

# **Genetics and Public Health in Oregon: A Summary of Assessment Methods & Findings**

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## Background

In June 2000 the Oregon Department of Human Services/Health Services (DHS/HS)/Office of Family Health (OFH) and the Child Development and Rehabilitation Center (CDRC) at Oregon Health & Science University (OHSU) received a federal grant from the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), Genetic Services Branch to conduct a genetics needs assessment in Oregon and develop a state strategic plan to improve existing or develop new services and programs. The Genetics Plan Advisory Council guided the assessment and planning process. In addition, DHS/HS and CDRC gathered ideas, insights, and concerns from a wide array of people living in Oregon.

The following report summarizes our assessment process and results that formed the basis for Oregon's Strategic Plan for Genetics and Public Health. The primary audiences for this document as well as the state strategic plan include public health program staff and management within DHS/HS and CDRC, state and local health policy makers, and health care professional and advocacy organizations. We hope it is of interest and useful to other stakeholders as well. With a collaborative effort among private and public health care providers, social and legal services, and public and private education, we can use the information gathered in this process to better ensure that people in Oregon benefit from advances in genetics without being harmed by them.

## Assessment Framework

The information we sought in our assessment activities fell into three general categories:

- Demographic and geographic information that:
  - depicts the impact of inherited conditions and birth defects on children and families living in Oregon and
  - affects delivery of health care services to those living in the state
- The public's perceptions and values about genetic issues
- The capacity of Oregon's public health system to address needs related to genetic issues

In *The Future of Public Health* (1988) the Institute of Medicine critically assessed the status of public health in the US, and recommended *three core functions*: assessment, policy development, and assurance. Later, in 1994, public health organizations elaborated on the three core functions by developing the “ten essential services of public health.” In order to assess current system capacity, we utilized the ten essential services as a framework. (See Figure 1.) This framework reminded us that in developing a comprehensive, coordinated, quality system of care in genetics, we needed to assess and plan for not only clinical genetic services but for data sources and linkages, health care provider education, public education, policy and legislation, partnerships, and research.

### Figure 1. Assessment Framework

1. Assess and monitor health status of children and families affected by genetic conditions and other special health needs, and respond to identified problems.
2. Diagnose and investigate genetic health problems and health hazards affecting children and families.
3. Provide information and education to the public and families about genetic health issues.
4. Mobilize community partnerships between policymakers, health care providers, families, the general public, and others to identify and solve genetic health problems/issues.
5. Provide leadership for priority setting, planning and policy development to support community efforts to assure the health of families affected by genetic disorders.
6. Promote and enforce legal requirements pertaining to genetics that protect and promote child and family health.
7. Facilitate family access to comprehensive, high quality genetic services.
8. Assure public health and personal health workforce capacity and competency to effectively address genetic issues.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based genetic services.
10. Support research and demonstrations to gain new insights and innovative solutions to genetic health problems.

(Adapted from *Public MCH Framework: Essential Public Health Services to Promote Maternal and Child Health in America*. HRSA/MCHB. December 1995.)

To guide us in our use of the ten essential services as an assessment and planning framework, we relied on several valuable resources including:

- Beskow LM, Khoury MJ, Baker TG, Thrasher JF. Centers for Disease Control and Prevention, Genetics and Disease Prevention, "The integration of genomics into public health research, policy, and practice in the United States," *Community Genetics* 4, no. 1 (2001 July): 2-11. [www.cdc.gov/genomics/info/reports/research/wheel.htm](http://www.cdc.gov/genomics/info/reports/research/wheel.htm)
- Association of State and Territorial Health Officials, Framework for state public health genetics policies and practices in state and local public health agencies (2001).
- Centers for Disease Control and Prevention, Translating advances in human genetics into public health action: a strategic plan (1997). [www.cdc.gov/genomics/about/strategic.htm](http://www.cdc.gov/genomics/about/strategic.htm)

We used the "topic areas" of the ten essential services to develop broad-based assessment questions. In addition to the "essential services" assessment questions, we developed a number of assessment questions related to public perception of genetics issues including people's beliefs, attitudes, and experiences.

## Assessment Methods

To answer the assessment questions, we collected and analyzed data and information from a variety of sources. First, for each of our topic areas, we conducted a thorough literature search in order to review salient national or state-specific guidelines, frameworks, or reports. We then analyzed regularly collected Oregon-specific data that could help us in answering our assessment questions, such as birth certificate data, infant death data, and newborn screening data. We also gathered any genetics-related information that had been collected in Oregon recently, such as results from a survey conducted by an Oregon geneticist regarding primary care physicians' attitudes and utilization of genetic services, and results from focus groups conducted by a local advocacy organization regarding the public's attitudes about genetic privacy issues.

While providing useful information, these existing data sources could not answer all of our assessment questions, so we collected our own information through twenty-two assessment activities. We conducted surveys, interviews, focus groups, and group processes with the public, consumers, health care providers, genetic service providers, public health professionals, and others. For each activity, whenever possible, we gathered instruments that had been developed from national studies or by other states and then modified them for our purposes. When previously developed tools were not available, we designed our own. We conducted a number of the activities in partnership with students and faculties at Oregon's universities.

Each assessment activity resulted in a report of findings. Those findings are integrated throughout this assessment report. The following is a list of the activities conducted as part of the assessment and planning process.

<b>Assessment Activities</b>		
	<b>Participants</b>	<b>Purpose</b>
<b>Interviews</b>		
1	Leaders of Oregon's diverse communities	To gather beliefs and attitudes regarding advances in genetics
2	Faculty and staff from health care provider education programs	To determine the extent to which genetics is incorporated into the health care curriculum
3	Genetic service providers	To collect information on services provided, populations served, barriers to service, plans for service expansion
4	Genetic service providers and billing specialists	To better understand reimbursement practices for genetic services
5	Practitioners of non-traditional medicine	To gather beliefs and attitudes regarding advances in genetics
6	Consumers	To identify areas of concern with delivery of health services
7	Public health managers	To discuss ways to integrate genetics into public health programs
8	Faculty of Oregon's public health program	To determine the genetics content in Oregon's master of public health program
<b>Surveys</b>		
9	Public health nursing supervisors	To better understand how genetics will affect health practice and to determine educational interests
10	Public health practitioners	To better understand how genetics will affect health practice and to determine educational interests
11	Family practice physicians	To better understand how genetics will affect health practice and to determine educational interests
12	K-12 school educators and administrators	To determine the genetics content in Oregon public schools
13	Those with developmental disabilities	To identify areas of concern with delivery of genetic services
14	Participants at an African American health fair	To gather beliefs and attitudes regarding advances in genetics
15	Support group participants	To identify areas of concern with delivery of genetic services
<b>Focus Groups</b>		
16	Oregon State University students	To gather beliefs and attitudes regarding advances in genetics
17	Consumers	To identify areas of concern with delivery of genetic services
<b>Nominal Group Processes</b>		
18	Genetics Plan Advisory Council	To identify priority areas to be addressed in the assessment and plan
19	Genetics Plan Advisory Council	To determine key concepts for public and health care provider education
20	Genetics Steering Committee	To identify assessment questions/issues for key stakeholder groups
21	Genetic service providers	To obtain input in developing the state genetics plan
22	Administrators of programs serving Native Americans	To gather beliefs and attitudes toward advances in genetics

