Washington (WA) State is focusing on three key domains – child health, children and youth with special health care needs, and cross-cutting issues. These are described in Section 1360.

### 1330 Omnibus Budget and Reconciliation Act of 1989

In 1989, the Omnibus Budget and Reconciliation Act (OBRA) enacted amendments to a number of programs targeted to women, children, and families. The Title V MCH Block Grant was included in the amendments. The amendments redefined the mission of the state CYSHCN programs. OBRA 1989 changes to Title V (MCH Block Grant) legislation recognized and strengthened the vital role of Title V agencies in addressing national priorities of promoting health and well-being of women, infants and children.

The amendments included specific provisions that addressed the relationship between Title V and Title XIX. They reinforced the need for working partnerships and interagency agreements between these two programs. In 1997, the Federal Maternal and Child Health Bureau (MCHB), together with its partners identified six national performance measures for state CYSHCN programs.<sup>1</sup> These performance measures were used to measure progress towards the development of community based systems of service for all children including CYSHCN and, at the time, were consistent with MCHB goals and Healthy People 2020 initiatives.

---

<sup>1</sup> Kogan MD, Dykton C, Hirai AH, et al. A New Performance Measurement System for Maternal and Child Health in the United States. *Maternal and Child Health Journal*. 2015;19(5):945-957. doi:10.1007/s10995-015-1739-5.

## 1340 Individuals with Disabilities Education Act (Formerly PL 99-457)

In April of 1970, Congress passed Public Law (PL) 91-230, the Education of the Handicapped Act (EHA). Congress, in 1975, amended the EHA with the passage of PL 94-142, the Education for Handicapped Children Act. This act mandated a "free, appropriate public education to school-aged children, regardless of handicapping condition" and provided incentive grants to serve children from the age of three years (i.e., preschool). The EHA was further amended in 1986 when Congress passed PL 99-457, the Education for the Handicapped Act Amendments of 1986.

PL 99-457 amended the EHA, Parts A-G, including a requirement that states provide a "free, appropriate public education" for children, ages three to five, who have handicapping conditions by school year 1990-91. Further, PL 99-457 created a new program, Part C (previously Part H), to help states develop comprehensive statewide early intervention programs for infants and toddlers, age birth to three, with disabilities and/or delays, and their families. It is Part C of PL 99-457 that has the greatest impact on infants and toddlers with disabilities, their families, and the many agencies that serve them.

Congress, in passing PL 99-457, felt that early intervention services are critical if children with disabilities and/or delays are to meet their developmental potential. PL 99-457 acknowledges the need to enhance the capacity of families in meeting the needs of their children with disabilities. Further, the law recognizes that to meet the needs of these children and their families, services need to be provided which are interagency and multidisciplinary. Consequently, PL 99-457 has implications for a wide range of agencies serving children and families, unlike PL 94-142, which primarily affected educational agencies. PL 99-457 requires collaboration and coordination among all service providers in order to deliver high quality, family centered services. This law was subsequently updated through amendments PL 101-476.

In October 1991, PL 102-119, the Individuals with Disabilities Education Act (IDEA) strengthened outreach activities, parent training, and personnel development goals. It required states to assure smooth transitions from early intervention to preschool services, updated definitions and terminology, and clarified parent rights.

IDEA Amendments of 1997 (PL 105-17) supported initiatives for transition services from high school to adult living. Because of these mandates, each student's Individualized Education Program (IEP) must include transition plans or procedures for identifying appropriate employment and other post-school adult living objectives for the student; referring the student to appropriate community agencies; and linking the student to available community resources, including job placement and other follow-up services. The amendment specifies that transition planning should begin at age 14 and the IEP must specifically designate who is responsible for each transition activity. For Early Intervention, the 1997 amendments changed Part H to Part C and clarified the natural environment requirement and the need to provide justification for each service not provided in the natural environment.

Reference is commonly made to two specific areas:

- IDEA Part B is the federal law that provides for special education and related services for children three through twenty-one.
- IDEA Part C is the federal law that promotes a comprehensive, coordinated early intervention system for infants and toddlers, birth to age three, with disabilities and/or delays, and their families. (See Section 1380).

## 1350 The American with Disabilities Act

The Americans with Disabilities Act (ADA) was signed into law in July 1990. ADA is intended to protect qualified individuals with disabilities from discrimination on the basis of disability. ADA is the most

comprehensive federal civil-rights statute protecting the rights of people with disabilities. It affects access to employment; state and local government programs and services; access to places of public accommodation such as businesses, transportation, and non-profit service providers; and telecommunications. WA State agencies, contractors and grantees must comply with the ADA of 1990.

ADA disability is defined as a physical or mental impairment, substantially limiting one or more major life activities. The ADA includes both obvious disabilities and many "hidden" disabilities, such as seizure disorder, diabetes, HIV/AIDS, specific learning disabilities and/or former drug and alcohol abuse.

