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MARYLAND

INSURANCE
ADMINISTRATION

WORKGROUP ON ACCESS TO HABILITATIVE SERVICES BENEFITS

FINAL REPORT

MSAR #9129

OCTOBER 28, 2013

WORKGROUP ON ACCESS TO HABILITATIVE SERVICES BENEFITS

Membership Roster

Maryland State Senate Member
Co-Chair
The Honorable Senator Richard S. Madaleno, Jr.
District 18, Montgomery County

Maryland House of Delegates Member
Co-Chair
The Honorable Ariana B. Kelly
District 16, Montgomery County

Maryland Insurance Commissioner
Therese M. Goldsmith

Representative of the Maryland Health Care Commission
Bruce Kozlowski

Representative of the Maryland State Department of Education
Steven D. Sorin

Representative of the Maryland Developmental Disabilities Council
Rachel London, Esq.

Representative of the Maryland Department of Disabilities
Rachael Faulkner, MSW

Representative of the Department of Health and Mental Hygiene
Debbie Badawi, M.D.

Physical Therapist
Ginny Paleg, DScPT

Occupational Therapist
Lori Tolen, OTR/L

Speech-Language Pathologist
Kimberly A. Bell, M.S., CCC-SLP

Pediatricians
Robert L. Blake, M.D.
Abila Tazanu-Legall, M.D.

K-12 Educator
Nancy FitzGerald, M.S.

Early Intervention Educator
Brian Morrison, Ph.D.

A Parent of a Child with Special Needs
Vacant

Representatives of Insurers
Joe Winn, Aetna
Deborah R. Rivkin, Esq., CareFirst BlueCross BlueShield
Bernard Lapine, Esq., Coventry Health Care of Delaware
Joseph A. Vander Walde, M.D., Kaiser Permanente
Edward P. Koza, M.D., United HealthCare

The workgroup would like to acknowledge the contributions of former parent representative Kelli Nelson, former educator representative Thomas Stengel, and former insurer representative Brenda Myrick, MSN, to the work of the workgroup.

The findings and recommendations included in this report represent those of the majority of the members of the workgroup. Not all members agreed with all of the workgroup's findings and recommendations.

Staff

Tinna Damaso Quigley, Esq.
Director of Government Relations
Maryland Insurance Administration

Brenda Wilson
Associate Commissioner, Life and Health
Maryland Insurance Administration

Nancy J. Egan, Esq.
Assistant Director of Government Relations
Maryland Insurance Administration

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I. ESTABLISHMENT OF WORKGROUP ON ACCESS TO HABILITATIVE SERVICES BENEFITS

During the 2012 Regular Session, the Maryland General Assembly passed Senate Bill 744/ House Bill 1055 (Chapters 293/294), which require, among other things, the Maryland Insurance Commissioner (Commissioner) to establish a workgroup on access to habilitative services benefits and report to the Senate Finance Committee and House Health and Government Operations Committee on its findings and recommendations.[1]

The workgroup's charges are to determine: (1) whether children who are entitled to and would benefit from habilitative services under health insurance policies or contracts or health maintenance organization contracts are actually receiving them; (2) if the children are not receiving the habilitative services, the reasons why; (3) any actions needed to promote optimum use of the habilitative services to maximize outcomes for children and reduce long-term costs to the education and health care systems; and (4) the costs and benefits associated with expanding habilitative services coverage to individuals under the age of 26 years.

In June 2012, the Commissioner convened a workgroup consisting of a physical therapist, an occupational therapist, a speech-language pathologist, pediatricians, K-12 and early intervention educators, a parent of a child with special needs, representatives of insurers, the Maryland Insurance Administration (MIA), the Maryland Health Care Commission, the Maryland State Department of Education (MSDE), the Maryland Developmental Disabilities Council, the Maryland Department of Disabilities, and the Department of Health and Mental Hygiene. Senator Richard Madaleno, appointed by the President of the Senate, and Delegate Ariana Kelly, appointed by the Speaker of the House, served as co-chairs of the workgroup. The health care provider and educator members of the workgroup were recruited from state agencies or professional associations and the parent member was recommended by MIA staff. The insurers selected to be included in the workgroup were chosen based on market share and health benefit plan offerings in the State.[2]

Since establishment of the workgroup in 2012, several changes in membership occurred due to other personal or professional commitments. It should be noted that while the workgroup completed its work with one vacancy for a parent of a child with special needs, several other members of the workgroup are the parents of children with special needs.

II. BACKGROUND ON MARYLAND HABILITATIVE SERVICES BENEFITS MANDATE AND MARYLAND INSURANCE LAW

A. Habilitative Services Benefits Mandate

The Maryland habilitative services mandated benefit was enacted by Chapter 92 of the Acts of 2000 and was codified as § 15-835 of the Insurance Article, Annotated Code of

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[1] Copies of the chapter laws appear in Appendix 1.

[2] The insurers represented on the workgroup offer health insurance policies and health maintenance organization contracts in the individual, small group, and large group markets in the State. Some insurers also provide third party administrator services for self-funded plans.

Maryland. The mandate applies to insurers, nonprofit health service plans, and health maintenance organizations (carriers). It requires carriers to provide coverage for habilitative services for a child under the age of 19. The term "habilitative services" is defined in the law to mean "services, including occupational therapy, physical therapy, and speech therapy, for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function." The term "congenital or genetic birth defect" is defined to mean "a defect existing at or from birth, including a hereditary defect." Chapter 92 of the Acts of 2000 also required a carrier to provide an annual notice about habilitative services coverage to its insureds and enrollees.

Since 2000, the laws regarding the habilitative services benefits mandate have been amended twice. The first amendments, made in 2002, clarified the definition of "congenital or genetic birth defect" to specifically include autism, autism spectrum disorder and cerebral palsy and clarified that a child did not have to have both a congenital and genetic birth defect to qualify for the benefits.[3] The 2002 amendments also provided that denial of a request for habilitative services or payment for habilitative services on the grounds that a condition or disease was not a congenital or genetic birth defect is an adverse decision and subject to appeal to the MIA.

Chapters 293/294 of 2012 amended the habilitative services benefits mandate for the second time since 2000, further clarifying the definition of congenital or genetic birth defect to include intellectual disability, Down syndrome, spina bifida, hydroencephalocele and congenital or genetic developmental disabilities. The annual notice requirement regarding the habilitative services benefits mandate also was amended to require the notice to be provided to insureds and enrollees in print and on the carrier's website. Chapters 293/294 also required the Commissioner to establish a workgroup on access to habilitative services benefits and the Department of Health and Mental Hygiene (DHMH), in consultation with the Commissioner, to establish a technical advisory group on the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders. Chapters 293/294 further required the Commissioner, on or before November 1, 2013, to adopt regulations based on the technical advisory group's recommendations. On April 25, 2013, the Secretary of Health and Mental Hygiene submitted recommendations to the Commissioner on behalf of the technical advisory group.[4] Based on the recommendations, the Commissioner proposed regulations regarding utilization review for autism and autism spectrum disorders that appeared in the August 9, 2013 issue of the Maryland Register.[5]

The federal Patient Protection and Affordable Care Act (ACA) made a number of changes to private insurance plans, including the establishment of a package of essential health benefits which must be included in all insured non-grandfathered health benefit plans offered in the individual and small group markets on or after January 1, 2014.[6] Since enactment of Chapters 293/294, the Maryland Health Care Reform Coordinating Council selected a

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[3] Chapter 382, Acts of 2002.

[4] The autism technical advisory group's recommendations to the Commissioner can be found at: http://www.mdinsurance.state.md.us/sa/docs/documents/news-center/legislative-information/042513_atag_recommendations_final.pdf.

[5] As of the date of this report, the proposed regulations have not been finalized.

[6] A non-grandfathered health benefit plan is a plan that was issued on or after March 23, 2010.

benchmark plan establishing the essential health benefits for the individual and small group markets in Maryland for contracts issued on or after January 1, 2014.[7] The benchmark plan requires coverage for habilitative services benefits consistent with the State mandate for children up to the age of 19 with no limits on visits. For individuals age 19 and older, Maryland's benchmark plan permits habilitative services benefits to be subject to the same visit limits that apply to rehabilitative services benefits.

B. Plans Subject to Maryland Insurance Law

Maryland residents obtain health insurance from a variety of sources, including from their employers, in the individual market, or from the State or federal government. An employer that provides health insurance benefits to its employees may choose to offer an insured plan or a self-funded plan. Insured plans offered by private-sector employers in Maryland are subject to the insurance laws of the State and the regulatory oversight of the MIA. An employer self-funded plan is pre-empted from state regulation by ERISA.[8] Additionally, employer out-of-state contracts, federal employee health benefit plans, and self-funded Maryland State or county employee plans are not required to comply with Maryland insurance laws, including the laws regarding mandated benefits.

A health benefit plan sold in the individual market to a Maryland resident is subject to the insurance laws of Maryland and the regulatory oversight of the MIA. However, if a Maryland resident purchased a plan from an out-of-state association, the association plan is not subject to the insurance laws of Maryland or the regulatory oversight of the MIA. This changes effective January 1, 2014, with the implementation of the ACA, when association plans will be required to include the essential health benefits, which include benefits for habilitative services.

Medicare and Medicaid are not subject to the insurance laws of Maryland or the regulatory oversight of the MIA.

The habilitative services benefits mandate for children under the age of 19 is a Maryland law that applies to insured plans issued in Maryland. Using data reported to the MIA by carriers offering health benefit plans in Maryland, only 24% of Maryland's population currently is covered by a plan that is subject to Maryland insurance laws and the regulatory authority of the MIA.[9] A Maryland resident who has a health benefit plan that is not subject to the insurance laws of the State has the option to purchase a plan in the individual market that is subject to

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[7] Under the ACA, each state is required to establish a benchmark plan that includes all of the categories of essential health benefits that must be included in all health benefit plans offered on or after January 1, 2014.

[8] Employment Retirement Income Security Act of 1974.

[9] Each year, carriers are required to report to the MIA, in accordance with § 15-133 of the Insurance Article, the estimated number of insured and self-insured contracts for health benefit plans in Maryland. The data is self-reported and unaudited. Based on this data, the MIA submits a report to the General Assembly regarding the number of covered lives in the State. The most recent report is the 2012 Health Benefit Plan Covered Lives Report, published in November 2012.

Maryland insurance laws, including the laws mandating coverage for habilitative services benefits.[10]

Because not all health benefit plans are subject to Maryland law, many Maryland residents do not have the protection of the habilitative services mandated benefit. In addition, parents of children with special needs may change employers, which also may result in a change in coverage. As such, parents of a child with special needs may not be aware of the habilitative services benefits that may be available to their child.

III. FINDINGS

A. *Determine whether children who are entitled to and would benefit from habilitative services under health insurance policies or contracts or health maintenance organization contracts are actually receiving them.*

If the children are not receiving the habilitative services, the reasons why.

1. Evidence from Parents

a. Open Forum

A portion of the workgroup's July 31, 2013 meeting was designated as an open forum for parents to provide information to the workgroup regarding their experiences in accessing habilitative services benefits for their child with special needs. As only five parents, from Baltimore, Carroll, and Montgomery Counties participated in the open forum, the workgroup makes no representations as to whether the views expressed by the parents are held by the greater parent community. Based on the experiences shared, several areas of concern were identified by the parents, including: a lack of quality in-network providers; an insufficient number of in-network providers in certain areas of the State; long waiting lists to see in-network providers; low reimbursement rates by carriers that limit provider participation; a fragmented public and private delivery and payment system that requires greater clarity and consistency; lack of coordination between educational goals and medical goals; difficulty in filing claims in order to obtain the habilitative services benefits under a health benefit plan; lack of knowledge by carriers' customer service representatives regarding the differences between the habilitative services benefits and rehabilitative services benefits; and some consumers' lack of awareness regarding the Life and Health Complaints Unit and Appeals and Grievance Unit at the MIA. Some parents expressed concern regarding retaliation by carriers for filing a complaint with the MIA. In other cases, parents and workgroup members reported positive outcomes after filing a complaint with the MIA; however, in some instances, problems regarding claims handling later recurred.

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[10] Financial assistance under the ACA, in the form of advance premium tax credits or cost-sharing subsidies are only available to individuals without access to employer-sponsored plans that are affordable or that provide minimum value.

Parents also expressed frustration in having to repeatedly provide documentation to carriers that their child has a congenital or genetic birth defect that makes the child eligible for habilitative services benefits.

b. MIA Complaint Data

While anecdotal evidence from parents and health care providers suggests that children who are entitled to habilitative services under health insurance policies or contracts are not always receiving the services, complaint data from the MIA indicates that parents or guardians are either not filing complaints or have health benefit plans that are not subject to Maryland law. Each year, the MIA investigates approximately 4,500 to 5,000 complaints relating to health insurance. These complaints are investigated by either the Life and Health Complaints Unit, which investigates complaints regarding benefits and coverage, or by the Appeals and Grievance Unit, which investigates complaints involving denials of coverage based on medical necessity. The MIA identifies or "codes" complaints based on the information provided by the complainant. For a child with special needs, that information usually consists of information regarding the denial of coverage or prior authorization or delay in processing a claim for a service, such as occupational therapy, physical therapy, speech therapy, or behavioral therapy. It is only after investigation that a complaint may be found to be related to a habilitative services benefit. Complaints related to the habilitative services benefits mandate are not coded in the MIA's complaint system as such; therefore, complaint data from the MIA is limited.

For calendar year 2011, the MIA was able to identify only six child-related complaints concerning physical therapy, occupational therapy, or speech therapy that were handled by the Appeals and Grievance Unit. Of these six complaints, three were not subject to the Maryland mandate regarding habilitative services benefits. Two complaints were sent to an independent review organization (IRO) for review for medical necessity. In one case, the IRO ruled in favor of the complainant; in the second case, the IRO ruled in favor of the carrier because the clinical notes did not indicate a congenital or genetic birth defect. The carrier authorized the treatment for the third complaint before the case was sent for review to an IRO.

c. Maryland Parent Survey from Office for Genetics and People with Special Health Care Needs

Initial discussions by a subset of workgroup members tasked with gathering data from parents of children with special needs regarding access to habilitative services benefits involved developing a survey to be sent to parents through established parent networks. The group identified The Parents' Place of Maryland (Parents' Place), a parent-run information and resource center for parents of children with special needs, as a potential channel for distribution. Parents' Place, in conjunction with the Office for Genetics and People with Special Health Care Needs (Office) in DHMH, distributes a survey every three years to their parent network, with the last survey conducted in 2010. The group hoped to include a few questions regarding access to habilitative services benefits in the 2013 survey. Unfortunately, Parents' Place decided to delay distribution of its survey until the fall of 2013 because the Maryland State Department of Education (MSDE) was in the process of closing out another parent survey.

Parents’ Place and the Office were able to provide data from a 2010 survey of families with children and youth with special health care needs.[11] The 2010 survey sought information from the families regarding insurance gaps and focused heavily on habilitative services – 772 families responded to the survey. Of the 772 families, 62.7% responded that they had private health insurance. When asked for which services private health insurance was not paying, 19.9% of families reported that their child was not receiving any or enough speech/language therapy, 14.9% reported their child was not receiving any or not enough occupational therapy, 8.8% reported their child was not receiving any or not enough behavioral therapy, 6.7% reported their child was not receiving any or not enough alternative therapies, 5.8% did not identify a specific therapy type, and 5% reported their child was not receiving any or not enough physical therapy.

2. Evidence from Providers

Workgroup members expressed concerns about limited access to habilitative services benefits on the Eastern Shore and Western Maryland due to a lack of providers in those areas of the State and assertions that reimbursement rates from carriers are inadequate. A subset of workgroup members was established to determine how and whether children with special needs are being referred by pediatricians, family physicians, and other primary care clinicians for further assessment or services. The group also was to determine where allied health providers offer services in the State and the level of insurance participation by the allied health providers.

The group developed two surveys, one for pediatricians, family physicians, and other primary care providers and one for allied health professionals, to further explore the workgroup members’ concerns.[12] Both surveys were sent to a number of professional associations in the State.[13] The surveys were distributed in July 2013 and responses were requested by September 11, 2013. As described more fully below, the response rate for both surveys was quite low. The workgroup makes no representations as to the statistical validity of the data gathered by each survey described below.

a. Survey of Pediatricians, Family Physicians, and Other Primary Care Clinicians

There were 44 responses to the survey for pediatricians, family physicians, and other primary care clinicians practicing in every county in the State except Calvert, Garrett, Kent, Queen Anne’s, St. Mary’s, Somerset, and Washington counties. Sixty-two percent of respondents indicated that they were in private practice and 81% participate with private health

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[11] A summary of the results of the survey was prepared by the Office for Genetics and People with Special Health Care Needs and can be found in Appendix 3. The families responding to the survey have children with special health care needs, some of whom may or may not qualify for habilitative services benefits under Maryland law, as the law applies to children with congenital or genetic birth defects.

[12] Copies of the surveys developed by the workgroup appear in Appendix 2.

[13] The surveys were distributed to the following organizations for electronic distribution to their memberships: Maryland Academy of Advanced Practice Clinicians, Nurse Practitioner Association of Maryland, Maryland Academy of Family Physicians, Maryland Chapter of the American Academy of Pediatrics, Maryland Speech-Language-Hearing Association, Maryland Occupational Therapy Association, American Physical Therapy Association of Maryland, Inc., Maryland Association of Nonpublic Special Education Facilities, MedChi, the Maryland State Medical Society, and Kennedy Krieger Institute.

insurance plans. Nearly half of the respondents to this survey (47.7%) reported that they were somewhat uncomfortable or not at all comfortable understanding the distinction between habilitative services and rehabilitative services; 77.3% of the respondents indicated that their office staff was either somewhat uncomfortable or not at all comfortable in their understanding of the distinction between habilitative services and rehabilitative services.

b. Survey of Allied Health Professionals

There were 89 responses to the survey for allied health professionals practicing in every county in the State except Allegany, Caroline, Dorchester, Garrett, Kent, Somerset, Talbot, and Wicomico counties. Thirty-six percent of the respondents were occupational therapists, 20% were physical therapists, 18% were speech-language pathologists, 9% provided behavioral health services, and 15% practiced in other disciplines, including psychology, art therapy, and music therapy. Over 86% of the respondents to this survey indicated that they were very comfortable or somewhat comfortable in understanding the distinction between habilitative services and rehabilitative services; 71.6% of the respondents indicated that their office staff was also very comfortable or somewhat comfortable in understanding the distinction between habilitative services and rehabilitative services. Only 51.1 % of respondents indicated that they participate with private health insurance. When asked why they did not accept insurance, 77.1% of respondents ranked low reimbursement rates as 1, 2, or 3 on a scale of 1 to 6 with 1 being the most important reason; 73.7% of respondents to the question ranked too much paperwork as 1, 2, or 3.[14]

3. Evidence from Carriers

The five carriers participating in the workgroup provided certain data for insured and self-funded plans for plan years 2010 and 2011.[15] The data included claims or requests for physical therapy, occupational therapy, and speech therapy. Noting limitations in their ability to collect such data due to the vagueness of the definition of "congenital or genetic birth defect" in the law, the carriers based their data collection efforts on 20 diagnosis codes that the carriers agreed would most likely be used for a child with a congenital or genetic birth defect that would be covered under the Maryland mandate.[16] The data also included whether the claims or requests were paid/approved or denied.

The differences in systems design among carriers make it difficult to compare data or derive any conclusions regarding the reasons that claims or requests for services are denied by carriers. Some carriers require prior authorization for habilitative services benefits and require a provider to specify a medical diagnosis of a congenital or genetic birth defect, as defined by Maryland law, before authorizing services to be provided under the habilitative services benefit. Some carriers do not require prior authorization for habilitative services benefits and will request

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[14] It should be noted that while 54 respondents indicated that they either did not take insurance or took limited insurance, there were 61 responses to the question regarding the reasons why the provider did not take insurance.

[15] The carriers that provided data to the workgroup were Aetna, CareFirst, Coventry, Kaiser Permanente, and United Healthcare.