## Role of the Genetics Plan Advisory Council and Work Groups

The Genetics Plan Advisory Council was formed to provide input and guidance into the development of a state genetics plan, utilizing the information obtained in the assessment process and through personal experience. The group began as an internal steering committee made up of DHS and CDRC representatives. In May 2001 the group was expanded to include a number of additional partners including consumers, advocacy groups (March of Dimes), genetic service providers (physicians, nurses, and counselors), other medical providers, insurance payors, and ethicists. The Advisory Council met on a monthly basis. The Council reviewed and discussed inventory information and results from various assessment activities. Two work groups were formed to delve more deeply into the issues of “Public and Health Care Provider Education” and “Access to Genetic Services.” Several other important issues, including newborn metabolic screening, newborn hearing screening, genetics data collection/integration (FamilyNet), and genetic privacy were being addressed by other state committees or work groups, but information from these groups was incorporated into Advisory Council deliberations. The Advisory Council was responsible for prioritizing issues and assisting in the creation of the strategic plan.

## Assessment Findings

The assessment findings are summarized in the following three sections:

- A. Profile of Oregon: *What Oregon Looks Like*
- B. Public Attitudes and Beliefs About Genetics: *What Oregon Thinks*
- C. Public Health System Capacity in Genetics: *What Oregon Has, What Oregon Needs*

## Profile of Oregon: *What Oregon Looks Like*

### Introduction

Understanding Oregon's geography, population diversity, economic outlook, and health indicators is important for planning genetic health services and programs. This information provides a context for understanding current genetic resources and services and identifying future needs for the state.

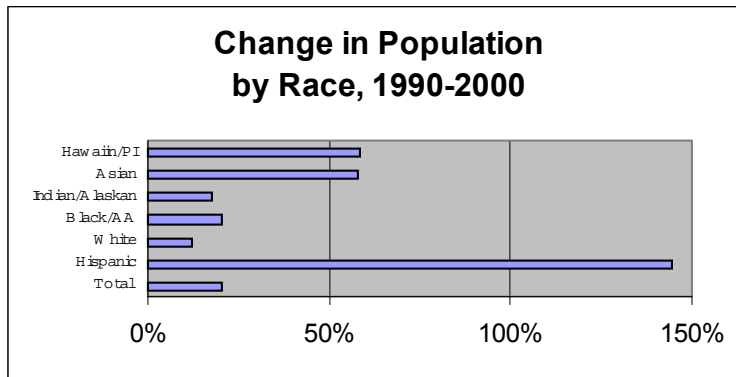
### Geographic Diversity

Though only the twenty-eighth largest by population density, Oregon is the ninth largest state in the nation by land mass (96,002 square miles).<sup>1</sup> The state is shaped roughly like a rectangle bordered on the west (left) by the Pacific Ocean, on the east by Idaho, on the north by Washington and on the south by California. The most populous region of the state is the Interstate-5 (I-5) corridor, a north-south line stretching between the Washington and California borders, approximately sixty miles inland from the Pacific Ocean. Mountain ranges separate the I-5 corridor from the coastal region to the west and high desert region to the east, both largely rural and rugged areas. There is one large urban center, Portland, at the northern end of the I-5 corridor and several moderate sized communities along I-5 (Salem, Eugene, and Medford), one in central Oregon (Bend), and one in eastern Oregon (Pendleton). The rest of the state, the southeast in particular, is rural and sparsely populated. Large areas with small population densities and the presence of physical obstacles such as mountain ranges create challenges for health care service delivery.



<sup>1</sup> Encarta.com

## Population Diversity & Distribution



The 2000 census registered Oregon's population as 3,421,399, a 20% increase from 1990. Oregon's average population density is less than half of the national average (35.6 people per square mile in Oregon, compared to the national average of 79.6).<sup>2</sup> On the other hand, Oregon is the eleventh fastest-growing state in the country. Forty-five percent of Oregon's population is concentrated in the counties immediately surrounding Portland, though the central Oregon region around Bend is the state's fastest growing area.<sup>3</sup>

Though 85% of Oregon's population is White, the 2000 census showed an almost doubling in the number of Hispanics in many areas of the state since 1990. Hispanics now make up 8% of the population of Oregon. This percentage may underestimate the number of migrant and seasonal farmworkers (mostly Hispanics) who are in Oregon for extended periods each year. In addition to the Hispanic population growth over the past decade, Oregon saw close to a 60% increase in the Asian, Native Hawaiian, and Pacific Islander population, as well as a 21% increase in the Black and African American population. According to a report in the *Oregonian*, "the Northwest added more people of Russian and Ukrainian descent since 1990 than any other region of the country." Altogether, about 7% of Oregonians were born overseas—the highest level since 1940.<sup>4</sup> In addition to an increase in the racial and ethnic diversity of the population, in 2000 Oregon saw an increased influx of retirees along the California border in towns such as Klamath Falls, Medford, and Ashland.

Changes in the state's population makeup have introduced the challenge of creating a health care system, including genetic services, to meet the needs of an increasingly diverse and multicultural population. At the same time, the absolute numbers of individuals with conditions common in non-white ethnic groups remain relatively low. Experience has confirmed estimates of

<sup>2</sup> Oregon Office of Rural Health & Population Research Center, Portland State University.

<sup>3</sup> *USA TODAY*, 2001 March 27.

<sup>4</sup> *The Oregonian*, 2001 August 6.

approximately two to four new babies a year detected by universal newborn screening for sickle cell disease, an inherited condition that is more common in the Black/African American population.<sup>5</sup> This presents the challenge of providing comprehensive team-based services to this very small but important number of individuals and families.

## **Economic Diversity**

Oregon is faced with a number of economic challenges that impact individuals' as well as the state's ability to finance health care services, including genetic services. In 2000 Oregon had a per capita personal income of \$27,649—which ranked twenty-seventh in the US and was 6% below the national average of \$29,451. Close to 13% of Oregon's population is living in poverty (three year 1998-2000 average), compared to 11.9% in the US.<sup>6</sup> Twenty-one percent of children under eighteen live in poverty. In early 2002 Oregon had the highest unemployment rate, 7.5% compared to 5.5% nationally.<sup>7</sup> In addition to individual economic hardship, the state government has a large deficit and is in the process of cutting services, including health and other human services, rather than adding new services and programs.