## 1360 National MCH Objectives for the Year 2020

The Healthy People initiative process began in 1979 with *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention*, which was followed in 1990 by Healthy People 2000. Healthy People 2020 represents the fourth time that the U.S. Department of Health and Human Services (DHHS) has developed 10-year health objectives for the Nation.

The new initiative, Healthy People 2020, is a 10-year action plan to improve the health of all Americans, including children and youth with special health care needs. The plan's overarching goals include:

- Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death.
- Achieve health equity, eliminate disparities, and improve the health of all groups.
- Create social and physical environments that promote good health for all.
- Promote quality of life, healthy development, and healthy behaviors across all life stages.

In 2015, the Bureau transformed the MCH Block Grant. The MCHB of the Health Resources and Services Administration (HRSA) led a 21-month visioning process to engage input from MCH stakeholders and other national, state and local MCH leaders, families and other partners to improve, innovate, and transform the Title V MCH Services Block Grant. The process has helped inform the development of a new grant guidance for the next 5-year cycle beginning in fiscal year 2016. The triple aims of the transformation are to reduce burden, maintain flexibility, and increase accountability.<sup>2</sup>

Children and youth with special health care needs and their families are best equipped to meet these goals when systems are in place to meet the performance measures established by the federal MCHB some of which are specific to children and youth with special health care needs and others are for all children. These align with the National Standard for Systems of Care for children and youth with special health care needs.

MCHBG Population Domain: Developmental Screening	Child Health
MCHBG Population Domain: Medical Home	Children and Youth with Special Health Care Needs
MCHBG Population Domain: Adequate Insurance	Cross-Cutting

<sup>2</sup> Maternal Child Health J. 2015; 19(5): 927–931. Published online 2015 Feb 18. doi: [10.1007/s10995-015-1736-8](https://doi.org/10.1007/s10995-015-1736-8); PMID: PMC4428533. [Transformation of the Title V Maternal and Child Health Services Block Grant](#); Michael C. Lu, Cassie B. Lauver, Christopher Dykton, Michael D. Kogan, Michele H. Lawler, Lauren Raskin-Ramos, Kathy Watters, and Lee A. Wilson

In addition, the program works to insure that there are provisions for “older” Block Grant performance measures.

- Families of children and youth with special health care needs are partners in decision-making at all levels and are satisfied with the services they receive.
- Children and youth with special health care needs receive coordinated comprehensive care within a medical home.
- Families of children and youth with special health care needs have adequate private and/or public insurance to pay for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based services for children and youth with special health care needs are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including health care, work, and independence.

### 1370 Institute of Medicine Report: The Future of Public Health

In 1988, the Institute of Medicine published its landmark report *The Future of Public Health*. The report defined the mission and core function of public health agencies. The mission of public health is to assure healthy conditions for all people. Core functions include assessment, policy development, and assurance. The report focused on ways to strengthen governmental public health infrastructure.

The Committee on Assuring the Health of the Public in the 21<sup>st</sup> Century was convened in 2001 with the charge to create a framework for public health in the United States that was more inclusive than the 1988 report. In the 2001 report, *The Future of the Public's Health*, the Committee uses the term “public health system” in a manner that builds on the 1988 usage, reflects present realities, and embraces the Healthy People goals. It recognizes both governmental components of the public health system and contributions of other sectors and entities. The report focuses on government public health *infrastructure and potential* partners in the public health system: the community, health care delivery systems, employers and business, the media, and academia.

In 2009 the Robert Wood Johnson Foundation asked the Institute of Medicine to convene a committee to examine measurement, the law, and funding in relation to public health. The institute of medicine subsequently released 3 reports with specific recommendations.

- For the Public's Health: The Role of Measurement in Action and Accountability (2010)
- For the Public's Health: Revitalizing Law and Policy to Meet New Challenges (2011)
- For the Public's Health: Investing in a Healthier Future (2012)

These three reports make a case for increased accountability of all sectors that affect health (clinical delivery systems, business, academia, government and non-government organizations, communities, and mass media). The committee reinforced the recognition that population health improvement is dependent on addressing the multiple determinants of health and needs to focus on a life course perspective.

### 1380 Early Intervention Services

The coordination and enhancement of WA State's existing early intervention services for infants and toddlers with disabilities was also addressed during the 1992 legislative session. A bill addressing early intervention services was incorporated into the Family Policy Initiative legislation as an amendment and passed as part of the Family State Policy Initiative bill.

State statute now requires that the Governor appoint a State Interagency Coordinating Council (SICC) and ensure that state agencies involved in the provision of, or payment for, early intervention services coordinate and collaborate in the planning and delivery of services. The Division of Children, Youth and Families (DCYF) is designated as the lead agency for planning and implementing IDEA, Part C (see Section 1340); formerly, the lead agency was the Department of Social and Health Services (DSHS). The Department of Health (DOH) appoints a representative to the SICC who usually comes from the CYSHCN Program. The legislation also establishes County Interagency Coordinating Councils as part of state law, calls for formal interagency agreements defining relationships and financial and service responsibilities, and prohibits supplanting of funds or interruption of existing early intervention services.