[16] The non-insurer members of the workgroup were not made privy to the diagnosis codes used by the carriers.

documentation before providing benefits under the habilitative services benefit only after the limit for visits under the rehabilitative services benefit has been met.[17]

The U.S. Centers for Disease Control and Prevention estimates that approximately 1 in 88 children in the U.S. has been identified with an autism spectrum disorder, approximately 1 in 303 children in the U.S. has cerebral palsy, and 1 in 700 infants in the U.S. is born with Down syndrome. Given that the State has a population of children ages 19 and under of approximately 1.5 million, the data provided by the carriers seems to indicate that there is low utilization of the habilitative services benefit in the State.[18]

Carrier 1 requires prior authorization for habilitative services benefits and showed that for the two-year reporting period, only fifteen requests for services under the habilitative services benefit were submitted. All were approved.

Carrier 2 also requires prior authorization for habilitative services benefits and showed that 1,861 requests for services under the habilitative services benefit were submitted for the two-year reporting period, with 1,353 or 73% approved. Of the 508 denials, 223 or 12% were under insured plans. For the denials under insured plans, the carrier determined that more than 98% did not meet the criteria for either a congenital or genetic birth defect or for habilitative services under Maryland law. This carrier's claim processing is unique among the five carriers as it allows a provider to indicate whether requested services are for habilitative services or rehabilitative services on prior authorization request forms.

Carriers 3, 4, and 5 indicated that they make no distinction between services for physical therapy, occupational therapy, or speech therapy provided under a habilitative services benefit and services provided under a rehabilitative services benefit; therefore, data regarding the denials of claims provided by the three carriers includes denials for services under both the habilitative services benefit and rehabilitative services benefit. Reasons for the denial of claims were not provided by the carriers that do not distinguish between services provided under a habilitative services benefit and services provided under a rehabilitative services benefit.

Carrier 3 only provided utilization data for 2011 for physical therapy, occupational therapy, and speech therapy. Carrier 3 reported that 3,207 of its members were diagnosed with a congenital or genetic birth defect, with approximately 11% receiving physical therapy, 3% receiving occupational therapy, and 5% receiving speech therapy. No data regarding claim denials was provided by this carrier.

Carrier 4 indicated that for insured plans, 3,635 claims were submitted for the two-year reporting period with 341 or 9% of the claims denied. For self-funded plans, 1,961 claims were submitted for the two-year reporting period with 205 or 10% of the claims denied.

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[17] Under most health benefit plans, the rehabilitative services benefit includes an annual limit on the number of visits. Under Maryland law, there may be no limit on the number of visits for medically necessary habilitative services for children up to the age of 19.

[18] Figures based on 2010 Census data.

Carrier 5 indicated that for insured plans, 2,508 claims were submitted for the two-year reporting period with 181 or 7% of the claims denied. For self-funded plans, 40 claims were submitted for the two-year reporting period with 3 or 7% of the claims denied.

4. Evidence from Maryland State Department of Education

The Maryland State Department of Education (MSDE) serves as the State's lead agency for administration of the statewide early intervention system. The Maryland Infants and Toddlers Program (MITP), under the auspices of the MSDE, provides early intervention services to young children with developmental delays and/or disabilities and their families. The MITP is designed to enhance a child's potential for growth and development before reaching school age and may provide physical therapy, occupational therapy, and speech therapy at no cost to the family. Approximately 3.4% of the pediatric population in the State is served by the MITP with no coordination of services between MSDE and private insurance. Early intervention services are provided through an Individualized Family Service Plan (IFSP). The MITP focuses primarily on a child's developmental progress and school readiness.

At the age of 3, a child with special needs may be identified as requiring special education to support the child's development with a focus on the instructional program and not a child's medical needs. Provisions for related services under an older child's Individualized Education Program (IEP) are determined by an IEP team, of which a parent is a part, and are based on the specific needs of the student. Medical records, including psychological evaluations, are considered as part of the review process. Services recommended by the medical community might not be related to the child's educational development. Related services under an IEP are provided to students to enable them to access their educational needs.

When a child transitions from the MITP to an IEP, the focus of services changes as well. With services now provided to address that child's educational needs, it may not be clear to families that services provided by the local school system may need to be supplemented. Some suggested ways for providing information to parents about habilitative services benefits were: 1) on a global basis to all parents at PTA meetings or distribution packets at the beginning of the year; 2) prior to the IEP transitional meeting with parents of children with special needs; 3) at different diagnostic points for older children; and 4) through informational packets provided by DHMH.

B. *Determine any actions needed to promote optimum use of the habilitative services to maximize outcomes for children and reduce long-term costs to the education and health care systems.*

In order to provide parents with information regarding how to access insurance coverage for habilitative services benefits, the workgroup developed two documents for parents.[19] The first document provides guidance to parents when contacting their carriers to access habilitative services benefits. The second document is a guide for parents of a child with special needs describing habilitative services, how coverage for habilitative services benefits could differ

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[19] Both documents can be found in Appendix 4.

between plans subject to the mandate and plans not subject to the mandate, and the services provided through the health care system and those provided under a child's educational plan.

The *Parents' Guide to Habilitative Services* and *Questions to Ask Your Health Insurance Company or HMO about Your Child's Access to Habilitative Services Benefits* are available on the websites of the MIA and DHMH. Pathfinders for Autism also has posted both documents on its website.

C. *Determine the costs and benefits associated with expanding habilitative services coverage to individuals under the age of 26 years.*

The legislation establishing the workgroup did not include funding to conduct an actuarial determination of the costs associated with expanding the habilitative services benefits mandate to children under the age of 26 years. However, similar studies have been conducted in the past, one as recently as 2011, that provide some information as to the estimated costs of providing habilitative services benefits to expanded populations.[20]

In 2011, the Annual Mandated Health Insurance Services evaluation prepared pursuant to § 15-1501 of the Insurance Article for the Maryland Health Care Commission by the actuarial consulting firm Mercer included estimates for a six-year phase-in of an expansion of the habilitative services benefit up to the age of 25. Mercer sought input from health plan medical directors, conducted carrier surveys, and used updated data from its 2007 evaluation in estimating the costs for the expanded coverage. In the evaluation, Mercer estimated that the average annual cost per employee ranged from $6 to $10 for year 1, $11 to $18 for year 2, $18 to $31 for year 3, $23 to $38 for year 4, $26 to $43 for year 5, and $29 to $49 in the last year of the phase-in.

In 2007, Mercer provided a range of cost estimates for the expansion of habilitative services benefits to individuals aged 19 through 64 using two different methods. These cost estimates were based on information from three primary sources, including 1) national associations that provide services for or research about individuals with developmental disabilities; 2) surveys of carriers; and 3) Medicaid data in other states. Using the first method, Mercer estimated the additional annual per-employee cost for policies issued in Maryland would range from $39 to $261. Using the second method, additional annual per-employee costs were estimated to range from $50 to $100.

The estimates provided in the 2007 and 2011 reports also assumed that the parameters for the services to be provided would not be extended to include additional services.

It is important to note that during the time since the workgroup was charged with examining this issue, the law with respect to habilitative services for adults has changed. As discussed in Section III. A. of this report, the ACA requires habilitative services benefits be included as an essential health benefit, regardless of age. In Maryland, all health benefit plans issued on or after January 1, 2014 must include coverage for habilitative services benefits for

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[20] Two such studies can be found in Appendix 5.

individuals age 19 and older and may apply the same limits to the benefits as are applicable to rehabilitative services benefits.

IV. RECOMMENDATIONS

Based on the anecdotal evidence received by the workgroup, survey results, and data provided by the MIA and carriers, the workgroup makes the following recommendations to help ensure that children who are entitled to and would benefit from habilitative services under health insurance policies or contracts or health maintenance organization contracts are actually receiving them.

1. If a carrier has determined that a child has a congenital or genetic birth defect the carrier should not require any re-determination that the child has a congenital or genetic birth defect for the purpose of providing benefits under the habilitative services benefits mandate, absent an intervening event.

2. Carriers should distinguish between rehabilitative services and habilitative services in their claims systems.

3. Carriers should not classify occupational therapy, physical therapy, speech therapy, and behavioral therapy as habilitative or rehabilitative until after the carrier has reviewed the information necessary to determine whether the patient has a congenital or genetic birth defect that qualifies the patient for medically necessary habilitative services.

4. Carriers, professional organizations, and other stakeholders should conduct educational activities for medical providers, especially primary care providers, regarding habilitative services.

5. Carriers should offer contracts that develop networks of physicians and non-physician health professionals that meet the needs of pediatric populations.

6. Carriers should educate customer service representative staff and others who handle complaints from their members or policyholders about the habilitative services benefits mandate.

7. The Maryland Insurance Administration should add a complaint code for behavioral health upon final adoption of regulations regarding utilization review for autism and autism spectrum disorders.

8. The General Assembly should consider whether the definition of “congenital or genetic birth defect” should be further clarified without identifying or listing additional specific disabilities and/or medical conditions.

9. The Maryland State Department of Education should disseminate information to families about access to habilitative services, including the *Parents' Guide to Habilitative Services* developed by the workgroup. Information should be provided at the following times:

a) on a global basis to all parents at PTA meetings or through distribution packets at the beginning of the year;

b) at the transitional meeting between the MITP and K-12 program with parents of children with special needs; and

c) at different diagnostic points for older children, including at IEP meetings and upon approval or denial of parent requests for educationally based occupational therapy, physical therapy, speech therapy, or behavioral therapy.

10. Carriers should provide a link to the *Parents' Guide to Habilitative Services* and *Questions to Ask Your Health Insurance Company or HMO about Your Child's Access to Habilitative Services Benefits* in the online and printed notices required by § 15-835 of the Insurance Article.

Appendix 1

Chapter 293

(Senate Bill 744)

AN ACT concerning

Health Insurance – Habilitative Services – Required Coverage ~~and~~, Workgroup, and Technical Advisory Group

FOR the purpose of ~~altering the age under which certain insurers, nonprofit health service plans, and health maintenance organizations must provide coverage of habilitative services;~~ specifying the format in which certain insurers, nonprofit health service plans, and health maintenance organizations must provide a certain notice about the coverage ~~must be provided~~ of habilitative services; requiring that certain determinations made by certain insurers, nonprofit health service plans, and health maintenance organizations be made in accordance with certain regulations beginning on a certain date; requiring the Department of Health and Mental Hygiene, in consultation with the Maryland Insurance Commissioner, to establish a technical advisory group on the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders; establishing the composition of the technical advisory group; requiring the technical advisory group to develop certain recommendations and obtain certain input; requiring the Commissioner, on or before a certain date, to adopt certain regulations based on the recommendations of the technical advisory group; requiring the ~~Maryland Insurance~~ Commissioner to establish a workgroup on access to habilitative services benefits; specifying the composition of the workgroup; requiring the workgroup to make certain determinations; requiring the Commissioner to ~~report~~ submit certain reports on the findings and recommendations of the workgroup, on or before ~~a certain date~~ certain dates, to certain legislative committees; altering a certain definition; providing for the construction of this Act; and generally relating to health insurance coverage of habilitative services.

BY repealing and reenacting, with amendments,
Article – Insurance
Section 15–835
Annotated Code of Maryland
(2011 Replacement Volume)

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

Article – Insurance

15–835.

(a) (1) In this section the following words have the meanings indicated.

(2) (i) "Congenital or genetic birth defect" means a defect existing at or from birth, including a hereditary defect.

(ii) "Congenital or genetic birth defect" includes, but is not limited to:

1. autism or an autism spectrum disorder; **[**and**]**

2. cerebral palsy**;**

3. INTELLECTUAL DISABILITY;

4. DOWN SYNDROME;

5. SPINA BIFIDA; ~~**AND**~~

6. HYDROENCEPHALOCELE<u>; AND</u>

<u>7. CONGENITAL OR GENETIC DEVELOPMENTAL DISABILITIES</u>.

(3) "Habilitative services" means services, including occupational therapy, physical therapy, and speech therapy, for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function.

(4) "Managed care system" means a method that an insurer, a nonprofit health service plan, or a health maintenance organization uses to review and preauthorize a treatment plan that a health care practitioner develops for a covered person using a variety of cost containment methods to control utilization, quality, and claims.

(b) This section applies to:

(1) insurers and nonprofit health service plans that provide hospital, medical, or surgical benefits to individuals or groups on an expense–incurred basis under health insurance policies or contracts that are issued or delivered in the State; and

(2) health maintenance organizations that provide hospital, medical, or surgical benefits to individuals or groups under contracts that are issued or delivered in the State.

(c) (1) An entity subject to this section shall provide coverage of habilitative services for children under the age of [19] ~~21~~ years and may do so through a managed care system.

(2) An entity subject to this section is not required to provide reimbursement for habilitative services delivered through early intervention or school services.

(d) An entity subject to this section shall provide notice annually to its insureds and enrollees about the coverage required under this section**:**

(1) IN PRINT; AND

(2) ON ITS WEB SITE.

(e) A determination by an entity subject to this section denying a request for habilitative services or denying payment for habilitative services on the grounds that a condition or disease is not a congenital or genetic birth defect is considered an "adverse decision" under § 15–10A–01 of this title.

(F) BEGINNING NOVEMBER 1, 2013, A DETERMINATION BY AN ENTITY SUBJECT TO THIS SECTION OF WHETHER HABILITATIVE SERVICES COVERED UNDER THIS SECTION ARE MEDICALLY NECESSARY AND APPROPRIATE TO TREAT AUTISM AND AUTISM SPECTRUM DISORDERS SHALL BE MADE IN ACCORDANCE WITH REGULATIONS ADOPTED BY THE COMMISSIONER.

SECTION 2. AND BE IT FURTHER ENACTED, That:

(a) The Department of Health and Mental Hygiene, in consultation with the Maryland Insurance Commissioner, shall establish a technical advisory group on the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders.

(b) The technical advisory group shall be composed of individuals with expertise in the treatment of children with autism and autism spectrum disorders.

(c) The technical advisory group shall develop recommendations for the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders.

(d) When making a recommendation, the technical advisory group shall consider whether the recommendation is:

(1) objective;

(2) clinically valid;

(3) compatible with established principles of health care; and

(4) flexible enough to allow deviations from norms when justified on a case by case basis.

(e) In its work, the technical advisory group shall obtain input from the public, including input from:

(1) parents of children with autism and autism spectrum disorders; and

(2) the insurers, nonprofit health service plans, and health maintenance organizations that are subject to § 15–835 of the Insurance Article, as enacted by Section 1 of this Act.

(f) Based on the recommendations of the technical advisory group, the Commissioner, on or before November 1, 2013, shall adopt regulations that relate to the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders for purposes of § 15–835 of the Insurance Article, as enacted by Section 1 of this Act.

SECTION 3. AND BE IT FURTHER ENACTED, That:

(a) The Maryland Insurance Commissioner shall establish a workgroup on access to habilitative services benefits.

(b) The workgroup shall consist of :

(1) one member of the Senate of Maryland, appointed by the President of the Senate;

(2) one member of the House of Delegates, appointed by the Speaker of the House; and

(3) physical therapists, occupational therapists, speech pathologists, pediatricians, K–12 and early intervention educators, a parent of a ~~special needs~~ child with special needs, and representatives of insurers, the Maryland Insurance Administration, the Maryland Health Care Commission, the Maryland State Department of Education, the Maryland Developmental Disabilities Council, the Maryland Department of Disabilities, and the Department of Health and Mental Hygiene.

(c) The workgroup shall determine:

(1) whether children who are entitled to and would benefit from habilitative services under health insurance policies or contracts or health maintenance organization contracts are actually receiving them;

(2) if the children are not receiving the habilitative services, the reasons why; ~~and~~

(3) any actions needed to promote optimum use of the habilitative services to:

(i) maximize outcomes for children; and

(ii) reduce long–term costs to the education and health care systems; and

(4) the costs and benefits associated with expanding habilitative services coverage to individuals under the age of 26 years.

(d) (1) On or before November 1, 2012, the Commissioner shall submit an interim report, in accordance with § 2–1246 of the State Government Article, to the Senate Finance Committee and the House Health and Government Operations Committee on the findings and recommendations of the workgroup.

(2) On or before November 1, 2013, the Commissioner shall submit a final report, in accordance with § 2–1246 of the State Government Article, to the Senate Finance Committee and the House Health and Government Operations Committee on the findings and recommendations of the workgroup.

SECTION 4. AND BE IT FURTHER ENACTED, That the changes made under Section 1 of this Act to the definition of "congenital or genetic birth defect" in § 15–835(a)(2) of the Insurance Article are intended to clarify the scope of coverage of services required under § 15–835 as it existed before the effective date of this Act, and are not intended, and may not be interpreted or construed, to expand the coverage of services required under § 15–835 as it existed before the effective date of this Act.

SECTION ~~3.~~ 5. AND BE IT FURTHER ENACTED, That this Act shall take effect July 1, 2012.

Approved by the Governor, May 2, 2012.

Chapter 294

(House Bill 1055)

AN ACT concerning

Health Insurance – Habilitative Services – Required Coverage ~~and~~, Workgroup, and Technical Advisory Group

FOR the purpose of ~~altering the age under which certain insurers, nonprofit health service plans, and health maintenance organizations must provide coverage of habilitative services;~~ specifying the format in which certain insurers, nonprofit health service plans, and health maintenance organizations must provide a certain notice about the coverage ~~must be provided~~ of habilitative services; requiring that certain determinations made by certain insurers, nonprofit health service plans, and health maintenance organizations be made in accordance with certain regulations beginning on a certain date; requiring the Department of Health and Mental Hygiene, in consultation with the Maryland Insurance Commissioner, to establish a technical advisory group on the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders; establishing the composition of the technical advisory group; requiring the technical advisory group to develop certain recommendations and obtain certain input; requiring the Commissioner, on or before a certain date, to adopt certain regulations based on the recommendations of the technical advisory group; requiring the ~~Maryland Insurance~~ Commissioner to establish a workgroup on access to habilitative services benefits; specifying the composition of the workgroup; requiring the workgroup to make certain determinations; requiring the Commissioner to ~~report~~ submit certain reports on the findings and recommendations of the workgroup, on or before ~~a certain date~~ certain dates, to certain legislative committees; altering a certain definition; providing for the construction of this Act; and generally relating to health insurance coverage of habilitative services.

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2. cerebral palsy**;**

3. INTELLECTUAL DISABILITY;

4. DOWN SYNDROME;

5. SPINA BIFIDA;

6. HYDROENCEPHALOCELE; **AND**

7. ~~DEVELOPMENTAL DISORDERS (LEARNING, READING, MATHEMATICS, SPEECH, AND SPELLING)~~ <u>CONGENITAL OR GENETIC DEVELOPMENTAL DISABILITIES</u>.

(3) "Habilitative services" means services, including occupational therapy, physical therapy, and speech therapy, for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function.

(4) "Managed care system" means a method that an insurer, a nonprofit health service plan, or a health maintenance organization uses to review and preauthorize a treatment plan that a health care practitioner develops for a covered person using a variety of cost containment methods to control utilization, quality, and claims.

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(c) (1) An entity subject to this section shall provide coverage of habilitative services for children under the age of **[**19**]** ~~21~~ years and may do so through a managed care system.

(2) An entity subject to this section is not required to provide reimbursement for habilitative services delivered through early intervention or school services.

(d) An entity subject to this section shall provide notice annually to its insureds and enrollees about the coverage required under this section**:**

(1) IN PRINT; AND

(2) ON ITS WEB SITE.

(e) A determination by an entity subject to this section denying a request for habilitative services or denying payment for habilitative services on the grounds that a condition or disease is not a congenital or genetic birth defect is considered an "adverse decision" under § 15–10A–01 of this title.

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(c) The technical advisory group shall develop recommendations for the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders.

(d) When making a recommendation, the technical advisory group shall consider whether the recommendation is:

(1) objective;

(2) clinically valid;

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(e) In its work, the technical advisory group shall obtain input from the public, including input from:

(1) parents of children with autism and autism spectrum disorders; and

(2) the insurers, nonprofit health service plans, and health maintenance organizations that are subject to § 15–835 of the Insurance Article, as enacted by Section 1 of this Act.