## **Health Insurance Coverage**

Oregon is among the states with the highest penetration of managed care. In 1998, 45.46% of the population was enrolled in a managed care program (either commercial, Medicaid, or Medicare).<sup>8</sup>

Oregon is also home to the often-cited Medicaid program known as the Oregon Health Plan (OHP), which had 340,197 people enrolled as of November 1999. OHP utilizes a public input and prioritization approach to health care services coverage, covering treatment and services for those conditions that fall above a designated line on a comprehensive list of health conditions. As of January 2000, 90% of Medicaid enrollees were in fully-capitated managed care plans.

Despite the availability of OHP, lack of health insurance remains a concern for Oregon. In 2000, 12.3% of Oregonians did not have health coverage, including 8.1% of children and 15.9% of working age adults, according to the Office of Health Policy and Research.<sup>9</sup> Rates of uninsurance are higher in rural areas than in urban areas and for certain population groups (24.9% uninsurance for Hispanic population vs. 10.8% for non-Hispanics), which adds to access

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<sup>5</sup> Oregon State Public Health Laboratory, Newborn Screening Program data.

<sup>6</sup> United States Census 2000.

<sup>7</sup> Bureau of Economic Analysis, 2001 September.

<sup>8</sup> Office of Health Policy and Research, [www.ohppr.state.or.us](http://www.ohppr.state.or.us).

<sup>9</sup> Oregon Health Resources Commission (OHPRC), *Oregon's Uninsured: Preliminary Findings from the 2000 Oregon Population Survey* (2002 March).

problems. In Oregon, Medicaid/OHP eligibility for pregnant women is up to 170% of poverty, for children <6 up to 133% of poverty, and for children 6-18 up to 100% of poverty. The State Children's Health Insurance Program (SCHIP) covers children not eligible for Medicaid or other insurance up to 170% of poverty, though it is believed that a significant proportion of the eligible children are not enrolled. The Urban Institute estimates that up to 77,000 Oregon children were eligible but not enrolled in Medicaid or SCHIP.<sup>10</sup> For many adults who are above the income cutoff for OHP and who do not have coverage through employers, insurance is still too expensive and they opt to go without. A significant population of undocumented immigrants who do not carry health insurance coverage is another concern for the state, particularly in the area of pregnancy care. Each year an estimated 5,500 women are unsponsored for prenatal care in Oregon either due to citizenship or lack of qualification for health insurance due to income.<sup>11</sup> Children, pregnant women, and families without adequate health insurance coverage are at high risk for not having access to genetic services such as prenatal genetic counseling and testing. Today in 2002, there are concerns that the state budget crisis may increase the number of individuals in Oregon without adequate coverage.

## **Health Care Providers**

While Oregon does not have an overall shortage of health care professionals, certain areas of the state have a low ratio of practitioners to total population. This unequal distribution of providers is a key concern for health care access. Based on a 1999 rural health report, the practitioner to population ratio was <1:400 in Oregon's only urban county (Multnomah), while in some rural areas the ratio was > 1:2500.<sup>12</sup> According to the 1999 report, there were approximately 7331 practicing physicians, 695 nurse practitioners, and 182 physician assistants in Oregon. Of these, 79% of physicians, 72% of nurse practitioners, and 77% of physician assistants were in Oregon's urban and mixed urban/rural counties where 69% of the population lives.<sup>13</sup> As will be discussed in further detail in later sections of this report, clinical genetics professionals (physicians and genetic counselors) are located mainly in the Portland metro area with a very limited number in other areas of the state. Other specialty providers are also in low supply in non-urban areas.

## **Health Indicators**

### *Perinatal Health*

The proportion of women in Oregon of childbearing age (15-44) relative to the total population has remained relatively constant over the last ten years, from

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<sup>10</sup> From the Urban Institute, as reported by Covering Kids, [www.coveringkids.org](http://www.coveringkids.org) (2002 August).

<sup>11</sup> Oregon DHS Perinatal Program estimates based on Citizen Alien Waived Emergent Medical data.

<sup>12</sup> Oregon Health Council, *Access to Health Care in Oregon: Problems and Strategies*, Preliminary Draft (2002).

<sup>13</sup> Oregon Rural Health Plan, [www.ohsu.edu/oregonruralhealth/](http://www.ohsu.edu/oregonruralhealth/) (1999).

23% in 1990 to 21% in 1999.<sup>14</sup> Age-specific birth rates have decreased 2% for women age 15-34 while they have increased 18% for women over the age of thirty-five. Twelve and a half percent of births are to women age thirty-five and over, a population that is at higher risk of having babies with chromosomal disorders such as Down syndrome. This delay in childbearing for a significant proportion of Oregon women indicates the need for continued availability and potential expansion of prenatal counseling/screening and other genetic services in the future.

Although rates of pregnancies, live births, and abortions have remained fairly constant in Oregon over the last decade, infant mortality has steadily declined in Oregon to a 1999 figure of 5.4 deaths per 1,000 infants.

### *Children with Special Health Care Needs*

The CDRC estimates that at least 15% of Oregon's 982,051 children under the age of twenty-one years have special health care needs; many of these children have congenital or inherited conditions requiring special medical and educational services. A percentage of these children are in need of care coordination services because of the complexity of their conditions. Of the approximately 15,000 children who are believed to need care coordination services, CDRC estimates that approximately 27% are receiving these services.<sup>15</sup>

In 2001 the CDRC provided 40,245 services to 9,375 children and young adults. These data include a 4% increase in patients seen through CDRC tertiary level specialty clinics and a 20% increase in the number of evaluation and management services provided through the clinics, since the prior year. The number of services provided to children with special health needs (CSHN) through the CDRC's community-based programs, CaCoon and Community Connections, has remained steady over the past several years. In 2001, 6,898 services were provided to 1,487 CSHN through the CaCoon program. In 2001 Community Connections clinic services (in fourteen rural sites) were provided for 216 children and another 133 children were triaged and referred to other services.

Families of color experience a disproportionate rate of disabilities. CaCoon reported 2,035 contacts to 351 Hispanic children and their families during 2000. This number represents 23% of the CaCoon nurses' caseload, contrasted with about 13% of the total infant and child population who are identified as Hispanic. In some counties more than 50% of the families followed by the nurses are of Hispanic origin. Families in poverty also experience a disproportionate rate of disabilities. During 2001, 73% of children less than twenty-one years of age visited by the CaCoon nurses received health insurance coverage through

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<sup>14</sup> Oregon Vital Statistics.

<sup>15</sup> Oregon Title V Block Grant 2003.