## 1400 Washington State Perspective

### 1440 Organizational and Program Descriptions

#### ***1441 Washington State Board of Health***

The mission of the WA State Board of Health is to develop policies to promote, protect, maintain, and improve the health of all Washingtonians. To fulfill this mission, the Board is mandated by statute to serve as the focal point for professional and citizen health concerns and to gather these concerns into a coherent policy. For more information, go to: <http://sboh.wa.gov/AboutUs>

#### ***1442 Department of Health***

The Department of Health (DOH) protects and improves the health of people in WA State.

Our programs and services help prevent illness and injury, promote healthy places to live and work, provide information to help people make good health decisions and ensure our state is prepared for emergencies.

Our programs and services help ensure a safer and healthier WA by:

- Working to improve health through disease and injury prevention, immunization, and newborn screening
- Providing health and safety information, education and training so people can make healthy choices
- Promoting a health and wellness system where we live, learn, work, play and worship
- Addressing environmental health hazards associated with drinking water, food, air quality and pesticide exposure
- Protecting you and your family by licensing healthcare professionals, investigating disease outbreaks and preparing for emergencies

To accomplish all of these, we collaborate with many partners every day!



### ***1443 Prevention and Community Health Division***

The Prevention and Community Health (PCH) Division supports the DOH's mission by collaborating with our partners and stakeholders to enhance the health of individuals, families, and communities. We work to prevent disease and promote a healthy start, healthy choices, and access to services. The division employees work in two primary locations and a few local health departments, to deliver public health services statewide.

### ***1444 Office of Family and Community Health Improvement***

In WA, the Office of Family and Community Health Improvement (OFCHI), in the DOH, is the Title V agency that administers the federal Title V MCHBG.

The OFCHI is dedicated to making the healthy choice the easy choice in homes, communities, workplaces, healthcare settings, and schools. We work to prevent disease and promote health at every stage of life by implementing policies, systems, and environmental changes with a focus on health equity.

### ***1445 Access, Systems and Care Coordination***

The OFCHI – Access, Systems and Coordination (ASC) Section supports coordinated state and local systems to improve access to health services and information, increase health equity and improve the health of individuals, families and specific populations. Specifically, ASC focuses on Maternal and Infant Health, Genetics, Early Hearing Loss in Infants, Healthy Starts and Transitions, Child Health and Development, Children and Youth with Special Health Care Needs, Adolescent Health, Pregnant and Parenting Teens, and Women's Health.

### ***1446 Healthy Starts and Transitions***

The Healthy Starts and Transitions (HST) Unit supports integrated systems that improve access, linkages and coordination directed toward health, early and ongoing learning and development, and safe environments for all children and their families.

The Child Health and Development unit works to improve the health, development, learning, and well-being of children prenatally throughout childhood by increasing access to services, education/knowledge, and resources, including work through the different federal grants focusing on child abuse and neglect prevention, early mental health and developmental screening, and access to resource and referral. Additionally, the unit works to support the Help Me Grow Washington Partnership to meet the needs of children and families, child care providers, medical providers and other community partners.

The Children and Youth with Special Health Care Needs unit supports culturally competent, community-based, integrated systems of care for children and youth with special health care needs and their families and includes MCHBG, Medicaid and other federally funded activities such as AS3D (Innovation in Care Integration for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities) grant.

### ***1447 Children and Youth with Special Health Care Needs Program***

The Children and Youth with Special Health Care Needs Program (CYSHCN) is in the HST unit in the OFCHI at the DOH. The CYSHCN Program, in partnership with families, national, state and local leaders, private and non-profit organizations, identifies and acts on emerging health issues facing children and youth with special health care needs and their families. Together with our partners, CYSHCN promotes and provides information leadership, linkages and joint problem solving.

The program promotes an integrated system of services for infants, children and youth up to age 18 years who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond what is generally needed.

At the state level, the program collaborates with families, policy makers, health care providers, agencies, and other public-private leaders to identify and improve health system issues that impact this population.

At the local level, the program supports contractors to help families with resources and linkages to community services including family support, care coordination, and health information. More details are described below.

This work is guided by the following principles:

- Families are the core of the health services system

Families are equal partners with experience, expertise and have many strengths. Families should be included in decision making at all levels.

- The community is the center of service provision

Services for children and youth with special health care needs and their families should be delivered as close to home as possible. Community capacity is built through joint decision making, problem solving, sharing of knowledge, understanding of diversity, integration of service systems, and coordination between systems of care.

- Systems of care are comprehensive

Comprehensive systems of care are holistic, taking into consideration the child, family, providers, communities, health plans and the non-medical impacts on the health of the child. Comprehensive systems of care reflect full participation and joint responsibility, are cost effective, and assure quality services.

- Systems of care are culturally competent

Culturally competent systems of care incorporate the health beliefs and values of all by recognizing and acknowledging the importance of culture in all aspects of peoples' lives. This is reflected in flexible systems of care which recognize and respect the values of all.

*Organizational charts for DOH, PCH, OFCHI, HST, and CYSHCN are in the Appendices.*