(f) Based on the recommendations of the technical advisory group, the Commissioner, on or before November 1, 2013, shall adopt regulations that relate to the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders for purposes of § 15–835 of the Insurance Article, as enacted by Section 1 of this Act.

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(1) one member of the Senate of Maryland, appointed by the President of the Senate;

(2) one member of the House of Delegates, appointed by the Speaker of the House; and

(3) physical therapists, occupational therapists, speech pathologists, pediatricians, K–12 and early intervention educators, a parent of a ~~special needs~~ child with special needs, and representatives of insurers, the Maryland Insurance Administration, the Maryland Health Care Commission, the Maryland State Department of Education, the Maryland Developmental Disabilities Council, the Maryland Department of Disabilities, and the Department of Health and Mental Hygiene.

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(1) whether children who are entitled to and would benefit from habilitative services under health insurance policies or contracts or health maintenance organization contracts are actually receiving them;

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SECTION 4. AND BE IT FURTHER ENACTED, That the changes made under Section 1 of this Act to the definition of "congenital or genetic birth defect" in § 15–835(a)(2) of the Insurance Article are intended to clarify the scope of coverage of services required under § 15–835 as it existed before the effective date of this Act, and are not intended, and may not be interpreted or construed, to expand the coverage of services required under § 15–835 as it existed before the effective date of this Act.

SECTION ~~3.~~ 5. AND BE IT FURTHER ENACTED, That this Act shall take effect July 1, 2012.

Approved by the Governor, May 2, 2012.

Appendix 2a

Survey for Pediatricians, Family Physicians and Primary Care Clinicians

1. Demographic information

		Response Percent	Response Count
(a) Professional discipline/specialty:		**100.0%**	**44**
(b) Years in practice		95.5%	42
		answered question	**44**
		skipped question	**0**

2. In what city/county(ies) do you practice? (Check all that apply.)

	Response Percent	Response Count
Allegany County	2.3%	1
Anne Arundel County	13.6%	6
Baltimore City	18.2%	8
Baltimore County	15.9%	7
Calvert County	0.0%	0
Caroline County	2.3%	1
Carroll County	2.3%	1
Charles County	2.3%	1
Cecil County	2.3%	1
Dorchester County	2.3%	1
Frederick County	9.1%	4
Garrett County	0.0%	0
Harford County	2.3%	1
Howard County	4.5%	2
Kent County	0.0%	0
Montgomery County	**29.5%**	**13**
Prince George's County	9.1%	4
Queen Anne's County	0.0%	0
St. Mary's County	0.0%	0
Somerset County	0.0%	0
Talbot County	2.3%	1
Washington County	0.0%	0
Wicomico County	2.3%	1

Worcester County	0.0%	0
	answered question	**44**
	skipped question	**0**

3. Practice Setting(s):

	Response Percent	Response Count
Private Community Practice	**62.8%**	**27**
Occupational Health Center (OHC)	2.3%	1
Hospital Clinic	18.6%	8
Academic/Teaching	14.0%	6
Other (please specify)	20.9%	9
	answered question	**43**
	skipped question	**1**

4. Do you participate with private health insurance plans?

	Response Percent	Response Count
Yes	**81.4%**	**35**
No	18.6%	8
	answered question	**43**
	skipped question	**1**

5. How comfortable are you in your understanding of the distinction between habilitative services and rehabilitative services?

	Response Percent	Response Count
Very comfortable	22.7%	10
Somewhat comfortable	**29.5%**	**13**
Somewhat uncomfortable	18.2%	8
Not at all comfortable	**29.5%**	**13**
	answered question	**44**
	skipped question	**0**

6. How comfortable is your office staff in their understanding of the distinction between habilitative services and rehabilitative services?

	Response Percent	Response Count
Very comfortable	4.5%	2
Somewhat comfortable	18.2%	8
Somewhat uncomfortable	**43.2%**	**19**
Not at all comfortable	34.1%	15
	answered question	**44**
	skipped question	**0**

7. How comfortable are you in your understanding of the distinction between fully insured health plans and self-insured health plans?

	Response Percent	Response Count
Very comfortable	14.0%	6
Somewhat comfortable	**48.8%**	**21**
Somewhat uncomfortable	23.3%	10
Not at all comfortable	14.0%	6
answered question		**43**
skipped question		**1**

8. How comfortable is your office staff in their understanding of the distinction between fully insured health plans and self-insured health plans?

	Response Percent	Response Count
Very comfortable	9.1%	4
Somewhat comfortable	**36.4%**	**16**
Somewhat uncomfortable	34.1%	15
Not at all comfortable	20.5%	9
answered question		**44**
skipped question		**0**

9. How do you identify children who may have special needs? (Check all that apply.)

	Response Percent	Response Count
Screening	86.4%	38
Surveillance	70.5%	31
Parental report	**93.2%**	**41**
Educator report	72.7%	32
Other (please specify)	13.6%	6
	answered question	**44**
	skipped question	**0**

10. If you perform screening to identify children who may have special needs, at what ages do you screen? (Check all that apply.)

	Response Percent	Response Count
9 months	76.2%	32
18 months	**85.7%**	**36**
24 months	83.3%	35
30 months	42.9%	18
36 months	57.1%	24
	Other (please specify)	14
	answered question	**42**
	skipped question	**2**

11. What additional criteria, if any, do you use to decide whether to refer a child who may have special needs for further assessment or services? (Check all that apply.)

	Response Percent	Response Count
The presence or absence of an obvious physical finding	**86.4%**	**38**
The child's age	45.5%	20
Repeat screening results on subsequent visits	68.2%	30
Other (please specify)	25.0%	11
answered question		**44**
skipped question		**0**

12. Where have you referred children in your practice who have developmental or mental health needs? (Check all that apply.)

	Response Percent	Response Count
State Early Intervention Program	**86.4%**	**38**
School-Based Special Education	75.0%	33
Developmental Pediatric Specialist	79.5%	35
Physical Medicine Specialist	31.8%	14
Physical Therapist	72.7%	32
Occupational Therapist	72.7%	32
Speech-Language Pathologist	75.0%	33
Mental Health Practitioner	70.5%	31
Hospital/Clinic	27.3%	12
Insurance Company	9.1%	4
	Other (please specify)	4
	answered question	**44**
	skipped question	**0**

13. How do you make such referrals/contacts? (Check all that apply.)

	Response Percent	Response Count
I make the referral/contact directly.	**39.5%**	**17**
I or my office staff recommends that the child's parent or guardian make the contact.	**39.5%**	**17**
My office staff makes the referral/contact.	20.9%	9
Other (please specify)		5
answered question		**43**
skipped question		**1**

14. What are the barriers, if any, to making such referrals? (Check all that apply.)

	Response Percent	Response Count
Concerns about lack of insurance coverage	**70.7%**	**29**
Cost of services	51.2%	21
Limited access to qualified providers in the geographic area	**70.7%**	**29**
Limited access to in-network providers	56.1%	23
Lack of familiarity with the referral process	14.6%	6
Other (please specify)		7
answered question		**41**
skipped question		**3**

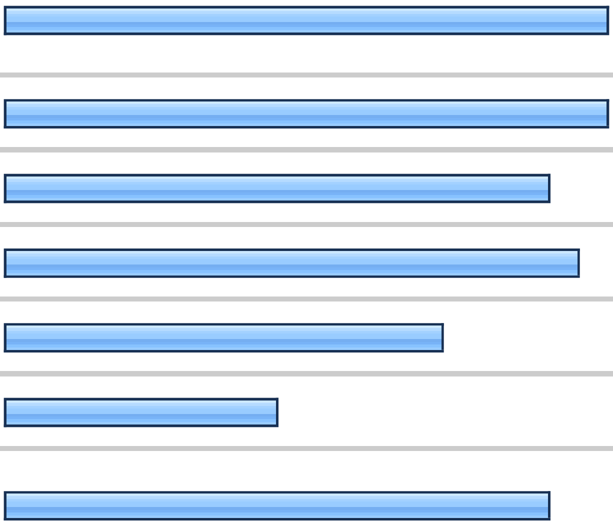
15. Do you, or does your staff, confirm whether your patient has insurance coverage for the services for which you make a referral?

		Response Percent	Response Count
Yes		**54.5%**	**24**
No		45.5%	20
		answered question	**44**
		skipped question	**0**

16. How do you confirm that services for which you make such referrals are furnished? (Check all that apply.)

		Response Percent	Response Count
Contact from service provider		**78.6%**	**33**
Parental report		71.4%	30
		Other (please specify)	8
		answered question	**42**
		skipped question	**2**

17. What are the medical diagnoses of patients for whom you make such referrals? (Check all that apply.)



	Response Percent	Response Count
Autism or autism spectrum disorder	**90.9%**	**40**
Cerebral palsy	**90.9%**	**40**
Intellectual disability	81.8%	36
Down syndrome	86.4%	38
Spina bifida	65.9%	29
Hydroencephalocele	40.9%	18
Congenital or genetic developmental disability	81.8%	36
	Other (please specify)	5
	answered question	**44**
	skipped question	**0**

18. Do you have any additional comments you wish to share about your clients' access to habilitative services benefits?

		Response Count
		14
	answered question	**14**
	skipped question	**30**

Q1. Demographic information

(a) Professional discipline/specialty:		
1	Family Practice	Sep 8, 2013 8:16 AM
2	Family Practice	Sep 6, 2013 3:49 PM
3	General Pediatrics	Sep 2, 2013 9:20 AM
4	Pediatric orthopedics	Sep 2, 2013 6:50 AM
5	Speech-Language Pathology	Aug 29, 2013 9:30 AM
6	Pediatrics	Aug 28, 2013 7:11 AM
7	Speech & Language Pathologist	Aug 28, 2013 5:39 AM
8	PEDIATRICS	Aug 27, 2013 6:09 AM
9	MD, pediatrics	Aug 26, 2013 11:35 AM
10	pedistrics	Aug 26, 2013 5:21 AM
11	Pediatrics	Aug 25, 2013 4:16 PM
12	Pediatrics	Aug 23, 2013 10:05 AM
13	pediatrics	Aug 23, 2013 6:55 AM
14	Pediatrics	Aug 22, 2013 2:20 PM
15	pediatrics	Aug 20, 2013 11:18 AM
16	MD, Pediatric	Aug 14, 2013 9:01 AM
17	Pediatric Nurse Practitioner - Private Practice	Aug 14, 2013 7:21 AM
18	Pediatrics	Aug 14, 2013 7:08 AM
19	pediatric nurse practitioner	Aug 13, 2013 7:55 PM
20	Pediatrics	Aug 13, 2013 2:02 PM
21	Pediatric Orthopedic surgery	Aug 13, 2013 10:12 AM
22	Pediatric Nurse Practitioner	Aug 13, 2013 5:25 AM
23	Pediatrics	Aug 12, 2013 7:49 PM
24	Pediatrics	Aug 12, 2013 6:40 PM
25	Neurodevelopmental Disabilities	Aug 12, 2013 9:18 AM
26	pediatrics	Aug 11, 2013 4:48 PM

Q1. Demographic information

27	Pediatrics	Aug 11, 2013 12:14 PM
28	Pediatrics	Aug 11, 2013 5:38 AM
29	Pediatrics	Aug 11, 2013 5:19 AM
30	Obstetrics & Gyn	Aug 10, 2013 4:27 AM
31	pediatrics	Aug 9, 2013 1:48 PM
32	Neonatology	Aug 9, 2013 10:16 AM
33	Pediatrics	Aug 9, 2013 6:56 AM
34	Pediatrician	Aug 9, 2013 6:47 AM
35	pediatrics	Aug 8, 2013 6:33 PM
36	Pediatrics	Aug 8, 2013 3:32 PM
37	Orthopedic surgery	Aug 8, 2013 2:51 PM
38	pediatrics	Aug 8, 2013 2:48 PM
39	Pediatrics	Aug 8, 2013 12:16 PM
40	PEDIATRICS	Aug 8, 2013 11:24 AM
41	Pediatrics	Aug 8, 2013 10:53 AM
42	Family Medicine	Aug 2, 2013 1:22 PM
43	Pediatrics	Aug 2, 2013 5:45 AM
44	Endocrinology	Jul 21, 2013 5:35 AM
	(b) Years in practice	
1	12	Sep 8, 2013 8:16 AM
2	20	Sep 6, 2013 3:49 PM
3	23 years	Sep 2, 2013 9:20 AM
4	33	Sep 2, 2013 6:50 AM
5	15	Aug 29, 2013 9:30 AM
6	26	Aug 28, 2013 7:11 AM
7	41	Aug 28, 2013 5:39 AM
8	25	Aug 27, 2013 6:09 AM

Q1. Demographic information		
9	20	Aug 26, 2013 11:35 AM
10	25	Aug 26, 2013 5:21 AM
11	23	Aug 25, 2013 4:16 PM
12	21	Aug 23, 2013 10:05 AM
13	16	Aug 23, 2013 6:55 AM
14	35	Aug 22, 2013 2:20 PM
15	19	Aug 20, 2013 11:18 AM
16	6	Aug 14, 2013 9:01 AM
17	11	Aug 14, 2013 7:21 AM
18	27	Aug 14, 2013 7:08 AM
19	32	Aug 13, 2013 7:55 PM
20	20	Aug 13, 2013 2:02 PM
23	33	Aug 12, 2013 7:49 PM
24	9	Aug 12, 2013 6:40 PM
25	17	Aug 12, 2013 9:18 AM
26	12	Aug 11, 2013 4:48 PM
27	28	Aug 11, 2013 12:14 PM
28	15	Aug 11, 2013 5:38 AM
29	8	Aug 11, 2013 5:19 AM
30	10	Aug 10, 2013 4:27 AM
31	3	Aug 9, 2013 1:48 PM
32	20	Aug 9, 2013 10:16 AM
33	4	Aug 9, 2013 6:56 AM
34	17	Aug 9, 2013 6:47 AM
35	17	Aug 8, 2013 6:33 PM
36	30	Aug 8, 2013 3:32 PM
37	5	Aug 8, 2013 2:51 PM

Q1. Demographic information		
38	5	Aug 8, 2013 2:48 PM
39	22	Aug 8, 2013 12:16 PM
40	17	Aug 8, 2013 11:24 AM
41	25	Aug 8, 2013 10:53 AM
42	16	Aug 2, 2013 1:22 PM
43	27	Aug 2, 2013 5:45 AM
44	2	Jul 21, 2013 5:35 AM

Q3. Practice Setting(s):		
1	Multispecialty self insured HMO	Sep 8, 2013 8:16 AM
2	Non public Special Ed school	Aug 29, 2013 9:30 AM
3	HMO	Aug 27, 2013 6:09 AM
4	HMO (kaiser)	Aug 26, 2013 11:35 AM
5	HMO	Aug 26, 2013 5:21 AM
6	Group Practice HMO	Aug 23, 2013 10:05 AM
7	hmo	Aug 23, 2013 6:55 AM
8	Hospital Priviledges at AAMC	Aug 14, 2013 7:21 AM
9	hospital ward and hospital peds ed	Aug 13, 2013 2:02 PM

Q9. How do you identify children who may have special needs? (Check all that apply.)		
1	Soecialist referral	Sep 2, 2013 9:20 AM
2	Referral from pediatrician	Sep 2, 2013 6:50 AM
3	Prerequisite for enrollment in my facility	Aug 29, 2013 9:30 AM
4	Formal evaluation	Aug 28, 2013 5:39 AM
5	Expert assessment	Aug 12, 2013 9:18 AM
6	experience	Aug 9, 2013 6:47 AM

Q10. If you perform screening to identify children who may have special needs, at what ages do you screen? (Check all that apply.)		
1	ages 5 to 21	Aug 29, 2013 9:30 AM
2	as needed dev testing	Aug 28, 2013 7:11 AM
3	Whenever they are referred to me	Aug 28, 2013 5:39 AM
4	all well checks	Aug 20, 2013 11:18 AM
5	actually screen with each well visit, but in terms of a formal questionnaire such asPEDS, M-CHAT, those are done at these specific ages	Aug 13, 2013 7:55 PM
6	do not screen in my present professional setting, but the survey did not allow me to not pick an age, it required an answer. This is a flaw in your survey, you need to add an answer that says "I do not screen"	Aug 13, 2013 2:02 PM
7	n/a	Aug 13, 2013 10:12 AM
8	All the patients I see have special needs. When you say special needs, you really mean developmental delays. They are different. You are misusing the term special needs in place of developmental delays or developmental problems.	Aug 12, 2013 9:18 AM
9	screen in our NICU clinic every 4-6 months	Aug 9, 2013 10:16 AM
10	at every check up	Aug 8, 2013 6:33 PM
11	whenever I get the opportunity to see them	Aug 8, 2013 2:51 PM
12	2, 4, 6,12, 15,months	Aug 8, 2013 12:16 PM
13	EVERY OFFICE VISIT	Aug 8, 2013 11:24 AM
14	every well child visit	Aug 2, 2013 5:45 AM

Q11. What additional criteria, if any, do you use to decide whether to refer a child who may have special needs for further assessment or services? (Check all that apply.)

1	Degree of delay or abnormality	Sep 2, 2013 9:20 AM
2	Direct observation of an area of need	Aug 29, 2013 9:30 AM
3	To delineate the full extent of the disability	Aug 28, 2013 5:39 AM
4	evals from referrals, vanderbuilt forms, early intervention recommndations, school daycare or preschool concerns,	Aug 20, 2013 11:18 AM
5	validated parental concern	Aug 13, 2013 7:55 PM
6	Many of these children with special needs are pretty obvious on exam	Aug 12, 2013 7:49 PM
7	This question is vague and ambiguous. Children with developmental delays should be referred when they are identified. Other special needs would be handled on case by case basis.	Aug 12, 2013 9:18 AM
8	abnormal results on screening or report from Daycare, parent or school	Aug 11, 2013 12:14 PM
9	If special needs are apparent, the child is referred.	Aug 8, 2013 12:16 PM
10	When I am unable to pinpoint a problem but know the toddler is "different"	Aug 8, 2013 10:53 AM
11	parent/teacher report or concern	Aug 2, 2013 1:22 PM

Q12. Where have you referred children in your practice who have developmental or mental health needs? (Check all that apply.)

1	We participate with BCBS medical home program	Aug 14, 2013 7:21 AM
2	Kennedy Institute and Carter Center	Aug 12, 2013 7:49 PM
3	Neurology, orthopedics, genetics, multidisciplinary clinic, etc.	Aug 12, 2013 6:40 PM
4	Montgomery County Infants and Toddlers, and Child Find	Aug 8, 2013 12:16 PM

Q13. How do you make such referrals/contacts? (Check all that apply.)		
1	If the referral is within my organization , I make the contact. If outside such as State programs,I ask the parent to make the contact.	Sep 2, 2013 9:20 AM
2	through the IEP process	Aug 29, 2013 9:30 AM
3	it is always me who makes the recommendation, I do not delegate this to my staff although they may help with referral if necessary	Aug 13, 2013 7:55 PM
4	Survey only allowed one response although says check all that apply. For goverment services, we recommend that parent make contact. For referrals to other medical specialists, we make referrals.	Aug 12, 2013 9:18 AM
5	All of the above	Aug 11, 2013 5:19 AM

Q14. What are the barriers, if any, to making such referrals? (Check all that apply.)		
1	na	Aug 23, 2013 10:05 AM
2	insurance compainies that refuse to provide ongoing therapy coverage	Aug 20, 2013 11:18 AM
3	limited access would apply most specifically to psychiatrists or mental health care providers who take specific or any insurance	Aug 13, 2013 7:55 PM
4	Family follow through or difficulty in navigating a complex system.	Aug 12, 2013 9:18 AM
5	Waiting lists for services	Aug 11, 2013 5:38 AM
6	Mental health- quality and quantity of providers!!	Aug 11, 2013 5:19 AM
7	Availability of appointments	Aug 2, 2013 5:45 AM

Q16. How do you confirm that services for which you make such referrals are furnished? (Check all that apply.)