Medicaid. According to the Social Security Administration report, 6,230 children (a 6% increase since 2000) received Supplemental Security Income (SSI) as of December 2001, and therefore were eligible for Medicaid.

The number of children and youth who receive special education services for disabilities also continues to increase in Oregon. As of December 2001, 78,000 students were enrolled in special education.<sup>16</sup> This represents a 5.5% increase over 1999 enrollment data. The number of children ages 0-5 enrolled in Early Intervention and Early Childhood Special Education has increased 4% from 6,795 in 2000 to 7,086 in 2001. In some districts the Early Intervention enrollment has increased as much as 9%. The increasing number of children, especially those with multiple and complex disabilities, paired with the state's budget shortfall challenges the education and health care systems to provide quality services to all children but especially to the children with special needs.

### *Birth Defects and Inherited Conditions*

Oregon does not have a birth defect registry or surveillance system, so true incidence and prevalence of most conditions is largely unknown. The March of Dimes estimates that 1,752 babies are born with a birth defect annually in Oregon.<sup>17</sup> Birth certificate records reveal that in 2000, 532 congenital anomalies, including conditions such as Down syndrome and other chromosomal disorders, were recorded out of 45,786 births.<sup>18</sup> The number of children with multiple anomalies was not identified. This suggests that only 1% of the newborns had an anomaly, significantly lower than the expected rate of 3-5% (based on national estimates). Underreporting is the most likely reason for low overall rates; this may in part be due to lack of recognition of conditions at birth, varying severity, documentation in medical record, and/or record extraction. In 2000, 25% of infant deaths (during the first year of life) and 32.7% of neonatal deaths (during the first month of life) were due to congenital anomalies including chromosomal disorders. These figures are consistent with numbers in previous years.

### *Neural Tube Defects*

In 2000, twenty children (0.44 per 1000) were diagnosed at birth with a neural tube defect, an abnormality in development of the nervous system (i.e., anencephaly or spina bifida) as reported on birth certificates. This incidence represents a decline from 0.55 per 1000 in 1993 and 0.83 per 1000 in 1971.<sup>19</sup> Rationale for the decline may be related to an increase in awareness and use of supplemental folic acid prior to and during the first few weeks of pregnancy, to

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<sup>16</sup> Oregon Department of Education.

<sup>17</sup> March of Dimes, State Perinatal Profiles (2000).

<sup>18</sup> Oregon Vital Statistics (2000).

<sup>19</sup> Pizacani B. Birth Prevalence of Anencephaly and Spina Bifida in Oregon 1971-1993, *Genetics Northwest* X, no. 4 (1996).

food fortification, or to other factors. Evidence suggests that adequate doses of folic acid may prevent up to 70% of neural tube defects.<sup>20</sup> In 1999, 79% of postpartum women surveyed in the Pregnancy Risk Assessment and Monitoring System survey indicated that they had heard that taking folic acid could help prevent some birth defects. However, only 30% of the women reported they were taking folic acid in the month prior to becoming pregnant, a critical time for prevention of neural tube defects.<sup>21</sup> Knowledge does not appear to translate into behavior change. Additional efforts to motivate women to take vitamins appear to be needed.

### *Fetal Alcohol Syndrome*

Little data exists to help us understand the true impact of fetal alcohol syndrome and other conditions related to teratogen exposure in Oregon. National incidence figures estimate that 1:1,000 children are born with fetal alcohol syndrome each year, which would translate to approximately forty-five children in Oregon/year. In 2000 fetal alcohol was identified as a “condition of the newborn” on nine birth certificates. It is unclear whether these newborns exhibited the characteristic physical features of fetal alcohol syndrome/fetal alcohol effects, which may not be immediately obvious at birth, or if the “diagnosis” was based on known maternal alcohol use during pregnancy. What is clear is that further efforts are needed to identify and intervene with women at risk for alcohol use during pregnancy as well as identify and intervene with children who are impacted by maternal alcohol use during pregnancy.

### *Disorders Detected Through Newborn Screening*

From 1996-2000, 190,814 Oregon newborns were screened for a panel of six inherited or congenital metabolic, endocrine and hemoglobin disorders through the state’s mandatory universal newborn screening program. During this time period, twenty-one children were identified with classical phenylketonuria (OR incidence 1:9,100; US incidence 1:15,900), two children with maple syrup urine disease (OR incidence 1:95,400; US incidence 1:150,000), six children with biotinidase deficiency (OR incidence 1:31,800; US incidence 1:60,000), two children with galactosemia (OR incidence 1:95,400; US incidence 1:60,000), eighty-eight children with primary hypothyroidism (OR incidence 1:2,200; US incidence 1:4,485) and ten children with sickle cell disease (OR incidence 1:19,100; US incidence 1:15,000).<sup>22</sup> Long-term information on the health status of these children is not available, though reduced morbidity and mortality associated with early identification of these conditions is believed to be significant.

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<sup>20</sup> March of Dimes.

<sup>21</sup> Oregon PRAMS Data, 1998-1999.

<sup>22</sup> Derived from National Newborn Screening and Genetics Resource Center Annual Newborn Screening Reports, 1996-2000.

Though exact figures are not available, it is estimated that 120-150 children (3 per 1,000) are born each year in Oregon with congenital hearing loss. Genetic changes are believed to be a primary cause for at least 50-60% of congenital hearing loss cases. Since the July 2000 implementation of mandatory newborn hearing screening legislation, over 90% of Oregon's newborns receive hearing screening at birth.<sup>23</sup>

### *Other "Genetic" Conditions*

While state specific data is not available, extrapolation of national incidence rates to Oregon can provide some insight into the expected burden of genetic conditions in the state. Two relatively common genetic conditions are cystic fibrosis and hemochromatosis. Some states are now considering or implementing population-based screening for these conditions. On average, these autosomal recessive conditions are passed on to one out of four offspring of parents who are both carriers of an abnormal gene.

It is estimated that 1:31 Americans (1:28 Caucasians or Whites) carry the gene for cystic fibrosis, a disease that affects multiple organ systems (particularly the lung and GI tract) and is the most common fatal genetic condition in Whites, who bear 95% of the burden of the disease. Based on an estimated incidence of 1:3,300,<sup>24</sup> we would expect approximately fourteen children to be born with cystic fibrosis in Oregon each year.

Hemochromatosis is an inherited condition that causes abnormal metabolism of iron with a resultant iron overload. Iron overload can cause damage to a number of organ systems, most notably the liver. An estimated 1:8-1:10 individuals in the US population carry an abnormal gene for hemochromatosis and an estimated 1/200-1/400 people have the disease. Based on these estimates there are likely between 8,500 and 17,000 affected individuals in Oregon, many who remain undiagnosed.

### *Genetics Services Clients*

From 1987-1994 the Council of Regional Networks (CORN) collected and published regional and state-specific genetic services data. Though standardized data about genetic service utilization in Oregon is no longer collected, rough estimates obtained through surveys of eight genetic service centers indicate that approximately 6,983 patients were seen in a prenatal or clinical genetics setting in 2000. Whether these estimates represent the number of individuals and families with a need for services is certainly not clear. While estimates (and percentages derived from them) must be taken with a grain of salt, they suggest

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<sup>23</sup> Oregon Early Hearing Detection and Intervention Program data, 2002.

<sup>24</sup> National Institute of Health, Consensus Statement 106: *Genetic Testing for Cystic Fibrosis* (1997).

that 76% percent of genetics patients were female and 41% were over thirty-five years of age (reflecting the utilization of prenatal genetic counseling and evaluation services for pregnant women over thirty-five years). Seven percent of genetics patients were less than one year of age and 24% were children between 1-18 years of age. The majority (76%) of patients were White, 12% were Hispanic, and 12% were other racial/ethnic groups, suggesting that the racial/ethnic profile of individuals accessing genetic services roughly mirrors the demographics of the state. Approximately 60% of genetics patients were insured by private HMO, 14% by private fee-for-service plans, 23% by public insurance (e.g., Oregon Health Plan), and 2% were uninsured.

### *Chronic Diseases and Cancers*

Major causes of morbidity and mortality in Oregon relate to chronic diseases and cancers. While these are not traditionally considered “genetic” conditions (i.e., those that are linked to a single gene mutation or chromosomal abnormality), there is growing scientific evidence about the inherited components of these conditions. Heart disease, diabetes, hypertension, cancers (e.g., breast, colon, ovarian, etc.), Alzheimers disease, asthma, obesity, schizophrenia, and manic depression are all examples of complex conditions that have known inherited components. Further study is likely to reveal additional genetic factors that contribute to these and other illnesses. In 1999 heart disease or stroke accounted for 100,000 hospitalizations and 34% of deaths in Oregon. Data from 1999 also reveal that 23% of adults in Oregon reported a history of hypertension, 4.7% had diabetes, and 20% were obese (body mass index >30).<sup>25</sup> Approximately 9% of adults in Oregon have asthma. In 1999, 18,264 reportable cancers were diagnosed in the state and 6904 people died of cancer-related causes.<sup>26</sup>

### **Summary**

Oregon is a growing and demographically changing state. Geographic, socioeconomic, and cultural challenges affect health care service delivery and access, including the delivery of genetic services. Limited data is currently available to assess the full impact of heritable conditions and birth defects in the state, however estimates suggest that these conditions are important causes of morbidity and mortality for Oregonians. As we learn more about the genetics of common chronic diseases and cancers, we hope to translate that information into prevention and treatment strategies for a significant proportion of Oregon’s population.

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<sup>25</sup> Oregon Vital Statistics (includes Behavioral Risk Factor Surveillance System [BRFSS] data), 1999.

<sup>26</sup> Oregon State Cancer Registry data, 1999.

## Public Attitudes and Beliefs About Genetics: What Oregon Thinks

*“...I put it [genetics] in the same category as the gun—it is a device that if used correctly can bring rewards, used incorrectly it can bring trauma...”*

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Participant,  
Oregon Genetics Assessment Activities

Throughout the needs assessment process, participants were asked questions designed to elicit their attitudes and beliefs about genetics and scientific advancements in genetics, including issues related to public policy, data collection, genetics education, genetic health services, and genetic research. Some of the most salient thoughts are highlighted below.

### Public Perceptions about Genetics

*What first comes to mind when you think of genetics?*

Participants in general responded with comments reflecting the scientific aspects of genetics, the fundamental role of genetics in life, and how genetics makes us each unique and yet connected to others...“what makes people who they are,” “what did I get from my long family history and what did I pass on,” “our secret formula,” “set of instructions,” “DNA, biology.” On the other hand, societal issues and concerns such as Tuskegee experiments, eugenics, sterilization of the mentally ill, genetic manipulation of foods, and cloning came to mind for others.

*Do you think genetic advancements are more likely to help or harm people?*

On the whole, most participants in our assessment activities felt that genetic advancements were more likely to help than harm people. A handful thought that the pros and cons were about equal, and only a few thought that the negatives outweighed the benefits. It was interesting to note that personal health values seemed to differ from perceptions of general public health values. When hypothetically asked about a loved one diagnosed with a serious genetic condition, several participants felt differently about this scenario as opposed to a general discussion of genetic developments. A few participants immediately changed their initial positions of suspicion (related to cloning and ethical issues) when faced with a more personal scenario.

*What do you see as potential benefits of genetic testing and other advances?*

Participants listed a number of potential benefits including:

- Better forecast, detection, prevention or treatment of disease
- Necessary preparation for the birth of a child with special needs
- Healthy lifestyle changes, such as a better diet or more exercise

- Discovery of new drugs or treatment for disease
- Cures and treatments for future generations as discoveries are made
- Informed decision making regarding reproductive decisions

*What do you see as potential pitfalls of genetic testing and advances?*

Participants saw a number of potential pitfalls:

- Discrimination by insurance companies, financing organizations, employers, and the government; for an individual, their offspring, or their family
- Loss of control over genetic information
- Diagnosis of a condition that does not have a treatment
- Significant negative psychological impact
- Increased use of abortion and stem cell research
- Pressure regarding reproductive decisions

No matter how much or how little benefit participants thought the advances would provide, almost all cautioned that the potential for harm could be great. Concerns about privacy and confidentiality were mentioned consistently, and while no one reported actually experiencing discrimination, many participants feared that genetic information in the hands of employers, insurers, or financial institutions could be very harmful.

## **Public Values**

A number of public values and “important issues” emerged through the assessment process.

### *Assuring Individual and Family Choice*

Almost all participants voiced that decisions about the use of genetic services (such as genetic testing or using a genetic counselor); the collection, use, dissemination, and storage of personal genetic data; and participation in research activities should be the choice of the individual and/or family (in cases where newborns or children were involved). Some participants thought that exceptions should only be made if a child’s life was in danger because religious or cultural values prevented parents from using medical testing or other services.

### *Protecting Privacy & Preventing Discrimination*

Of significant concern to many participants were issues of genetic testing by employers in hiring or firing practices (discrimination); the sharing of genetic information on medical records without permission (privacy); the use of genetic material, such as blood or tissue, without permission (informed consent); and research that people are against for cultural, religious, or other reasons (genetic research). It is important to note that on the whole, participants understood the

need to collect health data including genetic information to identify environmental problems, to look at trends, to direct resources, to plan for health programs, or to obtain funding for research and educational efforts; but they repeatedly raised issues of personal privacy, confidentiality, and discrimination. They felt that individuals should have control over their own information, and that the collection and use of information should be voluntary.