1	I provide the services	Aug 28, 2013 5:39 AM
2	na	Aug 23, 2013 10:05 AM
3	notice from insurance compainies that certain services aren't covered	Aug 20, 2013 11:18 AM
4	Mailed report from referral clinic	Aug 12, 2013 7:49 PM
5	Not done systematically.	Aug 12, 2013 9:18 AM
6	contact from insurance company	Aug 11, 2013 4:48 PM
7	My staff sometimes calls insurance company	Aug 11, 2013 5:19 AM
8	referral coordinator contacts family	Aug 2, 2013 5:45 AM

Q17. What are the medical diagnoses of patients for whom you make such referrals? (Check all that apply.)

1	Traumatic Brain Injury; post trauma injuries	Aug 28, 2013 5:39 AM
2	speech delay, motor delays, developmental delays in general, anxiety, depression, high risk behavior, suicide attempts, physical, sexual or mental abuses, adoptees,	Aug 20, 2013 11:18 AM
3	Developmental delay	Aug 13, 2013 7:55 PM
4	Prematurity, neurofibromatosis, etc.	Aug 11, 2013 5:19 AM
5	atypical development	Aug 9, 2013 10:16 AM

Q18. Do you have any additional comments you wish to share about your clients' access to habilitative services benefits?		
1	In a busy practice the time required for diagnosis and follow up is poorly compensated and not available. Psychological services, Speech Tx, OT, PT is often hard to find and get covered by insurance. There is often a CPT code "game": find a Dx code that is reasonably appropriate that will allow the best insurance reimbursement.	Sep 8, 2013 8:16 AM
2	Lack of access, lack of appropriate training for children with cognitive delays and lack of insurance coverage are the biggest barriers to getting these services for kids with special needs.	Sep 2, 2013 9:20 AM
3	insurance barriers repeatedly delay services-it shouldn't require an act of congress to get these children services	Aug 28, 2013 7:11 AM
4	The insurance companies make it very hard to navigate their systems. It takes perseverance and time to struggle through their policies, codes and reimbursement procedures. On top of everything else the families of children with disabilities have, the process is often disheartening and some just give up.	Aug 28, 2013 5:39 AM
5	access to appropriate providers and insurance coverage are the 2 biggest roadblocks to approp care	Aug 20, 2013 11:18 AM
6	There is a coarse line between needed services and those which are self referred by places like the Kennedy Institute. Does a 9 month old need "speech therapy?" There is still a lot of debate on how services for the disabled should be provided; early vs. later, intensive vs. sporadic? The goals of therapy are well defined, but what percentage of patients meet those goals? Granted, there is no uniformity in the diagnoses of disabled children, and that variability makes it difficult to compare results of treatment, but primary care practitioners need guidance on which child will benefit from which service at what point in his development.	Aug 12, 2013 7:49 PM
7	I don't find that insurance companies frequently distinguish between habilitative and rehabilitative services. This comes up occasionally, but is quite rare. I think that the most important aspect of getting a child with a developmental disability the services they need is a rational, appropriate justification for the service or equipment (often as part of a letter of medical necessity).	Aug 12, 2013 9:18 AM
8	in our area - limited access to qualified providers is the no. 1 barrier	Aug 11, 2013 4:48 PM
9	no	Aug 11, 2013 12:14 PM
10	Approximately 4 years ago I had a patient with obvious Spina Bifida (by exam) not identified prenatally. Their insurance company insisted that they be evaluated at UMMS, but pediatric neurosurgery was bot available at UMMS, and JHH refused to see the patient until they were eligible for REMS. REMS required MRI confirmation first, but I wanted to do this at JHH because that's where he would have the surgical repair. Eventually, after hours of phone calls and being put on hold/ phone transfers, we worked it out. This added to the parents high stress level also.	Aug 11, 2013 5:19 AM
11	This is a very underserved population	Aug 9, 2013 6:47 AM

Q18. Do you have any additional comments you wish to share about your clients' access to habilitative services benefits?		
12	The biggest problem is the time to get an appointment. Many of these children should be seen early so that intervention can be started. Place like Kennedy Kreiger which does an amazing workup can take several months to get an appointment. This delays the process of providing services.	Aug 8, 2013 12:16 PM
13	We certainly need more mental health providers in the pediatric field.	Aug 2, 2013 5:45 AM
14	none	Jul 21, 2013 5:35 AM

Appendix 2b

Survey for Allied Health Professionals

1. What is your discipline?

	Response Percent	Response Count
OT	**36.0%**	**32**
PT	20.2%	18
SLP	18.0%	16
Behavior	9.0%	8
Other (please specify)	16.9%	15
	answered question	**89**
	skipped question	**0**

2. In what city/county(ies) do you practice? (Check all that apply.)

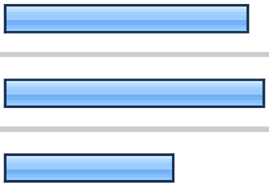
	Response Percent	Response Count
Allegany County	0.0%	0
Anne Arundel County	11.2%	10
Baltimore City	**43.8%**	**39**
Baltimore County	29.2%	26
Calvert County	1.1%	1
Caroline County	0.0%	0
Carroll County	11.2%	10
Charles County	2.2%	2
Cecil County	2.2%	2
Dorchester County	0.0%	0
Frederick County	3.4%	3
Garrett County	0.0%	0
Harford County	13.5%	12
Howard County	16.9%	15
Kent County	0.0%	0
Montgomery County	29.2%	26
Prince George's County	13.5%	12
Queen Anne's County	2.2%	2
St. Mary's County	1.1%	1
Somerset County	0.0%	0
Talbot County	0.0%	0
Washington County	1.1%	1
Wicomico County	0.0%	0

Worcester County	0.0%	0
	answered question	**89**
	skipped question	**0**

3. Ages served: (Check all that apply.)

	Response Percent	Response Count
0-3	59.6%	53
3-5	65.2%	58
6-12	**78.7%**	**70**
12 and up	75.3%	67
	answered question	**89**
	skipped question	**0**

4. Do you provide services as a part of the IFSP/IEP process or privately?



	Response Percent	Response Count
IFSP/IEP	36.4%	32
Privately	**38.6%**	**34**
Both	25.0%	22
	answered question	**88**
	skipped question	**1**

5. How would you describe your practice? (Check all that apply.)

	Response Percent	Response Count
non-profit	**43.7%**	**38**
for profit	35.6%	31
individual service type (e.g., only speech services provided)	24.1%	21
multidisciplinary	40.2%	35
part of a hospital	14.9%	13
	Other (please specify)	10
	answered question	**87**
	skipped question	**2**

6. How large is your practice?

	Response Percent	Response Count
<5 therapy staff	30.7%	27
5-9 therapy staff	19.3%	17
10-19 therapy staff	8.0%	7
20+ therapy staff	**42.0%**	**37**
	answered question	**88**
	skipped question	**1**

7. What is the main source of your referrals? (Check just one.)

	Response Percent	Response Count
physicians	28.4%	25
word of mouth	**39.8%**	**35**
school	30.7%	27
advertising	1.1%	1
Other (please specify)		15
answered question		**88**
skipped question		**1**

8. How comfortable are you in your understanding of the distinction between habilitative services and rehabilitative services?

	Response Percent	Response Count
Very comfortable	**53.9%**	**48**
Somewhat comfortable	32.6%	29
Somewhat uncomfortable	9.0%	8
Not at all comfortable	4.5%	4
answered question		**89**
skipped question		**0**

9. How comfortable is your office staff in their understanding of the distinction between habilitative services and rehabilitative services?

	Response Percent	Response Count
Very comfortable	**36.4%**	**32**
Somewhat comfortable	35.2%	31
Somewhat uncomfortable	20.5%	18
Not at all comfortable	8.0%	7
	answered question	**88**
	skipped question	**1**

10. How comfortable are you in your understanding of the distinction between fully insured health plans and self-insured health plans?

	Response Percent	Response Count
Very comfortable	18.0%	16
Somewhat comfortable	**36.0%**	**32**
Somewhat uncomfortable	25.8%	23
Not at all comfortable	20.2%	18
	answered question	**89**
	skipped question	**0**

11. How comfortable is your office staff in their understanding of the distinction between fully insured health plans and self-insured health plans?

	Response Percent	Response Count
Very comfortable	21.7%	18
Somewhat comfortable	30.1%	25
Somewhat uncomfortable	**31.3%**	**26**
Not at all comfortable	16.9%	14
answered question		**83**
skipped question		**6**

12. Do you typically have a wait list for providing services?

	Response Percent	Response Count
Yes	39.3%	35
No	**60.7%**	**54**
answered question		**89**
skipped question		**0**

13. Do you take private insurance?

	Response Percent	Response Count
Yes	38.6%	34
No	**48.9%**	**43**
Some limited types	12.5%	11
answered question		**88**
skipped question		**1**

14. Do you take medical assistance?

	Response Percent	Response Count
Yes	**58.4%**	**52**
No	41.6%	37
answered question		**89**
skipped question		**0**

15. If you take insurance, do you, as the clinician, deal with the insurance directly or do you have administrative personnel who do?

	Response Percent	Response Count
You	28.2%	24
Staff	**71.8%**	**61**
answered question		**85**
skipped question		**4**

16. If you work within a multidisciplinary program, do you find some services easier to get covered by insurance than others?

	Response Percent	Response Count
No	**54.9%**	**45**
Yes	45.1%	37
Which service(s) is/are easier		37
answered question		**82**
skipped question		**7**

17. If you do not take insurance, why not? (Rank with "1" being the most important reason.)

	1	2	3	4	5	6	Rating Average	Rating Count
Reimbursement rate too low	32.8% (20)	**37.7%** **(23)**	6.6% (4)	4.9% (3)	13.1% (8)	4.9% (3)	2.43	61
Too much paperwork	9.8% (6)	26.2% (16)	**37.7%** **(23)**	19.7% (12)	6.6% (4)	0.0% (0)	2.87	61
Takes too much time (for insurance to process/approve/deny)	8.2% (5)	13.1% (8)	24.6% (15)	**39.3%** **(24)**	9.8% (6)	4.9% (3)	3.44	61
Don't understand enough to process insurance	3.3% (2)	11.5% (7)	9.8% (6)	19.7% (12)	**41.0%** **(25)**	14.8% (9)	4.28	61
Problems getting services covered (confusion with coding, too many denials)	14.8% (9)	11.5% (7)	**19.7%** **(12)**	14.8% (9)	**19.7%** **(12)**	**19.7%** **(12)**	3.72	61
Other	31.1% (19)	0.0% (0)	1.6% (1)	1.6% (1)	9.8% (6)	**55.7%** **(34)**	4.26	61
							answered question	**61**
							skipped question	**28**

18. Do you have any comments you wish to share about your clients' access to habilitative services benefits?

	Response Count
	36
answered question	**36**
skipped question	**53**

Q1. What is your discipline?		
1	Special Educator	Aug 29, 2013 8:14 AM
2	Mental Health	Aug 29, 2013 7:05 AM
3	Neurodevelopmental Pediatrician	Aug 28, 2013 11:25 AM
4	Art Therapist (LCPAT; LCPC)	Aug 23, 2013 5:12 PM
5	ot / slp / behavior	Aug 20, 2013 10:59 AM
6	Psychology [Psychology]	Aug 11, 2013 11:28 AM
7	Psychologist [Psychology]	Aug 9, 2013 1:45 PM
8	psychologist [Psychology]	Aug 9, 2013 1:27 PM
9	Psychology [Psychology]	Aug 9, 2013 12:10 PM
10	Social Skills, Family Support, Support Groups, Counseling, Parent Training	Aug 7, 2013 8:22 PM
11	DDA Provide, and Adult medical day care	Aug 5, 2013 9:38 AM
12	Psychology [Psychology]	Aug 3, 2013 8:02 PM
13	Music Therapy (MT-BC)	Aug 3, 2013 5:53 AM
14	MT-BC	Aug 2, 2013 3:35 PM
15	All of the above	Aug 2, 2013 11:42 AM

Q5. How would you describe your practice? (Check all that apply.)

1	hospital run special education facility	Sep 6, 2013 1:01 PM
2	school based	Aug 28, 2013 8:19 AM
3	school	Aug 28, 2013 7:53 AM
4	PT and OT	Aug 27, 2013 10:26 AM
5	part of a private separate day school	Aug 27, 2013 4:39 AM
6	Inpatient brain/spinal cord injury unit	Aug 26, 2013 1:54 PM
7	private physical therapy practice	Aug 23, 2013 2:10 AM
8	school based therapy	Aug 16, 2013 7:28 PM
9	school system	Jul 31, 2013 9:05 AM
10	school system	Jul 25, 2013 9:38 PM

Q7. What is the main source of your referrals? (Check just one.)		
1	outside hospital referrals	Aug 28, 2013 2:40 PM
2	school systems	Aug 28, 2013 6:54 AM
3	outside hospitals	Aug 27, 2013 5:01 PM
4	Transferred from previous acute care facility	Aug 26, 2013 1:54 PM
5	other rehab professionals, parents	Aug 26, 2013 12:39 PM
6	Early intervention	Aug 18, 2013 3:17 PM
7	self	Aug 17, 2013 8:33 AM
8	parents	Aug 16, 2013 4:16 PM
9	Local agencies	Aug 9, 2013 12:10 PM
10	And being listed in Directories, referals from Insurance Companies	Aug 7, 2013 8:22 PM
11	Health Department	Aug 5, 2013 9:38 AM
12	some advertising, some doctors or other providers	Aug 5, 2013 5:25 AM
13	lists from TRICARE insurance	Aug 4, 2013 9:31 AM
14	resource fairs; organizations like the ARC making referrals	Aug 2, 2013 3:35 PM
15	Parent referral	Jul 31, 2013 9:35 PM

Q16. If you work within a multidisciplinary program, do you find some services easier to get covered by insurance than others?		
1	OT is easier than Speech	Sep 3, 2013 6:33 PM
2	SLP, OT	Aug 29, 2013 5:41 PM
3	SLP, OT	Aug 28, 2013 8:11 PM
4	OT is usually easier than Speech	Aug 28, 2013 6:34 PM
5	equipment related items	Aug 28, 2013 2:40 PM
6	pt and ot	Aug 28, 2013 11:25 AM
7	physical therapy	Aug 28, 2013 8:35 AM
8	I work in a school and I am not really aware of what is covered or not covered.	Aug 28, 2013 8:19 AM
9	Speech-Language	Aug 28, 2013 6:35 AM
10	OT	Aug 28, 2013 4:54 AM
11	Depends on the policy	Aug 27, 2013 5:01 PM
12	It depends on the insurance. The largest limiting factor is the limit in visits per year, or the excessive paperwork to submit for pre-authorization of visits.	Aug 27, 2013 10:26 AM
13	not able to answer this question, don't know	Aug 27, 2013 4:39 AM
14	OT/PT	Aug 26, 2013 1:54 PM
15	Physical therapy	Aug 23, 2013 2:10 AM
16	behavior	Aug 20, 2013 10:59 AM
17	PT, OT, speech	Aug 19, 2013 8:14 AM
18	PT is covered bettern then OT and Speech services	Aug 18, 2013 10:04 AM
19	IFSP does not bill insurance unless child has MA	Aug 16, 2013 4:16 PM
20	PT speech	Aug 16, 2013 8:36 AM
21	SLP	Aug 9, 2013 4:50 PM
22	specialty tx	Aug 9, 2013 1:27 PM
23	Not applicable to my practice as a solo practitioner.	Aug 9, 2013 12:10 PM
24	Counseling, Parent Coaching, Speech, OT,	Aug 7, 2013 8:22 PM
25	Do not work with a multidisciplinary tearm.	Aug 7, 2013 6:15 PM
26	Physical therapy and occupational therapy	Aug 7, 2013 7:52 AM

Q16. If you work within a multidisciplinary program, do you find some services easier to get covered by insurance than others?		
27	We only do ABA	Aug 7, 2013 3:26 AM
28	It is difficult to get PT or OT services covered for individuals over 18 even if they are needed to keep muscle tone or skills that are essential to continue movement or activities that helps the individual care for themselves.	Aug 5, 2013 9:38 AM
29	PT, then OT. SLP is very difficult	Aug 5, 2013 5:25 AM
30	Not applicable	Aug 5, 2013 3:55 AM
31	n/a	Aug 4, 2013 9:31 AM
32	Not working in a multidiscipline program	Aug 3, 2013 5:53 AM
33	Any service besides behavior	Aug 2, 2013 11:43 AM
34	i do not deal with coverage, as i am a school system employee and office staff submits for medicaid reimbursement. i only submit documentation for those kids with MA.	Jul 31, 2013 9:05 AM
35	n/a	Jul 25, 2013 9:38 PM
36	usually OT and PT over speech	Jul 25, 2013 3:04 PM
37	We only have SLPs at this time	Jul 16, 2013 6:40 PM

Q18. Do you have any comments you wish to share about your clients' access to habilitative services benefits?		
1	work in a school, very little contact with the insurance end of things	Sep 6, 2013 1:01 PM
2	As a private practitioner/owner of a private practice, I have researched extensively and find it difficulty to find any information regarding habilitative services and any laws pertaining to them. I believe that I understand it well but it is difficult to advocate for the clients, when I can not get clear answers myself.	Sep 3, 2013 6:33 PM
3	Recently we received 3 separate denials for OT services. We have never had denials. I was told by a reviewer that the child needed to have a disease like cancer or a diagnosis of Autism or Down Syndrome to get habilitation coverage. Yet in the past, if the child had a complicated birth or delivery or if they an involved earlier medical history - a diagnosis of idiopathic hypotonia would be covered.	Aug 28, 2013 6:34 PM
4	Over the past year many client's have been denied OT service because they are not covering OT for habilitative service; more than 50% of our referrals are for habilitative service. Often we are able to do the initial evaluation but unable to follow up with the treatment plan. The child often does not qualify for school based service so they are "at risk" for falling between the cracks. There is so much variability between insurance's that the clinician's rely on the office care management staff to provide updated/ regular information.	Aug 28, 2013 8:35 AM
5	I think it is important for students to receive related services in the school setting that will also help maintain skills and or use of compensatory strategies to assist with accessing their education. OT Service needs may change over time.	Aug 28, 2013 8:19 AM
6	Long term care is essential clients with chronic diagnoses. Ongoing therapy services are more cost effective and more efficient than needing surgical interventions and expensive equipment due to structural deficits due to limited therapy services.	Aug 27, 2013 5:01 PM
7	Access to habilitative benefits is very important to children with disabilities. The school system does a great job but cannot replace or provide all of the much needed medical care, particularly with PT and OT. The reimburse rate of insurances is very low and is a huge problem today for all PT and OT departments. The low reimbursement is causing private practices to be forced to stop taking insurance in the near future if they want to keep a viable business model. In addition, the excessive paperwork and time for insurance to process claims adds cost to running a business. If the access to the habilitative benefits could be streamlined to reduce paperwork, improve efficiency of payment and increase reimbursement it would be the best scenario to ensure patients with habilitative benefits get the medical care they need.	Aug 27, 2013 10:26 AM
8	We have a strong history of educating our families about the habilitative law; we work closely with the insurances and when we cannot get the insurance company to cooperate with the habilitative law,we have turned to the Insurance Commissioner of Health in Maryland. WE have learned how well the insurance companies respond to the inquires by the Insurance Commissioner. We have had several successes by appealing to the Insurance Commissioner's office for assistance when the insurances have denied us.	Aug 23, 2013 2:10 AM
9	When we call for coverage we are often unsure and do not receive clarity regarding a clients' coverage under habilitative services.	Aug 20, 2013 10:59 AM