### *Educating and Informing the Public*

Many participants in our assessment activities thought that medical and technological discoveries in genetics were outpacing people's understanding, acceptance, and emotional comfort with the advancements, and they voiced that education was key. They felt that all age groups needed to learn about genetics. They thought that not only individuals with or at risk for inherited health conditions should be better informed, but they also saw a need to educate family members, friends, and communities. *"When a child has Down syndrome, people in the community say, 'how sad.' They don't even see that the child might be doing really well...happy and healthy. The kids are seen as sick and vulnerable."* Only then can myths be dispelled and people with genetic conditions be better understood and accepted.

For many participants it was hard to discern how recent advances in genetics would affect their life today. Participants suggested that when talking to people in Oregon about genetics, the focus should be on disease prevention and health promotion—especially in regard to pressing health conditions such as diabetes, heart disease, asthma, obesity, and alcohol use. They also mentioned that it was very important to acknowledge people's fears and concerns—not to ignore these or pretend they aren't there.

A variety of genetic service providers, other health professionals, consumers, and the public have all stated that lack of knowledge about genetic services was one of the top reasons why someone would not seek genetic counseling or evaluation services. In addition, families reported information barriers as one of the top reasons preventing them from obtaining the care and services they needed for their children with special health care needs.

### *Educating Health Care Providers*

Participants, including the health care providers themselves, recognized the important role of education and training for health care providers in genetics issues. Consumers reported that a physician's lack of knowledge about particular genetic health conditions would keep them from receiving the care they or their family member needed.

### *Educating Policy Makers*

Participants noted how important it is for policy makers to know and understand basic genetics concepts, but more importantly, to know when they need information and where to go for it. They wanted policy makers to know that genetic disease can happen to anyone, that some birth defects are preventable, that genetic disorders may cause a tremendous financial and emotional burden, that people are influenced by their culture in making health decisions, and that privacy and confidentiality of health information is important. They also wanted policy makers to understand the complex role of genetics and governmental policies, and they thought that local genetics experts should be involved in developing and revising policies related to coverage of genetic services.

### *Assuring Access to Health Services for Families*

Participants saw the need for clear policies and procedures around coverage and reimbursement for genetic services and the need to educate health plan administrators about genetics issues, including the familial aspect of genetic services. It was felt that services should be available to individuals and families in all parts of the state, not just in the urban areas. There were concerns that the people who needed genetic services the most weren't getting them.

### *Respecting Cultural Values/Dispelling the Myths*

*One's perception and understanding of genetics can be strongly influenced by cultural and religious values and beliefs about families, origins of life, health, disease, health care, etc.* Participants thought that respecting cultural values and ideals at the same time as dispelling myths was important. They explained that many cultures have a variety of myths regarding the birth of a child with special needs or regarding an adult who develops a significant health condition. *"I gave my baby x, I ate something that gave my baby x, I did something that gave my baby x."*

## **Public Health System Capacity in Genetics: *What Oregon Has, What Oregon Needs***

The following section is organized using the “essential services of public health” framework. Under each “essential service,” summary bullet statements reflect what Oregon “has” or “doesn’t have” in place currently and what areas are viewed as “needs.” These statements reflect the “gestalt” or “bottom line” generated from inventory and assessment activities. Supporting information can be found in the appendices.

### **Monitoring Health Status: Data and Surveillance**

Oregon has:

- ❖ Some limited existing genetics-related health data from a variety of sources, including vital statistics, newborn metabolic screening program, newborn hearing screening program, population-based surveys (e.g., Pregnancy Risk Assessment and Monitoring System [PRAMS], Behavioral Risk Factor Surveillance System [BRFSS]), and genetic service centers/clinics that can be used for public health program planning and evaluation
- ❖ A newborn metabolic screening program data system that allows for individual case management as well as program planning and evaluation, but is not currently set up to monitor long-term health outcomes
- ❖ Current public health information system development initiatives that will support collection of health service and health outcome data for children and families, including but not limited to those identified with or at risk of inherited and congenital conditions. These initiatives include the development of FamilyNet (consolidated, client-based public health information system for children and families) and development of case-based newborn hearing screening tracking and follow-up
- ❖ Disease registries (e.g., cancer registry) and disease surveillance systems (e.g., asthma, diabetes) that do not currently include family history or other “genetic” information
- ❖ Moderate levels of public concern about privacy and confidentiality of personal genetic health information
- ❖ Genetic privacy law which offers some protection against inappropriate collection and disclosure of personal genetic information as well as initiatives related to compliance with the federal Health Insurance Portability and Accountability Act (HIPAA)

Oregon does not have:

- ❖ A birth defects or congenital condition registry or surveillance system

Oregon needs:

- ❖ New data and data sources to better understand the incidence, prevalence, morbidity, and mortality of inherited conditions and birth defects and to identify those who need genetics-related services and supports
- ❖ More information to determine the feasibility and desirability of developing a birth defects surveillance system
- ❖ Further exploration of the inclusion of family history/genetic information in disease registries and monitoring systems (e.g., cancer registry, asthma monitoring system)
- ❖ Adequate informed consent and data security systems in place to assure voluntary collection of data and maximal privacy and confidentiality of personal health data (including genetic information)

<b>Diagnosis and Investigation of Health Problems and Hazards</b>
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Oregon has:

- ❖ Population-based surveys to identify and investigate community health risks, including PRAMS, BRFSS, and Oregon Healthy Teens Survey
- ❖ Limited access to trained genetic epidemiologists at the state and local levels to investigate the genetic components of disease and the interaction of genes and environment in disease causation and prevention

Oregon needs:

- ❖ Identification and inclusion of additional questions related to “genetics” and “birth defects” risk factors on population surveys
- ❖ Additional expertise and resources within the state and local public health systems to address health risks due to genetics and gene-environment interaction

## Public Information, Education, and Empowerment

### Oregon has:

- ❖ People with widely varying degrees of understanding and experience with genetics issues, including many who are unaware of genetics resources and services in the state
- ❖ A few vocal community groups who are concerned about genetics issues and their impact on society
- ❖ A basic level of genetics education being delivered in K-12 schools but with room for improvement
- ❖ Media increasingly covering “genetic” interest stories, however often focusing on “hot topics” such as cloning or genetically modified foods
- ❖ Interest and willingness of representatives from diverse community groups to collaborate/participate in genetics health education activities
- ❖ Access to online genetics information and educational resources for the public and consumers
- ❖ Access to teratogen information services in the Pacific Northwest Region to assist the general public and health care providers in handling questions/concerns about teratogen exposures
- ❖ A significant proportion of women of childbearing age who are unaware of the benefits of periconceptual folic acid for the prevention of birth defects and/or who do not take multivitamins with folic acid as a preventative measure
- ❖ Citizens and legislators who are concerned about fetal alcohol syndrome recognition, treatment, and prevention