Q18. Do you have any comments you wish to share about your clients' access to habilitative services benefits?		
10	I feel some families are not educated properly regarding what services are aviliable to their child that are covered by insurance. They do not understand habilitative service benefits.	Aug 18, 2013 10:04 AM
11	Education system does not bill for private insurance.	Aug 17, 2013 8:33 AM
12	Transportation is a huge part of pt/family's ability to participate in services (clinic based ones, Balt city) Also, if the frequency of sessions is too small to make an impact families get frustrated with the lack of progress and may become disengaged. This is especially a problem for families with few resources to carry out a home program effectively if only seen infrequently (1x or less per week) by the therapist.	Aug 16, 2013 10:49 AM
13	My clients are receiving good services because they have the ability to pay - either out of pocket or by submitting claims for partial insurance reimbursement. Potential clients that do not have either these resources or the know-how to access these resources often do not receive important physical therapist services that they should have throughout their life span. I have on occasion seen some kids pro bono, but it is rare for these families to request services. If families, in general, had better access to regular habilitative care, then their children would be significantly better able to access society and be as independent as possible throughout all phases of their lives, with fewer complications later in life, less pain, less overall disability and less loss of function with increasing age and changing lifestyles. All of these issues are costly, both financially and personally. If they can be avoided or lessened with proper habilitative care, then everyone benefits. The cost of habilitative care (for all involved specialty services) over a child's life can be substantial, as I am sure you are aware, and bringing the personal financial cost down and the availability up for all people should be a basic right. Society benefits when specialists such as physical therapists are firmly and committedly involved in the habilitative care of people born with such needs. PS Questions 15 and 16 "require an answer" to complete this survey, but they may not apply to a particular survey taker, so it might be better to make them optional questions for people to whom they apply! Same with 9 and 11; someone may not have office staff	Aug 16, 2013 8:36 AM
14	For children and teens with autism spectrum disorders it is absolutely critical that they are able to access habilitative services in order to progress.	Aug 9, 2013 1:45 PM
15	Access to all services is piss poor and habilitative services are among the most difficult. I maintain a practice that provides access to excellent mental health services for people who live in poverty and that means that I am penalized financially. But, when I provide services to someone who needs basic habilitative services, it gets extraordinarily difficult.	Aug 9, 2013 12:10 PM
16	#17 wouldn't let me NOT answer. We DO take insurance.	Aug 7, 2013 8:22 PM
17	Due to the challenges of understanding the various insurance plans, the frequent omissions for need for referrals when verifying insurance on individuals with habilitative services, the changes regarding acceptable treatment codes thereby limiting coverage, and the errors in coding paper claims resulting in the need to resubmit, we are reducing insurance participating and shifting to private pay with claim forms given to clients for their submission. In addition, the definition for habilitative vs rehabilitative services seems to vary with some insurance	Aug 7, 2013 6:15 PM

	companies using a narrow interpretation of the definition and others using a broader interpretation. As a result, multiple children with need are not covered for services, families cannot pay for the occupational therapy services, and schools do not offer OT services since the child's problems do not match the academic definition. It would seem that if families are paying for insurance that includes an OT benefit, then the benefit should be available without all of the exceptions.	
18	Coverage for habilitative speech language services seems less frequent than coverage for physical and occupational therapy. The rates of reimbursement for speexch language services, when covered, makes accepting insurance virtually impossible.	Aug 7, 2013 7:52 AM
19	The information how how to get services should be easy for clients to access.	Aug 7, 2013 3:26 AM
20	It is very difficult to get insurance to pay for habilitative services for Adults.It would especially be helpful to some individuals who could gain employment if they had access to OT or PT keep specific needed skills after they have been initially developed.	Aug 5, 2013 9:38 AM
21	There are qualified providers out there who can not get the referrals to provide services due to low reimbursement, not being "in network" etc while the providers that are in network (primarily the big hospitals because they can get better rates or make up for the low rates elsewhere) have ridiculous wait lists. It is very frustrating for providers but even more so for families!	Aug 5, 2013 5:25 AM
22	About half the client calls I recieve are unable to get therapy unless the practice takes insurance. Unfortunately the insurance companies make it so difficult to get paid, I can't afford to take it.	Aug 5, 2013 3:55 AM
23	It is extremely sad that there is such a discrepency between the amount of coverage for ABA services for clients under the TRICARE insurance program compared to everyone else. Children with Autism need ongoing intervention throughout their childhood years to develop language, prevent the development of challenging behavior, address behavior challenges, address social anxiety and independence skills, and learn how to cope with their disability. I am constantly having to turn away potential clients because there is no insurance coverage for ABA services in Maryland and almost no other funding options for them to access. Most of our clients rely entirely on the LISS funds they are able to get or pay out of pocket for our services. This is so out of line with all of the surrounding states and many, many other states in the USA. I don't understand why Maryland, a state with some of the weathiest counties in the nation, has not been able to pass the necessary legislation to ensure that all children with Autism Spectrum Disorders are able to access the evidenced-based interventions that can make such a profound difference to them and their families and can prevent the very expensive to treat behavior challenges that can come about from years without access to the therapeutic services they need. Please act to make a change and improve the lives of people with Autism Spectrum Disorders and their families in Maryland. Having to wait 6-7 years for a funded place on the Autism Waiver program is completely unacceptable. The Autism Waiver program should be there to catch the kids without the insurance coverage and to top up services where insurance doesn't pay.	Aug 4, 2013 9:31 AM

Q18. Do you have any comments you wish to share about your clients' access to habilitative services benefits?		
24	Unless paid for privately, access to music therapy for habilitative services is severely limited!	Aug 3, 2013 5:53 AM
25	It has been hard for clients to continue their progress when funding has been short. We are exploring insurance reimbursement, but haven't yet tried to bill an insurance company. I've avoided it until now because I was worried about the headaches that it may cause in the end, however I would like services to be more accessible to families.	Aug 2, 2013 3:35 PM
26	Insurance companies and the physcians on their staff deny habilitative services even when it is a documented case of habilitatiion and I have submitted documentation and research findings, etc. It is insane trying to get speech-lanugage therapy services covered in this state! I tell parents I will help them fight but I just can't accept insurance. I would have been out of bussiness my first year in private practice!	Aug 2, 2013 11:59 AM
27	Maryland based plans do not have coverage for ABA. Fully-insured plans in VA do, as do medicaid plans in DC. But I usually just tell MD families that they are out of luck, even if that's what the doctor prescribed.	Aug 2, 2013 11:46 AM
28	Access to behavior services is extremely limited.	Aug 2, 2013 11:43 AM
29	I did not intend to respond to question 17, but could not complete the survey without a response to that question.	Aug 1, 2013 6:31 AM
30	II may be looking into doing some private work, and will be interested in the results of this study.	Jul 31, 2013 9:35 PM
31	would like clear guidelines on acceptable diagnostic codes and treatment codes for specific diagnosis.	Jul 31, 2013 7:54 PM
32	see comment for question 16, above	Jul 31, 2013 9:05 AM
33	Our clients submit insurance paperwork, we do not submit for them. But often we are involved in the process as they need information (ie number of sessions, duration, progress) from therapists.	Jul 26, 2013 3:08 AM
34	We have had 3 denials for outpatient occupational therapy services for children recently, back to back, after not having received any denials in years. Two were from Care First BlueCross BlueShield of Maryland. When I spoke with the medical reviewer he stated that the child must have a disease like Cancer, Down Syndrome or Autism. I explained that the mother was exposed to Fifth's Disease in the first trimester, it was a complicated birth and the child had craniostenosis. Further, I explained that I was treating his Hypotonia and Sensory Processing issues but that was not good enough. The child's services are not being covered by their health insurance plan.	Jul 25, 2013 3:04 PM
35	I work for a school system. Sometimes students need additional medical based services and cannot obtain them in a timely manner. It has been reported to me by parents that it can take 3-6 months to get a therapy appointment at National Children's Hospital in DC. Children and their families are not being served well.	Jul 24, 2013 1:31 PM
36	The BCBS definition of habilitative vs rehabilitative is different than the therapy	Jul 16, 2013 6:40 PM

Q18. Do you have any comments you wish to share about your clients' access to habilitative services benefits?

definition. Insurance defines had as a congenital disorder, such as autism, CP, genetic syndromes, etc. Insurance defines rehab as everything else--stuttering, apraxia, other speech impaired, swallowing, etc. We accept BCBS insurance only. The reimbursement rates for 92507 (speech-language) is much lower in MD than in any of the surrounding states! Even though. We take insurance, I would agree that: the rates are too low, there is too much documentation & paperwork to do, & that BCBS is not consistent in their approval or denial of services (some are approved, then the next session may be denied). The reimbursement rates for speech & swallowing CPT codes are not appropriate w/the level of care delivered, the documentation needed, and the layers of administrative time needed for paperwork and follow up w/denied or unpaid claims.

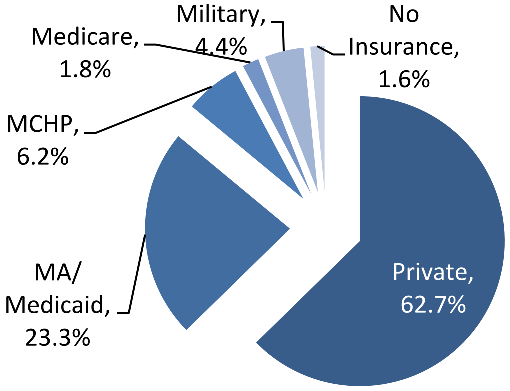
Appendix 3

What Isn't Covered Adequately Under Private Insurance for Maryland CYSHCN?
2010 MARYLAND PARENT SURVEY

Statewide Characteristics of Responding Families and their Children and Youth with Special Health Care Needs (CYSHCN)[i]

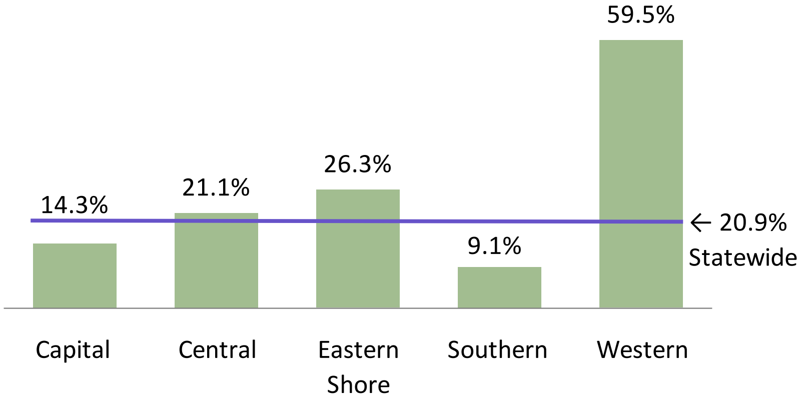
772 families with at least one CYSHCN (representing 1040 children) responded to the survey statewide.

Type of health insurance of responding families' children (n= 1,040 children*)



**some children have more than one type of health insurance*

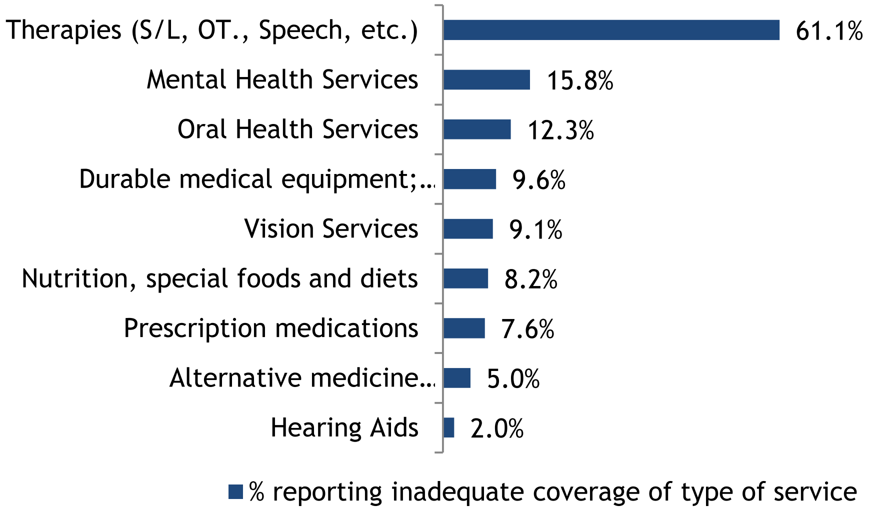
Percent of Families with at Least One CYSHCN at or Below 185 FPL (n = 772 families)



Some health services are not adequately covered for Maryland CYSHCN under private health insurance:

Of the 772 responding families with at least one CYSHCN, 44.3% (342 families) reported that, among CYSHCN with private health insurance, insurance did not pay for all needed health care services.

Health Services not adequately covered by private insurance for Maryland CYSHCN (n =342):

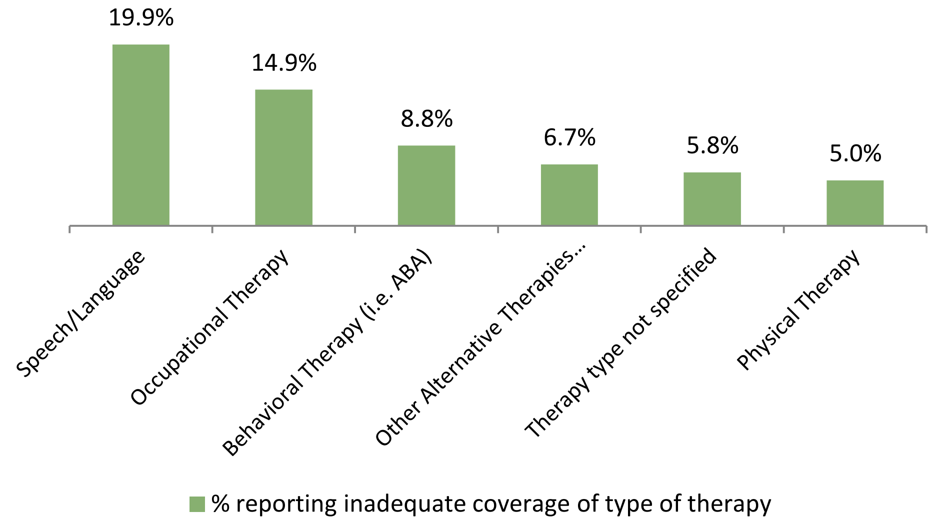


What Isn’t Covered Adequately Under Private Insurance for Maryland CYSHCN?
2010 MARYLAND PARENT SURVEY

Therapies are not adequately covered

When asked what services private health insurance wasn’t paying for, 61.1 % of families indicated some type of habilitative therapy. The majority of families who indicated what type of therapy their CYSHCN needed but was not receiving any or enough of was speech/language (almost 20%), followed by occupational (almost 15%), and behavioral (8.8%).

Types of therapies not adequately covered by private insurance for Maryland CYSHCN



What families are saying about private insurance coverage for therapies:

Many families reported that private insurance coverage for CYSHCN covered limited numbers of visits and/or only partial payments for approved therapies like speech/language, occupational, and physical therapies. Families also reported problems accessing therapy providers for their CYSHCN because the providers located in their area do not accept their child’s insurance. Below are direct quotes from families who took the survey:

“Most therapies are provided by small groups or individuals who cannot afford to accept private insurance. Speech and PT have to be paid 100% out of pocket.”

“We’ve had so many insurance submission hassles, they keep automatically rejecting claims and ask for a thorough review each time a claim is submitted, so I JUST STOPPED SUBMITTING THEM.”

“Many therapists in my area are not in my health network or don't specialize with autistic patients.”

“HMO - it will cover OT & Speech, but we could not find in network providers, so that's all been out of pocket. ABA was all out of pocket.”

“[Insurance does not cover] enough speech OT, PT; only pays for 20 visits annually - my child needs 2 speech sessions and one OT session per week.”

“It only pays one quarter to one third of OT expenses and the cut off is 30 visits. It is similar for speech therapy. It only pays for one hour of ABA per session that can be 2-3 hours and it only pays about one quarter of the cost.”

“It does not pay for ABA therapy. It only pays a miniscule amount of speech therapy and occupational therapy. On average, it pays only 1/3 of our costs for these therapies.”

“I only get 15 therapy sessions a year. 15 total - for ot/pt/speech. He is supposed to get 2 sessions of ot a week and one of speech. That gets me about 1 month of what he needs for the year.”

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i 2010 Maryland Parent Survey. The Parents’ Place of Maryland and the Maryland Office for Genetics and People with Special Health Care Needs, Maryland Department of Health and Mental Hygiene. Baltimore, MD

Appendix 4a

Parents' Guide to Habilitative Services

2013

This guide was developed by the Workgroup on Access to Habilitative Services Benefits, which was established through legislation passed by the 2012 Maryland General Assembly.

PARENTS' GUIDE TO HABILITATIVE SERVICES

- **What are habilitative services?**

Habilitative services are therapeutic services that are provided to children with genetic conditions or conditions present from birth to enhance the child's ability to function. Habilitative services are similar to rehabilitative services that are provided to adults or children who acquire a condition later on. The difference is that rehabilitative services are geared toward reacquiring a skill that has been lost or impaired, while habilitative services are provided to help acquire a skill in the first place, such as walking or talking.

Habilitative services include but are not limited to physical therapy, occupational therapy and speech therapy for the treatment of a child with a congenital or genetic birth defect.

- **May insurance companies or HMOs limit the number of habilitative services they will cover?**

Under Maryland law, insurance companies and HMOs may not limit coverage for medically necessary habilitative services. In contrast, insurance companies and HMOs may, and often do, limit coverage for rehabilitative services to 30 or 60 visits per year, for example.

- **Are insurance companies or HMOs required to cover habilitative services?**

It depends on the type of health plan you have. Health plans subject to Maryland insurance laws include:

- A health plan that you purchased in Maryland from an insurance company or an HMO; or
- A health plan that your employer purchased in Maryland.

If you are not sure whether your health plan covers habilitative services, contact your health plan or the benefits plan manager through your employer to find out. Ask them to send you a copy of those pages listing the services and benefits for habilitative services.

- **What health plans are <u>not</u> required by Maryland law to cover habilitative services?**

Group policies issued to the group's home office in another state. For example, if you work for an employer that has its home office in another state, your health insurance policy may have been issued in that other state.

The federal government's employee health benefit plans.

This guide was developed by the Workgroup on Access to Habilitative Services Benefits, which was established through legislation passed by the 2012 Maryland General Assembly.

Employer self-funded and self-insured plans. In this case, the employer may be using an insurance company to process the claims of the employees, but using the employer's funds to self-insure.

Medicare or Medicaid (Maryland Medical Assistance Program and Maryland's Children's Health Insurance Program).

**Even if it your health plan is not subject to Maryland law, your health plan could contain habilitative service benefits.*

Contact your insurance company or HMO and ask what the covered benefits for habilitative services are. If the customer service representative is not helpful, ask to speak to a supervisor. You also may contact the benefits plan manager through your employer to find out if your specific health plan includes coverage for habilitative services. Ask for a copy of those pages listing the services and benefits for habilitative services.

- **Would my child qualify for habilitative service benefits under my health insurance or HMO health plan?**

Under Maryland law, if your child has a congenital or genetic birth defect, he or she qualifies for habilitative services under your health insurance or HMO contract, if the services are medically necessary. "Congenital or genetic birth defect" means a defect existing at or from birth, including a hereditary defect. "Congenital or genetic birth defect" includes, but is not limited to:

- Autism or autism spectrum disorder;
- Cerebral palsy;
- Intellectual disability;
- Down syndrome;
- Spina bifida;
- Hydroencephalocele; and
- Congenital or genetic developmental disabilities.

- **My child receives services through an early intervention program or at school but I think my child needs more services. What should I do?**

Contact your child's pediatrician, family practitioner, internist (for older children), nurse practitioner, physician assistant, or other primary health care provider. He or she can examine your child and assess your child's needs, or refer your child to an appropriate specialist for further assessment. You also may choose to call private therapy providers directly, but you may be responsible to pay for their services if they are not part of your health plan's network or their services have not been approved by your health plan.

- **Not all of my child's special needs are being addressed through the educational system because they do not affect my child's educational outcome. What should I do?**

Some children need more services to address non-educational needs. For example, your child may need additional therapy to help with social interactions or other functions that do not interfere with accessing the educational curriculum. Contact your health insurer or HMO to determine its process for covering habilitative services. If a referral or other documentation is required, then contact your child's pediatrician, family practitioner, internist (for older children), nurse practitioner, physician assistant, or other primary health care provider. You also may choose to call private therapy providers directly, but you may be responsible to pay for their services if they are not part of your health plan's network or their services have not been approved by your health plan.

If your child's medical condition qualifies him or her for habilitative services coverage, make sure your health care provider and your insurance company or HMO have this information.