### Oregon needs:

- ❖ Increased integration of genetics concepts into the K-12 health and science curriculum with a shift in educational message from “nature vs. nurture” to “nature and nurture”
- ❖ Increased collaboration between state genetics program/genetics experts and the media to present accurate and balanced information about genetics and health to the general public

- ❖ Outreach to and partnership with community leaders/groups to offer genetics educational opportunities for community members
- ❖ Increased incorporation of genetics content into health education messages about common health conditions
- ❖ Continued efforts to maintain and enhance access to genetics information and educational resources, including teratogen information
- ❖ Continued efforts to educate the public about birth defects prevention (i.e., use of folic acid for prevention of neural tube defects, prevention of fetal alcohol syndrome and others)

<b>Partnership Mobilization</b>
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Oregon has:

- ❖ Several advisory committees and workgroups addressing genetics issues that include partners/stakeholders from a wide variety of professional backgrounds (i.e., consumers, clinical and laboratory genetics, general medicine, health plans, law, ethics) and from a number of state and local agencies
- ❖ Some difficulty in recruiting representatives from diverse racial and ethnic backgrounds and from rural and outlying areas of the state for ongoing advisory bodies
- ❖ The foundation for ongoing and future partnerships established during the assessment and planning process, including multicultural groups, academic faculty and students (e.g., Portland State University, Oregon State University), genetic services providers, and consumers
- ❖ Genetics program staff and genetics professionals participating in non-genetics public health activities (e.g., newborn hearing screening)

Oregon needs:

- ❖ Increased racial, ethnic, cultural, and geographic diversity on decision making bodies/advisory groups
- ❖ Increased outreach to diverse community groups for dialogue and partnership on genetics issues and activities
- ❖ Continued cultivation of partnerships with academic institutions, genetic service providers, consumers, etc.

## Policy Development and Planning

### Oregon has:

- ❖ The current assessment and planning process in place to determine needs related to genetics services and resources, and to develop a state plan to address those needs
- ❖ Several expert advisory bodies to assist in policy development and planning, including Advisory Committee on Genetic Privacy and Research, Genetics Advisory Committee, and Newborn Screening Program Advisory Committee
- ❖ State program staff who are involved in national and regional level genetics activities
- ❖ A handful of legislators who are informed and involved in genetics policy issues, particularly in regard to genetic privacy issues
- ❖ The perception that legislators and other state policy makers would benefit from additional information about genetics, including ethical, legal, and social implications of genetic advances
- ❖ Several issues that were identified through the assessment process for future policy consideration including reproductive technologies, adoption, gene patenting, repeal of consanguinity law, and insurance and employment discrimination

### Oregon needs:

- ❖ Educational efforts targeted at public policy makers
- ❖ Additional resources and commitment from partners and policy makers to carry out the state plan and conduct ongoing assessment and updating of the plan
- ❖ Ongoing systematic review and consideration of state and national public policy activities and priorities in the areas of genetics and birth defects (e.g., folic acid fortification of food) and incorporation into policy development and planning if appropriate
- ❖ Continuation/expansion of policy advisory bodies to address genetics issues, including newborn screening
- ❖ Consideration of policy issues related to reproductive technologies, adoption, gene patenting, and insurance and employment discrimination

## Enforcement of Laws and Regulations

Oregon has:

- ❖ Recently strengthened genetic privacy laws with criminal penalties for violations
- ❖ Strict rules for conducting genetic research, including informed consent and notification provisions
- ❖ Laws requiring mandatory testing of all newborns for metabolic disorders and hemoglobinopathies with a parent option to dissent
- ❖ Recently passed legislation and rules allowing the public health lab to increase the newborn screening fee to allow for implementation of tandem mass spectrometry testing
- ❖ Laws requiring insurance reimbursement for care and medical foods related to metabolic disorders identified through newborn metabolic screening
- ❖ Laws requiring newborn hearing screening in all hospitals with more than 200 births/year
- ❖ Consanguinity law banning first cousin marriages

Oregon does not have:

- ❖ Law mandating licensure of genetic counselors (available in some states)
- ❖ Law mandating insurance reimbursement or coverage for genetic services such as genetic counseling, prenatal screening, etc.
- ❖ Law mandating reporting of individual level newborn hearing screening data for tracking and follow-up
- ❖ Law mandating reporting of birth defects to the public health agency for improved monitoring and service delivery

Oregon needs:

- ❖ Continued study and discussion with stakeholders to determine feasibility and desirability of pursuing legislative initiatives above
- ❖ Consideration of repeal of consanguinity law

## Linkage to Personal Health Services/Provision of Health Care

Oregon has:

- ❖ A cadre of skilled clinical genetics professionals and an array of genetics services across the lifespan, including (1) identification of individuals and families with a genetic condition, and those at increased risk for developing a genetic condition or having a baby with a genetic condition (2) diagnostic and predictive evaluation, genetic counseling, and testing (3) management of conditions, and (4) support and advocacy
- ❖ A sufficient number of clinical genetics professionals and clinics to meet current demand (i.e., referrals) in the Portland metro area, but not in other areas of the state
- ❖ A perception among genetics service providers based on their clinical experience that the “need” for genetic services (i.e., individuals and families who would benefit from services) is greater than current “demand” for services (i.e., patients are not being referred or not utilizing services)
- ❖ A number of perceived barriers to accessing genetic services including:
  - Public and health care provider lack of knowledge about how and where to access services
  - Long travel time to genetic services
  - Cost of services/lack of insurance coverage
  - Concerns about privacy and confidentiality
  - Cultural and religious issues (language, beliefs)
  - Psychological issues (fear, guilt, social stigma)
- ❖ Significant concerns among genetics providers regarding difficulties in obtaining reimbursement for genetic services
- ❖ A strong newborn metabolic screening and follow-up program that is in the midst of an expansion of services to include screening for over twenty-four inherited and congenital disorders
- ❖ Availability of newborn hearing screening in all hospitals with greater than 200 births (serve over 90% of Oregon births)
- ❖ Availability of care coordination services through local public health agencies for many, but not all (due to limited resources), children with special health needs including children with inherited conditions
- ❖ An array of support services and programs for families impacted by inherited conditions (e.g., support groups, child care, respite care), though with some financial barriers to access