- **What is a "case manager"?**

A "case manager" is a person that works for your insurer or HMO who can help you coordinate comprehensive services for your child. The goal of case management for a child is that the child will receive the appropriate services and have the opportunity to function at his or her optimum level.

- **Is there any age limit to receiving covered benefits for habilitative services?**

Under Maryland law, insurers and HMOs are required to pay benefits for habilitative services until your child turns age 19. Check your policy to see if it provides benefits beyond this age.

- **My child has a congenital or genetic birth defect, but my health insurance company has denied or limited coverage. What should I do?**

First, contact your health plan. These services may or may not be covered by your policy. If you feel that the customer service representative does not understand your request or question, ask for a supervisor. If your child's medical condition qualifies him or her for habilitative services coverage, make sure your health care provider and your insurance company or HMO have this information.

If your health care provider tells you that a certain health care service is needed, but your health insurer or HMO disagrees, you have the right to appeal that decision and have it reviewed by an independent medical expert. Here's how the process works:

Step 1: You will receive a letter from your health insurer or HMO notifying you of its decision.

Step 2: Follow the instructions in the first denial letter you receive from your health insurer or HMO to ask your health insurer or HMO to reconsider its decision. If you would like some help, contact the Health Education and Advocacy Unit in the Attorney General's Office at 877-261-8807 for assistance. Your health care provider, or someone else you authorize to help you, also can do this for you.

Step 3: If your health insurer or HMO upholds its original decision to deny payment for the health care service, you may have your case reviewed by an independent medical expert, who will decide if the health care service your health care provider recommended is medically necessary. The Health Education and Advocacy Unit can help you with this too.

Step 4: If your health plan is subject to Maryland insurance laws (see question 3), you may file a complaint with the Maryland Insurance Administration (MIA). The MIA will send your case to an independent medical expert. Once the independent medical expert has rendered an opinion, the MIA will send you a copy of that opinion. If your health plan is not subject to Maryland insurance laws (see question 4), the MIA will be unable to process your complaint. However, your health insurer or HMO will send your case to an independent medical expert.

The letter from your health insurer or HMO will tell you if you can file a complaint with the Maryland Insurance Administration. There are time limits for filing a complaint, so please read the letter carefully.

You may skip to Step 4 and file a complaint directly with the Maryland Insurance Administration before receiving the health insurer's or HMO's decision if the health insurer or HMO waives its requirement that you first appeal to it; if the health insurer or HMO does not follow any part of its internal appeal process; or if you show a compelling reason, such as showing that a delay could result in death, serious impairment to a bodily function, serious dysfunction of a bodily organ, or could cause your child to be a threat to her/himself or others.

Step 5: If the independent medical expert finds the health care service recommended by your health care provider is medically necessary, the Insurance Commissioner, after considering all the facts of your case, may order your health insurer or HMO to pay for the health care service in accordance with your policy.

You have the right to appeal other coverage decisions made by your health insurer or HMO but those appeals may not necessarily be reviewed by an independent medical expert.

How to File a Complaint with the Maryland Insurance Administration:

Complaints must be received in writing and include a signed consent form. Contact the MIA to learn how to submit a complaint at:

Maryland Insurance Administration
Attn: Consumer Complaint Investigation
Life and Health/Appeals and Grievance
200 St. Paul Place, Suite 2700
Baltimore, MD 21202
Telephone: 410-468-2000 or 800-492-6116
TTY: 1-800-735-2258
Fax: 410-468-2270 or 410-468-2260 (Life and Health/Appeals and Grievance)
Or visit the website at **http://www.mdinsurance.state.md.us**.

How to Contact the Health Education and Advocacy Unit:

Office of the Attorney General
Health Education and Advocacy Unit
200 St. Paul Place, 16th Floor
Baltimore, MD 21202
Telephone: 410-528-1840 or 877-261-8807
Fax: 410-576-6571
Or visit the website at
www.oag.state.md.us/consumer/heau.htm

This information is also available at:
http://www.mdinsurance.state.md.us/sa/docs/documents/consumer/publicnew/agprocesscard.pdf

This guide was developed by the Workgroup on Access to Habilitative Services Benefits, which was established through legislation passed by the 2012 Maryland General Assembly.

Appendix 4b

QUESTIONS TO ASK YOUR HEALTH INSURANCE COMPANY OR HMO ABOUT YOUR CHILD'S ACCESS TO <u>HABILITATIVE SERVICES</u> BENEFITS

Before you call your insurance company or HMO, please refer to the "Parents' Guide to Habilitative Services." This guide is available at **http://www.mdinsurance.state.md.us**.

1. My child needs physical therapy and/or occupational therapy and/or speech therapy. Are these services covered under my plan?

2. Do I have coverage for habilitative service benefits under my plan?

3. Are there any limitations on habilitative services coverage under my plan? If so, what are they?

4. Are there any exclusions from coverage under my habilitative services benefit? If so what are they?

5. What cost-sharing will be applied to habilitative services for my child?
   Deductible__________________
   Copayment amounts_________________
   Coinsurance______________

6. Does my deductible apply to each calendar year or to a benefit year? If it applies to a benefit year, when does the benefit year begin and end?

7. Do I need a referral? If so, how do I get one?

8. Do I need prior authorization? If so, how do I get prior authorization?

9. Do I have better benefits if I use in-network providers? If so, who are the in-network providers in my area?

10. I think I need more information; may I please speak with a supervisor? *(as needed)*

Appendix 5a

MHCC
MARYLAND
HEALTH CARE
COMMISSION

Required Under Section 15-1501 of the Insurance Article

Annual Mandated Health Insurance Services Evaluation

December 20, 2007

Marilyn Moon, Ph.D.
Chair

Rex W. Cowdry, M.D.
Executive Director

Insurance Article, § 15-1501, Annotated Code of Maryland, requires that the Commission annually assess the medical, social and financial impacts of a proposed mandated health insurance service that fails passage during the preceding legislative session or that is submitted to the MHCC by a Legislator by July 1st of each year. The report is due to the General Assembly annually by December 31st. In 2007, one proposed mandate required such analysis: coverage of habilitative services, regardless of age.

Mercer, the Commission's consulting actuary, has prepared the following evaluation of the proposed mandate on coverage of habilitative services.

As presented, HB 1192/SB 944 (2007) would have required a health insurer, nonprofit health service plan, Medicaid managed care organization, or HMO (further referred to as a "carrier") to provide coverage for habilitative services for persons of all ages who suffered "congenital or genetic birth defects" including but not limited to autism spectrum disorder (ASD) or cerebral palsy (CP). Guidance from the Maryland Department of Legislative Services (DLS) indicated that the intent of this proposed mandate was *to limit services to individuals who suffered developmental disabilities resulting from these conditions*. As defined in the proposed legislation, habilitative services are occupational, physical and speech therapy (OT, PT and ST) treatments that enhance the functioning ability of a person with the prescribed conditions. Mercer used this interpretation and definition for its analysis. If, for any reason, either the parameters for the services to be provided or the population to whom these services would be extended is significantly different from that assumed, these estimates would not be appropriate.

The state of Maryland currently mandates coverage of these services for children who are developmentally disabled by birth defects, ASD or CP through the age of 18 years. This proposed mandate would extend coverage to affected persons between 19 and 64 years of age.

A discussion of the medical, social and financial impacts of this proposal follows.

MEDICAL IMPACT

- ***To what extent is the service generally recognized by the medical community as being effective and efficacious in the treatment of patients?***

Both the American Occupational Therapy Association (AOTA) and the American Speech-Language Hearing Association (ASHA) have position statements and practice guidelines endorsing their therapies for the target population.

AOTA's 2005 "Statement: The Scope of Occupational Therapy Services for Individuals with Autism Spectrum Disorders Across the Lifespan" addresses the value of the association's therapies for both children and adults with ASD:

> "Occupational therapy intervention helps individuals with autism develop or improve appropriate social, play, learning, community mobility, and vocational skills. The occupational therapy practitioner aids the individual in achieving and maintaining normal daily tasks such as getting dressed, engaging in social interactions, completing school activities, and working or playing."[1]

A 2005 feature article from AOTA's publication *OTPractice Online* advocates the role of OT for adults with developmental disabilities. It discusses specific ways OT can enhance employment, residential living and quality-of-life issues for adults with developmental disabilities.[2]

ASHA's 2005 "Principles for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span" states:

> "The broad-based challenges in social communication experienced by individuals with ASD and their families may make them eligible to receive the services of a qualified speech-language pathologist regardless of intellectual status, age, or presumed prerequisites."[3]

Similarly, ASHA's 2005 "Principles for Speech-Language Pathologists Serving Persons with Mental Retardation/Developmental Disabilities" recommends ST to meet the special communication needs of adults with developmental disabilities. It notes the importance of developing and nurturing the socialization skills of this adult population for improved quality of life.[4]

Although the American Physical Therapy Association (APTA) does not offer any position statements or policy guidelines regarding the treatment of developmentally disabled adults, these individuals are included in its Physical Fitness for Special Populations (PFSP) program. This recently developed program targets individuals with acute and chronic impairments, functional limitations, and disabilities related to movement, function, and health. PFSP encourages physical therapists to work closely with these individuals to improve their physical fitness and their access to traditional and non-traditional programs and venues promoting their fitness, as described below.

> "Physical therapy positively influences an individual's overall health, wellness, and fitness by providing services that positively impact physical fitness.

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[1] American Occupational Therapy Association, "Statement: The Scope of Occupational Therapy Services for Individuals with Autism Spectrum Disorders Across the Lifespan," *American Journal of Occupational Therapy,* (2005): 59, 680-683.

[2] Laura Vogtle and Bethany Brooks, "Common Issues for Adults with DD," *OTPractice Online*, http://www.aota.org/Pubs/OTP/Features/2005/f-090505.aspx.

[3] American Speech-Language Hearing Association, "Principles for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span," (2006) http://www.asha.org/docs/html/TR2006-00143.html#sec1.5.

[4] American Speech-Language Hearing Association, "Principles for Speech-Language Pathologists Serving Persons with Mental Retardation/Developmental Disabilities," (2005) http://www.asha.org/docs/html/TR2005-00144.html#sec1.2.

> Improving an individual's level of physical fitness can prevent, remediate, improve, maintain, slow the decline of, or lower the risk of impairments, functional limitations, and disabilities. Physical therapy services that impact physical fitness include: interventions that affect cardiovascular/pulmonary endurance; muscle strength, power, endurance and flexibility; relaxation; and body composition."[5]

In May 2006, APTA delivered public comments to the federal Medicaid Commission reiterating the role of physical therapists to "prevent, diagnose, and treat movement dysfunction and enhance the physical health and functional abilities of individuals in all age populations … [and] with disabilities."[6]

- ***To what extent is the service generally recognized by the medical community as demonstrated by a review of scientific and peer review literature?***

In the last 10 to 15 years, the benefits of OT, PT and ST for child populations that are affected by developmentally disabling birth defects, ASD and CP have been investigated quite thoroughly; however, the benefits for like adult populations have been researched significantly less. Mercer was unable to find any recent, large-scale studies supporting or disproving the effectiveness of these therapies to improve functional ability in developmentally disabled adults. However, there are some smaller-scale studies, case studies and anecdotal evidence that support therapeutic benefits and suggest the need for expanded research with adult populations.

A 1993 study published in the *American Journal of Mental Retardation* examined the effect of independent living training on 1,498 developmentally disabled adults living in their own homes. The study found that, by the end of the seven-year study period, individuals who had received greater amounts of independent living services and had improved or maintained their independent living skills were more likely to still live independently. However, there was no significant relation between the receipt of such services and the probability of improving or maintaining one's skills.[7]

A 2004 study by the American Association on Mental Retardation examined the effect of introducing a physical activity project into a day habilitation setting for a group of 12 older adults with intellectual disability and a variety of physical and behavioral conditions. Their findings indicated that, after 12 weeks, 92% of the participants had experienced improvement in at least one domain of physical function. Many participants

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[5] American Physical Therapy Association, "Physical Fitness for Special Populations," (2007) http://www.apta.org/AM/Template.cfm?Section=Physical_Fitness_for_Special_Populations1&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=267&ContentID=30270.

[6] American Physical Therapy Association, "Public Comments before the Medicaid Commission," (May 2006). *http://www.apta.org/AM/Template.cfm?Section=Medicaid_Resource_Center&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=30994*

[7] B Lozano, "Independent Living: Relation among Training, Skills, and Success," *American Journal of Mental Retardation*, 1993 Sep: 98(2): 249-62.

sustained functional gains one year after habilitation staff assumed responsibility for sessions.[8]

Although there are many studies and articles about the positive outcomes of the various therapies, the studies and articles do not access the cost of these therapies nor the cost benefit that results.

- ***To what extent is the service generally available and utilized by treating physicians?***

Data that track the use of these services by treating physicians for the target population were not available. The limited number of published studies and the limited amount of scientific literature indicate that some physicians are using these treatments for developmentally disabled adults, but it is not widespread.

Efforts to use data from the Maryland Medicaid program as a proxy proved problematic because claims data focus on the primary diagnosis being treated, not any underlying conditions that may have been present at birth. Therefore, a search of the claims data by diagnosis would yield a very modest return, especially for services rendered to adults. There is no clear identifier or reasonable proxy for sorting the Medicaid claims data.

SOCIAL IMPACT

- ***To what extent is the service generally utilized by a significant portion of the population?***

While there are multiple sources for national and state disability statistics, developmental disabilities as a subset seem to be less extensively tracked. The best source for estimating developmentally disabled populations by age appears to be the 1994 to 1995 Disability Supplement to the National Health Interview Survey (NHIS-D), which gathered specific information about civilian and non-institutionalized individuals with mental retardation and/or developmental disabilities (MR/DD). It is estimated that those with MR/DD account for 0.9% of the adult population between the ages of 17 and 64.[9] Of the *total* population (including children under the age of 17), it is estimated that those who have MR/DD and are between the ages of 17 and 64 account for 0.6% of the population.[10]

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[8] Carol Podgorski et al., "Physical Activity Intervention for Older Adults with Intellectual Disability: Report on a Pilot Project," *Mental Retardation*: Vol. 42, No. 4, 272–283, http://aaidd.allenpress.com/aamronline/?request=get-abstract&doi=10.1352%2F0047-6765(2004)42%3C272:PAIFOA%3E2.0.CO%3B2.

[9] Sheryl Larson, Ph.D. et al., "Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or With Family Members: NHIS-D Analysis," *MR/DD Data Brief*, Research and Training Center on Community Living and Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota (June 2001), http://rtc.umn.edu/docs/dddb3-2.pdf.

[10] See footnote 17.

Although it tracks developmental disability in children, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), initiated by the Centers for Disease Control and Prevention (CDC) in 1984, is widely referenced as the best and most current source for prevalence rates. Its most recent prevalence rates from 1994 (for mental retardation and CP) and 1996 (for ASD) are shown in the following table:[11]

Developmental Disability	Prevalence Rate per 1,000 Children
Mental Retardation	9.7
Cerebral Palsy	2.8
Autism	3.4
Total	15.9 (or 1.6%)

The National Institutes of Health suggests using a prevalence rate of 0.50% for autism which means that, at any one time, 0.50% of the population could be diagnosed with autism.[12] The Association for Science in Autism Treatment states that ASD may occur in as many as one in 160 people, or at a rate of 0.625%.[13]

Estimates for the prevalence rate of cerebral palsy vary from a low of 0.15% to a high of 0.3%.[14]

The CDC estimates the prevalence of mental retardation at 1.2%.

Combining all of these sources, we generate a range of prevalence for mental retardation, cerebral palsy and autism ranging from 1.25% to 2.125%.

Considering these sources, Mercer estimates the prevalence of developmentally disabling birth defects, ASD and CP among people age 19 to 64 to be between 1% and 2%. Due to the low prevalence rates, it can be presumed that only a small portion of the population generally uses these services.

- ***To what extent is insurance coverage already generally available?***

The extent to which insurance coverage is available depends somewhat on the inclusion of the word “habilitative” in the legislation. For most private insurers, “habilitative” refers to the development of age-appropriate skills that were never present due to genetic

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[11] National Center on Birth Defects and Developmental Disabilities, “Metropolitan Atlanta Developmental Disabilities Surveillance Program: Prevalence Rates,” (October 2004), http://www.cdc.gov/ncbddd/dd/maddsp.htm#prev.

[12] Jacobson, John W. Ph.D., “Is Autism on the Rise?” originally published in *Science in Autism Treatment*, Vol. 2, No. 1, Spring 2002, available on Association for Science in Autism. *http://www.asatonline.org/about_autism/ontherise.html*, Accessed November 2007.

[13] *About Autism: Defining Autism Spectrum Disorder.* Association for Science in Autism Treatment. *http://www.asatonline.org/about_autism/about_autism.html*, Accessed October 2007.

[14] Low estimate:“Cerebral Palsy,” by Christine Thorogood, MS, July 2005; High estimate: “Reaching for the States, a Foundation of Hope for Children with Cerebral Palsy.”

or birth defects. Medicaid defines "habilitative services" as those "designed to assist individuals in acquiring, retaining, and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community based settings."[15]

Coverage for OT, PT and ST provided under habilitative services is thereby largely restricted to adults who are so disabled as to be eligible for institutionalized care (Medicaid) or to children. Insofar as the legislation addresses the provision of "occupational therapy, physical therapy, and speech therapy…to enhance the individual's ability to function," limited coverage may be more widely available as rehabilitative services.

Mercer interviewed a board member of the Maryland Health Insurance Plan (MHIP), the high- risk pool for individuals who cannot pass health underwriting in the non-group market.[16] MHIP currently follows the mandates that have been adopted by MHCC for the Comprehensive Standard Health Benefit Plan (CSHBP) for the small group market. The CSHBP currently provides habilitative services for children with developmental disabilities attributable to congenital or birth defects. The CSHBP and MHIP generally adopt commercial insurers' interpretations of medically necessary services. Traditionally, these services for adults have not been viewed as insurable but have been defined as custodial-type care. MHIP probably would not extend habilitative coverage to adults.

Private insurance requires that services be medically necessary for the treatment of an illness or injury. Thus, insurance would cover rehabilitative services to the extent that such services result in continued and demonstrated improvement to recover skills that were lost due to an illness or injury. When these services no longer result in continued improvement, coverage is generally no longer available. In a previous study conducted by Mercer for the evaluation of habilitative services for children, it was found that about 60% of insurance companies provided these services in the absence of any mandate to some extent to enable the child to acquire as many age-appropriate skills as possible. Treatment plans would be required with periodic assessments to determine whether the therapies were working. If and when the therapies were no longer effective (and, therefore, no longer medically necessary) and/or continued treatment would no longer "enhance" the child's ability to function, treatment would cease to be covered, as the services would then represent custodial care. Because of the requirement that services be medically necessary and not custodial in nature, private insurance coverage for habilitative services for people 19 to 64 with developmental disabilities from birth defects, ASD or CP is generally not available.

Of four major private insurers surveyed in Maryland, only one specifically provides habilitative services for developmentally disabled persons beyond the mandated limiting

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[15] Centers for Medicare and Medicaid Services, (42 CFR §1915(c)), http://ecfr.gpoaccess.gov/cgi/t/text/text-idx?c=ecfr&sid=413a73fc1cf054156badc5da8e8429b5&rgn=div5&view=text&node=42:4.0.1.1.9&idno=42.

[16] Conversation with Dr. Rex Cowdry, board member of MHIP.

age, and that is in only about 5% of the insurer's plan offerings. Additional data regarding the enrollment and costs associated with such plans were not available. One insurer who does not differentiate between habilitative and rehabilitative services excludes OT and ST when the primary or only diagnosis for a member is mental retardation, perceptual handicaps, or developmental delay. However, this same insurer will sometimes provide therapy when the primary diagnosis is CP.

One carrier indicated that long-term rehabilitative therapy is not a covered benefit. If significant improvement is not achievable within a two-month period, benefits for rehabilitative services will be denied.