- ❖ Funding for several projects to enhance services for children with special health care needs, including adolescents
- ❖ An inadequate supply of primary care providers/medical homes for adults with complex health needs related to inherited conditions and some concern that needs of adolescents are not adequately addressed
- ❖ Feedback from consumers impacted by inherited conditions that services and supports are not always well coordinated
- ❖ Limited racial and ethnic diversity of genetics providers and limited availability of culturally appropriate genetics health education materials and services

Oregon needs:

- ❖ Increased public awareness of genetics services and resources, including population-based services such as newborn screening
- ❖ Increased availability of genetics services, both primary and secondary level, in rural and outlying areas of the state
- ❖ Improved coverage and reimbursement for genetic services, including coverage of genetic evaluation and testing of family members and more streamlined processes for reimbursement
- ❖ Increased availability of medical interpreters who are trained in genetic terminology, written materials in a variety of languages, and genetic service providers who speak a variety of languages (Spanish, Russian, Vietnamese, Chinese, etc.)
- ❖ Continued efforts to enhance communication between health care providers for individuals with inherited conditions in order to improve coordination of care
- ❖ Increased availability of/access to “medical homes” for adults with complex health needs due to inherited conditions
- ❖ Increased attention to the needs of adolescents who are impacted by inherited conditions (e.g., increased access to genetic counseling)
- ❖ Continued efforts to build and strengthen support systems for families impacted by inherited conditions

- ❖ Increased financial assistance for families needing respite care and child care
- ❖ Continued efforts to address underlying general health system concerns related to access to medical care for the uninsured/underinsured, access to care for residents of rural areas, and working within the managed care environment

<b>Health Care Workforce Competency</b>
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Oregon has:

- ❖ Public and personal health care providers who rate themselves as fairly familiar with basic genetics concepts but who are less familiar with recent advances in genetics and are often unfamiliar with available genetic services and resources in Oregon, including Oregon's genetic privacy law
- ❖ Primary care and public health providers who see genetics playing an increasingly important role in health care and are interested in learning more about genetics topics
- ❖ Insufficient incorporation of genetics concepts and tools in routine personal health care practice, including obtaining relevant family histories and referring appropriate patients to genetics professionals for counseling and evaluation/testing
- ❖ Limited application of genetics concepts in public health practice and programs and a perception that genetics issues are not the highest priority for public health at the current time
- ❖ Limited genetics content in many health professional training programs, particularly nursing, physician assistant, physical therapy, occupational therapy, speech pathology, social work, and public health
- ❖ A handful of recent continuing medical education opportunities/initiatives for primary care providers and other health care providers to learn more about genetics

Oregon needs:

- ❖ Increased practical genetics training opportunities for practicing health care providers
- ❖ Increased incorporation of genetics into all health professional training programs

- ❖ Increased opportunities for primary and specialty care providers to network and collaborate with genetics providers and learn about genetic practices in Oregon
- ❖ Increased education of health care providers about Oregon’s genetic privacy law and how to implement it

<b>Health Services Evaluation</b>
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Oregon has:

- ❖ A general “sense” that clinical genetic services and laboratory services are of high quality and are effective, but limited “hard” data to support
- ❖ Some data on the lack of basic genetic services in the primary care setting
- ❖ Limited and outdated standardized data on genetic service utilization and access (from previous CORN reports)
- ❖ Reluctance of genetic service providers to provide additional service data due to lack of time and resources and perceived non-usefulness of data
- ❖ Some consumer survey data indicating need for improved quality of services in the areas of communication/coordination of services among service providers and training of medical providers to effectively manage certain health conditions (e.g., neurofibromatosis)

Oregon needs:

- ❖ Further evaluation of the quality of genetic health services, including the effectiveness of providing primary level (basic) services in the primary care setting
- ❖ Buy-in from genetic service providers as to the value of collecting evaluation data
- ❖ Simplified methods for health services data collection and analysis

<b>Research &amp; Demonstration Projects</b>
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Oregon has:

- ❖ A growing scientific community that includes nationally recognized experts in genetic research, biotechnology development, and bioethics and a handful of well-designed, well-funded research studies currently in

- progress addressing questions in genetic epidemiology, health services, and health policy/communications
- ❖ Genetic service providers who on occasion facilitate their patients' participation in research studies, but who face liability and human subject requirement barriers to doing so
  - ❖ Laws and administrative rules governing genetic research in the state, including provisions for IRB review of genetic research, for specific informed consent for genetic research, for subjects to “opt-out” of anonymous genetic research and for recontact of research subjects
  - ❖ A broad-based state genetic research advisory body (Advisory Committee on Genetic Privacy and Research [ACGPR]) working to promote individual and family health and privacy without unduly restricting advancement in genetic science and technology
  - ❖ Public health interest in establishing a long-term tracking system with a research component for inherited health conditions, correlating health care and services received with health, developmental, and well-being outcomes

Oregon needs:

- ❖ More systematized way of identifying and incorporating relevant information from genetic studies into public and personal health care practice
- ❖ Mechanisms to translate genetics research findings for the general public
- ❖ Ongoing discussion of the ethical, legal, and social implications of genetic research

## **Development of Oregon's Strategic Plan for Genetics and Public Health**

With the wealth of information obtained throughout the assessment process, the Genetics Program staff and the Genetics Plan Advisory Council were faced with choosing and prioritizing the issues to be addressed in the strategic plan. The Council went through several prioritization activities with attempts to use objective criteria to make choices. This was difficult to do, particularly given the paucity of data about particular health conditions, etc. In the end, however, the Genetics Program and Advisory Council selected the **following issues as their highest priorities to address in the strategic plan:**

- Increasing public awareness of genetic services and resources
- Reducing out-of-pocket costs and increasing reimbursement for genetic services
- Decreasing cultural barriers to genetic services
- Increasing policy maker understanding of the ethical, legal, and social implications of genetics and technology
- Enhancing public and personal health care provider knowledge and skills in genetics
- Increasing availability of genetic services outside of the Portland metro area

**Other issues for which there were strong and diverse opinions about the role of the state Genetics Program and the state genetics plan included:**

- Improving availability and quality of data related to inherited conditions and birth defects
- Increasing public awareness and behaviors related to birth defects prevention (especially folic acid use)

**An issue that was seen as “mandatory” in order to carry out the plan was:**

- Increasing state genetics program capacity and sustainability (funding, staffing, management support)

**Needs that were seen as lower priorities for current focus were:**

- Increasing quality assurance/improvement activities related to genetic services
- Increasing data about utilization, access, and quality of genetic services

Based on priorities and identified needs, the strategic plan for the next 3-5 years (2002-2007) was drafted. In June 2002 the final draft plan was disseminated for review by the Advisory Council as well as other stakeholders (e.g., ACGPR,

genetics providers, genetics program coordinators from other states, etc.) and modified to incorporate suggested changes. The plan was finalized in September 2002 with general approval of the Advisory Committee.