In some cases, adults with developmental disabilities resulting from birth defects, ASD or CP, can receive a limited number of therapy treatments under the private insurer's umbrella of rehabilitative services. The services would be rendered in accordance with the effect of enhancing functional ability, not in an effort to meet the habilitative criteria. If the member can be treated on an outpatient short-term basis with expected achievable improvement, the services are covered up to the treatment limits, irrespective of diagnosis. While the legislation does not limit the number of treatments an individual may receive, private plans do – usually by number of visits per condition per year. It is difficult to say what portion of the population targeted by this bill might receive like services under rehabilitation, but it should be assumed that it would be a subset of members and treatments covered.

Medicaid covers habilitative services for children developmentally disabled by birth defects, ASD or CP. According to the Kaiser Family Foundation, "a majority of children receiving Supplemental Security Income (SSI), one of the primary pathways to Medicaid coverage for disabled children, has a primary diagnosis of mental disorder, including mental retardation, developmental disability and mental illness."[17]

Medicare and Medicaid provide habilitative services to persons 19 to 64 who meet the programs' eligibility requirements.[18] Eligibility requirements consider the applicant's disability and level of income. Some in the target population are eligible through both programs. Developmentally disabled adults ages 19 to 64 can only get Medicare through Social Security Disability Insurance (SSDI) if they have an employment history but are now disabled, or if they are the dependent child of a Social Security beneficiary. They also must be severely disabled under Social Security rules, meaning that they are not able to work and earn significant income.

Medicaid is the public alternative for the larger number of young adults with disabilities who cannot qualify for Medicare because they never worked and do not have retired parents. People who qualified for Medicaid assistance as children are re-evaluated when they become adults. The criteria are generally stricter, and not all people who qualified

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[17] Bob Williams and Jennifer Tolbert, "Aging Out of EPSDT: Issues for Young Adults with Disabilities," Issue Paper January 2007, Kaiser Family Foundation, www.kff.org.

[18] E Fishman, "Aging Out of Coverage: Young Adults with Special Health Needs," *Health Affairs* (2001): 20;(6): 254–266. http://content.healthaffairs.org/cgi/content/full/20/6/254.

for Medicaid as children continue to qualify as adults. According to the Kaiser Family Foundation, about 25% to 30% of these people lose Medicaid eligibility when they become adults.[19]

Medicaid provides habilitative services through the home and community-based service (HCBS) waivers. To participate in the waiver program, an individual must be so disabled as to be eligible for intermediate care facilities for persons with mental retardation (ICF/MR) services. Habilitative services may include OT, PT and ST as well as longer-term, custodial services such as case management, private nurse or personal care attendants, and home health services. Public or private providers may supply these services and supports. These services also may include "prevocational, education and supported employment services" that are not otherwise available through a local educational agency or through programs funded under section 110 of the Rehabilitation Act of 1973.

The state of Alaska now requires a treatment plan with specific goals, assessments and outcomes for each mentally retarded or developmentally disabled individual served by its Medicaid waiver program.[20]

Although habilitative services are covered only by the waiver and are technically not allowable under the Medicaid Rehabilitative Services Option, Medicaid has been providing reimbursement for habilitation services under the Rehabilitative Services Option for many years.[21] In this way, members whose severity of disability does not qualify them for waivers have been able to receive therapy treatments that enhance their ability to function. They have relied on some "grayness" between the habilitative and rehabilitative services, as both aim to maximally reduce the disability and restore and maintain the best possible functional level of ability.

In August 2007, the Centers for Medicare and Medicaid Services (CMS) proposed a new regulatory rule for the Medicaid Rehabilitative Services Option that would end this practice. For people with MR/DD, the rule clarifies that the rehabilitation service category does not cover habilitation services. Organizations within the disability community oppose the sudden differentiation between habilitative and rehabilitative services. These organizations believe that if the proposed rule is adopted, it could significantly impact Medicaid reimbursement for community rehabilitation services and severely restrict access to important programs for individuals with developmental, cognitive and other disabilities.[22]

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[19] See footnote 22.

[20] Alaska Health and Social Services, Senior and Disabilities Services, "Development of the Habilitation Plan of Care" (2007), *http://www.hss.state.ak.us/dsds/carecoordinationtraining/segmentM.html*

[21] Thomas, Peter, "Update on Administrative Changes to Medicaid Rehabilitative Services," ACCSES-DSPA Alliance, (October 2006), www.accses-dspa.org/vendorimages/Alliance/2006_ACCSES_DSPA_PPSV_Memo_Adm_Changes_Medicaid_(10.03.06).DOC.

[22] Ibid.

OT, PT and ST can also sometimes be provided to developmentally disabled adults through nonprofit organizations within the community. Many of these offer day habilitation programs for developmentally disabled adults that may include these services. Arc of Montgomery County serves 1,250 individuals, including developmentally disabled adults. According to the Maryland Developmental Disabilities Administration, more than 100 different organizations across the state of Maryland provide various types of assistance to adults disabled by birth defects, ASD and CP.[23] However, not all of them provide OT, PT and ST, and not all do so at no charge. There also can be long waiting lists for enrollment and services provided by these organizations. Some employers have special work programs in place to train disabled adults for positions within their organizations, but this is still more of the exception than the normal case.

- ***To what extent does lack of coverage result in individuals' avoiding necessary health care treatments?***

While some data (case studies, small-scale trials, surveys, etc.) suggest that adults with developmental disabilities from birth defects, ASD and CP benefit from therapies that enhance their abilities for self-care, employment and quality of life, there is a lack of large-scale studies to support the conclusion that these services are necessary health care treatments.

- ***To what extent does lack of coverage result in unreasonable financial hardship?***

Statistics for incidence and costs of habilitative services for adults disabled by birth defects, ASD and CP are not readily available.

One study of the costs of autism reported that, while the typical American spends about $317,000 over his or her lifetime in direct medical costs, incurring 60% of those costs after age 65, a person with autism will incur an additional $307,000 in direct medical costs, incurring 60% of these costs after age 21. Direct medical costs average about $1,500 per year. These are incremental costs above and beyond the costs a normal adult would expect to incur.[24] We will assume that a significant portion of these costs (50%) is attributable to therapies that would not be required for a person without this diagnosis, or $750 per adult diagnosed with autism per year in 2003 dollars. If we assume a medical trend of 10% per year, this would equate to approximately $1,100 per year in 2007 dollars. However, some unknown proportion of these additional medical costs will be borne by health insurance without the mandate, so the hardship associated with lack of coverage cannot be reliably estimated. This same study estimated the indirect costs of autism over a lifetime at approximately $2.6 million; the proportion of these indirect costs that could be averted through the proposed coverage is unclear.

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[23] Maryland Department of Health and Mental Hygiene – Developmental Disabilities Administration, "Services Provided by DDA," http://www.ddamaryland.org/services.html

[24] Ganz, Michael L., PhD. The Lifetime Distribution of the Incremental Societal Costs of Autism." Arch Pediatrics Adolescent Medicine, Vol. 161, Apr 2007. www.archpediatrics.com

Testimony given by an activist in support of the failed mandate indicated that the annual therapy costs for him and his brother, who both have cerebral palsy, exceed $17,000.[25] This equates to $8,500 per individual per year. Based on the statistics inferred by his testimony, therapy sessions cost $80 to $90, and individuals would attend 100 sessions per year, or approximately two sessions per week.

- ***What is the level of public demand for the service?***

The level of public demand for the services is relatively small and generally limited to those affected by the developmental disability (and their families) and organizations that advocate on their behalf, such as the American Congress of Community Support & Employment Services (ACSES) and the national and affiliated state chapters of The Arc of the United States, United Cerebral Palsy (UCP), and Autism Society of America (ASA). At the same time, lengthy waiting lists for both community-based and federally funded programs indicate that demand for services still outpaces supply.

- ***How interested are collective bargaining agents in negotiating privately for inclusion of this coverage in group contracts?***

Most collective bargaining agents that Mercer surveyed indicated that their existing benefits provide for habilitative services for children but do not extend coverage to adults. Most unions do not place the extension of habilitative services high on their priority list of collective bargaining issues. Most funds already extend coverage for disabled dependents beyond age 19, although habilitative services may not be covered. Unions understand that increased mandates and/or benefits translate into increased costs, making collective bargaining more difficult because there are generally only so many dollars available for higher wages and benefits combined. Most unions are focusing on retaining existing benefits and/or contributions to health care funds.

- ***To what extent is the service covered by self-funded employers in the state who employ at least 500 employees?***

Mercer's survey of insurance companies participating in the self-funded market in Maryland indicated that most self-funded employers in the state do not follow Maryland's mandates. While the insurance companies did not provide specific data, they indicated it would be unlikely for self-funded plans to modify their current definitions.

Mercer estimates that only a very small number of self-funded employers with at least 500 employees provide habilitative services to those age 19 to 64 with developmental disabilities resulting from birth defects, ASD, or CP. Only one of the major Maryland insurers even provides plans that cover habilitative services for adults, and these account for only 5% of their plan offerings.

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[25] Maryland Politics Watch. "District 18 Activist Aaron Kaufmann Testifies for Health Care." March 23, 2007. *http://maryland-politics.blogspot.com/2007/03/district-18-activist-aaron-kaufmann.html*

FINANCIAL IMPACT

Mercer surveyed four major carriers in Maryland to obtain information on current practices regarding habilitative services. Mercer also asked these companies to provide financial estimates as to how rates would be affected by the extension of habilitative services to adults.

As indicated previously, there is concern regarding the existing language contained in the current bill. Here are some examples of the responses received.

Carrier A

"It is very difficult to anticipate premium increases, but, in addition to costs of care, we anticipate programming and operational changes costing in the 10's of millions of dollars to include:

- Single benefit carve-outs within a product are difficult to administer and require costly system modifications – there could be a need to segregate these claims and process them manually.
- The systems changes and administrative burden in terms of service training, enrollment and account implementation, medical management tracking, audits, etc. would run in the multi-millions to accommodate this type of policy (covering one specific medical condition for the life of the patient).
- New/unique identification cards would need to be created and generated to clearly identify that the individual has coverage limited to habilitative services only.
- Contract language and eligibility schedules would need to be created, filed and approved by the MIA.
- Enrollment issues – termination dates are automatically loaded when enrollment is processed.
- What happens when the parents are Medicare beneficiaries and they have individual Medicare Supplemental policies?
- What if the child is married, has other health coverage, resides in another state, etc.?
- How would we deal with retroactivity and re-adding individuals to parent's policies?
- There are potential IRS tax implications to members and employer groups."

Carrier B

This company's actuaries indicated that there was no way to estimate the increase in premium based on the language in the proposed mandate. With no defined scope of services, and with the wide variety of possible conditions and treatments, they felt they could not begin to quantify that information.

Carrier C

Company C's response was: "Long term rehabilitative therapy is not a covered benefit. If significant improvement is not achievable within a 2-month period, benefits for rehabilitative services will be denied.….This has the potential to be a significant benefit modification. Removing age limits would require a rate increase of between $4.00 and $8.00 pmpm." Our calculations indicate that this equates to 2% to 3% of premium.

Carrier D

This is the only carrier that did not express concerns regarding the claims cost and/or administrative complexities regarding the language in the proposed mandate. This carrier estimated that premiums would increase by 0.7%.

In its Fiscal and Policy Note, the Maryland Department of Legislative Services (DLS) estimated that extending habilitative services to individuals with congenital or genetic birth defects regardless of age would increase the state plan expenditures by 2%. This translates into an increase of about $11 million in Fiscal Year 2008 (FY2008) to almost $16 million in FY 2012.[26]

Because of the very limited amount of data available on the use and cost of habilitative services for adults who suffer from developmental disabilities associated with congenital or genetic birth defects, Mercer is providing a range of estimates for the cost of this proposed mandate, outlined as Approach A and Approach B below.

All of these estimates assume that this mandate will impact 1% to 2% of the membership of the insured population.

Since these benefits are not generally covered under existing policies, Mercer assumes that the full cost and the marginal cost of providing these services would be the same.

Most policies have some type of cost-sharing provisions. Therefore, Mercer assumes that insuring entities would be responsible for 90% of total costs.

Approach A assumes that, based on previously-referenced testimony, the average cost for therapy is between $80 and $90 per session. It is typical for policies to have limits on the number of therapy sessions that are eligible for payments within a year. These limits typically range from 30 to 100 sessions.

Approach B starts with the Medicaid experience in the three states that provide habilitative services for adults with developmental disabilities, adjusts for the differences in costs among these states and Maryland, adjusts for differences in reimbursement levels for Medicaid and commercial payers, and applies the range in prevalence.

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[26] Maryland Department of Legislative Services, Health Insurance – Habilitative Services – Covered Persons, HB 1192, 2007. *http://www.mlis.state.md.us/2007RS/fnotes/bil_0002/hb1192.pdf*.

Please note that the estimates in the following table only reflect the impact on claims costs. These estimates do *not* reflect any administrative costs associated with implementing this change. Based on the comments from the carriers, administrative costs could be very significant.

	Approach A		**Approach B**	
	Low	**High**	**Low**	**High**
Estimated cost of mandated benefits as a percentage of average cost per Maryland small employer policy	0.8%	5.1%	0.9%	1.9%
Estimated cost as a percentage of average wage	0.1%	0.4%	0.1%	0.2%
Estimated annual per-employee cost of mandated benefits for Maryland's small employer group policies	$39	$261	$50	$100

Appendix 5b

January 20, 2011

Annual Mandated Health Insurance Services Evaluation

Prepared for the Maryland Health Care Commission
Pursuant to Insurance Article 15-1501
Annotated Code of Maryland

John Welch
Karen Bender, FCA, ASA, MAAA
David Kerr, ASA, MAAA
Randall Fitzpatrick, ASA, MAAA

Contents

Introduction

Evaluation of Proposed Mandated Health Insurance Services

Insurance Article, § 15-1501, Annotated Code of Maryland, requires that the Maryland Health Care Commission (the Commission) annually assess the medical, social and financial impacts of proposed mandated health insurance services that fail passage during the preceding legislative session or that are submitted to the MHCC by a Legislator by July 1st of each year. The assessment reports are due to the General Assembly annually by December 31st.

Mercer and its sibling company, Oliver Wyman Actuarial Consulting, Inc., have been contracted as the Commission's consulting actuary, and have prepared the following evaluations of proposed changes to existing mandates or proposed newly mandated benefits: Extension of habilitative services to older ages; parity cost sharing for oral chemotherapy drugs; limitations on cost sharing for specialty drugs; preventive physical therapy for insureds with muscular sclerosis; and private duty nursing for insureds with spinal muscular atrophy.

Patient Protection and Affordable Care Act

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (PPACA), which incorporates significant reforms in the commercial (i.e., non-Medicare and non-Medicaid) market. PPACA requires several benefit reforms to be effective on the first anniversary/renewal occurring on or after September 23, 2010 including:

- Extending coverage for adult children to age 26
- Elimination of lifetime maximums for essential benefits
- Phase in of elimination of annual maximums for essential benefits
- Guarantee issue to children <19 years of age
- Prohibition of policy rescissions in most cases
- Elimination of cost sharing for certain preventive services
- Requiring same cost sharing for emergency services in a non-network facility

- Participant's flexibility to choose providers in plans assigning or designation primary care physicians

Beginning with calendar year 2011, PPACA requires minimum loss ratios of 80% for each insurer's nongroup block of business; 80% for each insurer's small group block of business and 85% for each insurer's large group block of business.

These reforms may impact some of the proposed mandates more than others and some markets more than others. The combination of requiring guarantee issue (GI) to children <19, extending coverage for adult children to age 26 and prohibition of policy rescissions has a greater impact on the nongroup market than on the group market[1,2]. Another PPACA benefit impacting the nongroup market more than the group market is the elimination of cost sharing for certain preventive services. A 2007 study showed that only about 60% of nongroup high deductible health policies (HDHP) included any first dollar coverage for some preventive benefits where as 96% of small group and 99% of large group HDHP policies provided first dollar coverage for some preventive benefits.[3]

PPACA will magnify the impact of some of the proposed mandated benefits for the nongroup market, especially those proposed benefits for whom the major recipients will be children under age 26 (habilitative services, private duty nursing for members with spinal muscular atrophy). At least two carriers in Maryland are offering child-only policies in the nongroup market on a GI basis, which creates the possibility of significant anti-selection. All carriers operating in the nongroup market will be required to accept all children for family contracts and continue coverage until age 26. There are fewer members in the nongroup market for which to spread risks in general. Inclusion of mandated benefits targeted at these age groups may magnify the potential for even more anti-selection.

The major insurance reforms under PPACA are effective in 2014, including guarantee issue for all entrants; elimination of medical underwriting; elimination of most rating factors; creation of exchanges for nongroup and small group policies; expansion of Medicaid eligibility; availability of premium subsidies for individuals purchasing nongroup insurance through the exchange, among others. The benefit plans to be offered through the exchanges will be based upon "essential benefits" as defined by HHS.[4.]

PPACA requires the state to pay, for every policy purchased through the health benefits exchange, the additional premium associated with any state-mandated benefits that

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[1] Previously passed federal legislation (HIPAA) required GI for all small employers and portability of coverage for individuals between carriers in the group market. However, GI was not required for any (except individuals transferring from group to nongroup coverage within a prescribed period of time) in the nongroup market at the federal level.

[2] Rescissions of group contracts are almost unheard of, whereas, while representing only about 3.7 per 1,000 policies issued, rescissions do occur in the nongroup market, mainly for failure to disclose pre-existing conditions. National Association of Insurance Commissioners (NAIC), Rescission Data Call of the NAIC Regulatory Framework (B) Taskforce, Draft, December 2009.

[3] AHIP, A Survey of Preventive Health Benefits in Health Savings Account (HSA) Plans, July 2007. AHIP Center for Policy and Research, November 2007. http://www.ahipresearch.org/pdfs/HSA_Preventive_Survey_Final.pdf

[4] HHS has not yet defined "essential benefits."

exceed the “essential benefits” determined by HHS. The essential benefits package is supposed to be similar to the benefits package offered in a typical self-insured employer’s plan, presumably nationwide. Interestingly, Mercer’s quadrennial mandate analysis performed for the Commission assesses the extent to which existing Maryland mandates exceed the benefits in a typical Maryland self-insured employer’s plan. Three years ago Mercer estimated this “marginal cost” of Maryland mandates at 2.2% of the premium. Legislators may wish to consider the possibility that, beginning in 2014, the State will bear the cost of any enacted mandates that have not been included in the essential benefits package.

This report includes information from several sources to provide more than one perspective on each proposed mandate. Mercer's intent is to be unbiased. At times, as a result, the report contains conflicting information. Although we included only sources that we consider credible, we do not state that one source is more credible than another. The reader is advised to weigh the evidence.

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Prescription Drug Cost-Sharing Obligations

Senate Bill 663 of the 2010 legislative session would prohibit carriers from imposing a cost-sharing obligation for a prescription drug that exceeds the dollar amount of the cost-sharing obligation for a prescription drug in a specified category.

Carriers that offer prescription drug coverage often incorporate cost-sharing tiers as a way to incent members to use lower-cost drugs. The cost-sharing charged for prescription drugs has traditionally been a fixed-dollar copay, which is lower for lower-tiered drugs. However, in recent years, some carriers have begun offering drug plans with coinsurance, where the member pays a constant percentage of the drug cost in an effort to share in the rapidly increasing drug costs. A tiered drug benefit program that only varies cost-sharing between generic and brand is called a “two-tier” program. A tiered drug program that further differentiates the cost-sharing between “preferred brand” and “non-preferred brand” is called a “three-tier” program. Nationwide, some carriers and health plans have begun to expand the differentiation even further, with a “four-tier” program, to reflect the very high cost of certain “specialty” drugs.

Specialty drugs are generally classified as drugs used to treat chronic and complex conditions, such as cancer, rheumatoid arthritis (RA), multiple sclerosis (MS), and hemophilia. Specialty drugs often have complex treatment regimens, and require special delivery and administration. Generally, these drugs are also considerably more expensive than non-specialty medications, often without lower-cost substitute drugs with similar effectiveness. The purpose of the proposed mandate is to protect individuals who may need these drugs from incurring large out-of-pocket costs.

Each plan that offers prescription drug coverage must provide members a list of drugs covered under the drug plan. This listing of drugs is known as the plan’s formulary. Each health insurance carrier structures its formulary differently, so formularies are not usually consistent among carriers. Some carriers structure drug benefit tiers by cost, with the most expensive drugs in Tier 4. Other carriers structure drug benefits based on medical necessity, with drugs in Tier 4 having an alternative available on another tier. Without each carrier’s formulary, it is impossible to determine whether the drugs provided in Tier 4 are high-cost specialty drugs, or drugs with alternatives available in other tiers. Based on information gathered from meetings with the medical directors of the largest plans in Maryland, we learned that carriers that offer four-tier plans predominantly use the fourth tier for specialty drugs.

For the purposes of this paper, non-preferred drugs are considered those drugs offered in Tier 3. Carriers that offer a four- or five -tier plan would be subject to cover drugs in Tier 4 and Tier 5 with cost-sharing provisions no higher than those in Tier 3 – which, in essence, would require plans to have a maximum of three tiers based on typical prescription drug coverage plan designs. Some specialty medications need to be administered by a physician. These medications may be covered under the medical plan rather than under the drug plan. This paper will focus on the implications of requiring carriers to pay for specialty drugs offered under a prescription drug plan at Tier 3 cost-sharing levels.

What follows is a discussion of the medical, financial, and social impacts of this proposed mandate.

Medical Impact

- **To what extent are specialty drugs recognized by the medical community as being effective in treating patients?**

- **To what extent is the efficacy of specialty drugs generally recognized by the medical community, as demonstrated by a review of scientific and peer review literature?**

- **To what extent are specialty drugs generally available and utilized by treating physicians or pharmacies?**

As mentioned above, specialty drugs are generally classified as drugs used to treat chronic and complex conditions, such as cancer, rheumatoid arthritis (RA), multiple sclerosis (MS), and hemophilia. Specialty drugs often have complex treatment regimens and require special delivery and administration. Generally, these drugs are also considerably more expensive than non-specialty medications, often without lower cost drug alternatives with similar effectiveness.

Before any drug (specialty as well as non-specialty) can be offered to the public, the Food and Drug Administration (FDA) must approve it to ensure it is safe and effective. For most drugs, the FDA requires a formal approval process, which takes an average of 12 years and costs over $350 million.[5] On average, 999 in 1,000 compounds never make it to clinical human testing.[6] Those drugs that do make it to clinical testing must undergo five stages of drug development and review:[7]

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[5] Drugs.com. New Drug Approval Process.

[6] FierceBiotech. "FDA Approval Process."

[7] U.S. Food and Drug Administration. "The FDA's Drug Review Process: Ensuring Drugs Are Safe and Effective."

In the first phase, Investigational New Drug Application (IND), the FDA reviews the manufacturer's preclinical testing results and determines whether the compound is safe enough for human testing. This phase can take over three years to complete.[8]. The next three phases are human clinical trials. The first phase of this process tests the drug on a small number of healthy patients (typically 100). This phase focuses on safety, i.e., how well the drug is processed, whether the dosing is correct, and how well the drug is tolerated. In the second phase of human clinical trials, the manufacturer tests the drug's overall effectiveness. In this phase, 100 to 300 people with the targeted disease are tested. The third phase expands on Phases 1 and 2 of clinical human trials, where 1,000 to 3,000 people with the targeted disease are tested. In this phase, the goal is to show the drug's safety and effectiveness. Once a drug has gone through the three human clinical trial phases (each trial usually takes several years), the manufacturer can submit a New Drug Application (NDA) to the FDA. The FDA then thoroughly reviews the NDA before granting approval.

Drugs that complete the formal FDA approval process described above have proven "clinical endpoints." Certain drugs can also be approved using the FDA's authority to streamline the approval process of drugs that provide innovative clinical outcomes for serious and life-threatening illnesses that lack satisfactory treatments. In the process's simplest form, drugs are approved based on laboratory findings that are likely to predict a clinical benefit, e.g., findings showing that a drug reduces the level of cancerous cells in a laboratory setting. Drugs that are approved using the accelerate approval process are required to complete post-marketing studies. Manufacturers are then required to report the status of these studies in annual status reports (ASR).

In short, the medical efficacy of individual prescription drugs varies considerably. The purpose of this section is not to determine the effectiveness of a specific drug, but to determine the overall effectiveness of specialty drugs. As outlined above, before a prescription drug is given FDA approval, years of clinical trials and research are invested to ensure the drug's safety and effectiveness. In addition, carriers cover only certain specialty drugs and limit utilization of these generally high -cost specialty drugs to certain circumstances where they are expected to be effective. For this reason, Tier 4 and Tier 5 specialty drugs are generally viewed as effective.

Social Impact

- **To what extent are specialty drugs generally utilized by a significant portion of the population?**

- **To what extent is the insurance coverage already generally available?**

- **To what extent does a lack of coverage result in unreasonable financial hardship?**

- **How interested are collective bargaining agents in negotiating privately for including this coverage in group contracts?**

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[8] FierceBiotech.

- **To what extent does a lack of coverage result in individuals' avoiding necessary health care treatments?**

- **To what extent is the proposed mandate covered by self-funded employers in the state who employ at least 500 employees?**

The mandate in question is a requirement for carriers to cover drugs in Tiers 4 and 5, with cost-sharing limited to Tier 3 levels.[9]. In turn, the mandate does not require a plan to cover drugs that are not currently available to plan members. We note that not all specialty drugs are covered by all carriers. Each carrier that offers prescription drug coverage has a predefined formulary stating which drugs are covered and specifying the cost-sharing applicable to each drug. Formularies vary from carrier to carrier. Some carriers structure the benefit plan by cost, with the most expensive drugs in Tier 4. Others structure the benefit based on medical necessity, with drugs in Tier 4 having an alternative drug available in another tier.

Each year, Mercer surveys employer-sponsored health plans regarding different aspects of the health care coverage they provide. In 2009, over 2,900 employers were surveyed, and over 1,700 of them had more than 500 employees. The proposed mandate would impact only those health plans that offer Tier 4 and Tier 5 benefit plans. Of the employers surveyed, 9% stated they offer drug coverage with four or five tiers.[10] The survey results are also available by state. In Maryland, 29 employers with more than 500 employees were surveyed; none of them reported offering drug coverage with four or five tiers.[11]. It is important to note that, while over 90% of the employers surveyed offer drug benefits with three tiers or fewer, that does not mean these employers cover any specialty medications. As mentioned earlier, formularies can vary significantly from plan to plan. Based on the Mercer survey, 9% of the large group employer plans would be affected if drugs in Tiers 4 and 5 were required to be offered at Tier 3 cost-sharing. Also, the mandated coverage could already be largely available, as none of the sampled Maryland plans had more than three tiers.

Specialty drugs are utilized by a small percentage of the population, but account for a significant portion of drug costs. According to CuraScript's 2009 Specialty Drug Trend Report, less than 1% of members nationwide utilized specialty drugs, yet specialty

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[9] Carriers can offer Tier 4 and Tier 5 drugs at lower cost-sharing levels than Tier 3, but the mandate states that the maximum cost-sharing for these drugs is the Tier 3 cost-sharing.

[10] Mercer. "2009 Mercer National Survey of Employer-Sponsored Health Plans."

[11] Mercer.

medications accounted for more than 12% of total costs. (The average cost per script in 2009 was $1,867.)[12]

The chart on the following page shows the prevalence of selected health conditions, the specialty drugs available to treat them, and the drugs' costs.[13]

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[12] CuraScript. "2009 Specialty Drug Trend Report: A Market and Behavioral Analysis." April 2010.

[13] Walgreens. "Outlook – State of the Industry Report." August 2009.

Condition/Therapy	Approximate U.S. Population Affected	Average Annual Specialty Drug Cost per Patient	Notable Specialty Products
Biologic response modifiers	Crohn's disease: 500,000 Psoriasis: Between 5.8 and 7.5 million Psoriatic arthritis: 10% to 30% with psoriasis Rheumatoid arthritis: 1.3 million Ulcerative colitis: 500,000	$12,000 to $78,000	Amevive®, Cimzia®, Enbrel®, Humira®, Kineret®, Orencia®, Remicade®, Rituxan® Simponi™
Bleeding disorders	Hemophilia A: 1 in 5,000 male births Hemophilia B: 1 in 25,000 male births von Willebrand disease: 1% to 2% of population	$150,000+	Advate®, Alphanate®, BeneFIX®, Humate-P®, NovoSeven®, RT, XYntha™
Hepatitis C	3.2 million chronically infected	$23,000 (for interferon alone) $33,000 (combination therapy with interferon and ribavirin)	Infergen®, Pegasys®, Pegintron™, ribavirin
HIV/AIDS	1.1 million	$26,000	Atripla®, Insetress®, Kaletra®, Norvir®, Prezista®, Reyataz®, Selzentry™, Sustiva®, Truvada®
Infertility	2.1 million females	$15,000 (based on 3 cycles)	Bravelle®, Cetrotide®, Follistim®, AQ, Ganirelix, Gonal-F®, Gonal-F® RFF, human chorionic gonadotropin, Luveris®, Menopur®, Ovidrel®, Repronex®
Multiple sclerosis	400,000	$36,000	Avonex®, Betaseron®, Copaxone®, Rebif®, Tysabri®
Oral chemotherapy	1.4 million new cancer cases per year	$42,000 to $130,000 Varies by type of cancer	Gleevec®, Nexavar®, Revlimid®, Sprycel®, Sutent®, Tarceva®, Tasigna®, Temodar®, Thalomid®, Tykerb®, Xelodia®
Respiratory syncytial virus	75,000 to 125,000 infants hospitalized per year	$6,000 to $12,000 based on variations in weight-based dosing	Synagis®
Transplant	> 163,000 persons living with a funtioning organ transplant	$16,000	CellCept®, Neoral®, Prograf®, Rapamune®

As shown in the table above, the cost of this sample of specialty drugs can range from $6,000 to over $150,000 annually. In 2009, roughly 25% of Americans lived in households with incomes that were under 133% of the Federal Poverty Level (FPL) and 32% of Americans lived in households with incomes over 400% FPL.[14] Based on the Health and Human Services 2009 poverty guidelines, an annual income of $10,830 is 100% FPL for a single person.[15] For a family of four at 400% FPL (or $88,200 in household income), prescription drug costs of $6,000 would be almost 7% of their income. Requiring members to pay a significant portion of the cost of specialty drugs could result in unreasonable financial hardship, though it is unclear what portion of the cost a member would actually pay for specialty drugs approved on a given formulary due to cost-sharing and out-of-pocket limits.

Health Affairs completed a study that analyzed the change in members' utilization given a change in their cost-sharing for specialty drugs taken for cancer, kidney disease, rheumatoid arthritis (RA), and multiple sclerosis (MS). In effect, the study analyzed the elasticity of demand. The study included pharmacy and medical claims from 55 health plans offered by 15 large employers in 2003 and 2004. The data covered approximately 1.5 million beneficiaries. On average, the population utilizing specialty drugs ranged from 1% to 5% of a typical plan membership. The study showed that the demand for these specialty drugs did not change considerably with an increase in cost. Doubling the copay resulted in a 1% reduction in use for cancer, a 21% reduction in use for RA, an 11% reduction for kidney disease, and a 7% reduction for MS.[16]

Given the seriousness of the underlying conditions, the inelasticity of demand for specialty drugs under the copay changes noted in the study is not surprising. However, in order to utilize these medications, one needs to be able to pay for them, and some studies have shown that financial issues preclude some people from utilizing the drugs they need.

> *"In 2007, one in seven Americans under age 65 reported not filling a prescription in the previous year because they couldn't afford the medication…The increase in affordability problems likely stemmed from higher prescribing rates, drug prices that are rising faster than workers' earnings, higher patient cost sharing in private insurance and the introduction of expensive new medications."*[17]

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[14] The Henry J. Kaiser Family Foundation. "Distribution of Total Population by Federal Poverty Level, states (2008-2009), U.S. (2009)."

[15] U.S. Department of Health and Human Services. "2009 HHS Poverty Guidelines."

[16] Dana P. Goldman, et al. "Benefit Design and Specialty Drug Use." *Health Affairs* Vol. 25, No. 5: 1319.

[17] Laurie E. Felland and James D. Reschovsky. "More Nonelderly Americans Face Problems Affording Prescription Drugs." The Center for Studying Health System Change. Tracking Report No. 22, January 2009.

A significant number of working-age adults with chronic conditions reported they have unmet prescription drug needs (21.3% of high-income earners and 41.3% of low-income earners). In addition, it is more likely that prescription drug needs are met for people in employer-sponsored plans than in individual or Medicaid plans, with uninsured individuals having the highest unmet prescription drug needs.[18]

It is likely that many of the individuals not receiving necessary drug therapies did not have drug coverage – or any health coverage at all. It is unclear from this study the extent to which increased cost-sharing for certain drugs led to Maryland residents not receiving necessary drug therapies.

Mercer surveyed six major carriers in Maryland to obtain information on the prevalence of drug plans with more than three tiers in the individual, small group, insured, and self-funded large group markets. We received responses from four carriers. The table below shows the average percentage of members that currently have a drug plan with more than three tiers.

Table 1

Health Plan	**Average Percentage of Members with Drug Plans with more than Three Tiers**
Carrier # 1	0%
Carrier # 2	60%
Carrier # 3	1%
Carrier # 4	10%

As previously mentioned, the proposed mandate does not require that coverage be expanded to additional medications, but it does require that drug plans with four or five tiers cover those drugs in Tier 4 and Tier 5 with cost-sharing provisions no higher than those in Tier 3. In essence, this would require plans to have a maximum of three tiers based on typical prescription drug coverage plan designs. The estimates provided above merely show the percentage of members that would be impacted by this mandate.

For those carriers that responded, drugs offered in Tier 4 are typically self-administered injectibles. Based on the responses, ***carriers in Maryland are currently providing Tier 4 drugs that are either subject to the same cost-sharing as Tier 3 drugs or include a separate out-of-pocket limit and/or per-drug cap in order to limit major financial hardship,.*** This indicates that currently carriers are affording Maryland insureds protection from extremely high cost sharing for these types of drugs, for which the annual cost for can vary from $6,000 to over $150,000. In the absence of separate out-of-pocket limits, Maryland residents would have a significant issue purchasing specialty medications.

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[18] Laurie E. Felland and James D. Reschovsky.

The collective bargaining agents surveyed do not know of any contracts that include this mandate, but they generally support the concept of capping the cost-sharing for Tier 4 and 5 drugs at Tier 3 levels. However, they recognize this would lead to increased costs, and they would rather see increases in coverage in other areas.

Financial Impact

In this section we estimate the cost of enacting the proposed mandate and compare the results of our analysis to other sources, including the estimates submitted by health carriers in Maryland.

In addition to asking carriers about the prevalence of prescription drug plans with more than three tiers, Mercer asked these carriers to provide cost and utilization statistics for Tier 4 drugs and the estimated premium impact if they are required to offer Tier 4 drugs at Tier 3 cost-sharing.

Of the responding carriers, only two identified more than 5% of the membership as having a drug plan with more than three tiers. Of these two, one carrier indicated that the drug premium impact of this mandate would range from 1.0% to 1.5%.[19] The other carrier stated that the mandate's cost would be 0%, as the cost-sharing for Tier 4 drugs is already the same as Tier 3. The other two carriers indicated that the proposed mandate would have no premium impact.

The financial impact would vary depending on the plan formulary and the difference in cost-sharing requirements between Tier 3 and Tier 4. Mercer completed an independent calculation of the cost impact under multiple cost-sharing assumptions. As discussed throughout this paper, drugs on Tier 4 are assumed to be specialty drugs.

According to CuraScript's 2009 Specialty Drug Trend Report, the 2009 average cost per script for specialty drugs was $1,867, roughly 1% of members utilized specialty drugs, and the average 2009 per-member per-year cost was $111.[20] Using this information, Mercer calculated the plan cost given specific cost-sharing amounts. Based on the responses from carriers and the Mercer large employer survey, the average Tier 3 copay in Maryland is roughly $45. For those Maryland carriers that offer four-tier drug plans, Mercer did not receive adequate information for the average Tier 4 cost-sharing. The single response we received stated that Tier 4 coinsurance is 25% with a $75 copay cap. Based on the 2010 CVS Caremark Benefit Planning Survey, representing 7.3 million lives, the specialty member cost-share goal for these employers is 20%.[21]. We estimated the increase in plan costs when changing the specialty cost-sharing from a $90 copay to a

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[19] The drug premium represents a relatively small percentage of the total premium for a typical health plan that offers medical and prescription drug coverage.

[20] CuraScript.

[21] CVS Caremark. "2010 Client Benefit Planning Survey."

$45 copay and from 20% coinsurance to a $45 copay. The following table summarizes the results.

Table 2

	Fixed Copay		Coinsurance	
	Member Copay	**Plan PMPM**	**Member Coinsurance**	**Plan PMPM**
	0	$9.25	0%	$9.25
	40	9.05	20%	7.40
	45	9.03	25%	6.94
	50	9.00	30%	6.48
	55	8.98	35%	6.01
	60	8.95	40%	5.55
	65	8.93	45%	5.09
	70	8.90	50%	4.63
	75	8.88		
	80	8.85		
	85	8.83		
	90	8.80		
Cost-Sharing Change		$90 copay to $45 copay		20% coins to $45 copay
Estimated PMPM Impact		$0.22		$1.63

As shown in the table above, reducing the member cost-sharing from $90 to $45 results in an increase in plan claim costs of $0.22 PMPM, or a 0.07% increase in the average cost of a group policy. Reducing the member cost-sharing from 20% coinsurance to a $45 copay results in an increase in plan claim costs of $1.63, or a 0.50% increase in the average cost of a group policy.

Continuing with the example above, the mandate's financial impact is moderate. The table below summarizes the mandate's cost impact on Maryland residents and carriers.

Table 3

	Cost
Estimated cost of mandated benefits as a percentage of average cost per group policy	0.07% to 0.5%
Estimated cost as a percentage of average wage	0.01% to 0.07%
Estimated annual per employee cost of mandated benefits for group policies	$5 to $36

These results are consistent with the responses we received from carriers reporting that the financial impact of this mandate is insignificant.

The estimates provided above assume the member pays the same cost-sharing for each drug dispensed. Based on survey responses provided by carriers, applying out of pocket and maximum copay limits to Tier 4 drugs is common. Including these types of cost-sharing in the plan design would dampen the premium increases.

One of the surveyed carriers emphasized that some employer groups have been requesting information on drug plans with four and five tiers. The additional tiers are one option to reduce the cost to provide coverage. The proposed mandate would not allow carriers the flexibility to reduce premiums by adding cost-sharing tiers to the drug plan. ***One option that carriers may elect as a means to contain premiums would be to increase the cost-sharing for all prescription drugs. Another unintended consequence of the proposed mandate could be carriers' moving away from fixed-dollar (copay) plans to coinsurance drug plans without any annual maximum out of pocket limitation, which could ultimately lead to a significant increase in member cost-sharing and member dissatisfaction.*** The coinsurance approach without annual out-of-pocket limit would significantly increase the insured's liability from the current levels based upon the responses from the carriers regarding their existing benefits and practices.

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Cancer Chemotherapy Cost-Sharing Equity

House Bill 626 would prohibit carriers that cover cancer chemotherapy from imposing different cost sharing levels for orally administered cancer chemotherapy that are less favorable than those that apply to cancer chemotherapy administered intravenously or by injection.

Anticancer medications can be administered in several ways, including the following:

- **Orally –** taken by mouth (usually as pills)
- **Intravenously –** infused through a vein
- **By injection –** injected into a muscle or under the skin.

Older, less common means also exist. Some medications can be applied topically, infused directly into another part of the body, or injected directly into a tumor.[22] Older injectable cytotoxic chemotherapeutic drugs, such as doxorubicin or cyclophosphamide, are used for many types of cancers. Due to their potential for severe side effects, these drugs need to be administered in a physician's office, clinic, or hospital by intravenous infusion in short cycles.

Oral anticancer medications have been available for several decades and are becoming an increasingly popular treatment option for cancer patients. Oral treatments offer certain advantages over other delivery methods, including increased convenience; fewer

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[22] California Health Benefits Review Program (CHBRP). "Analysis of Senate Bill 161, Health Care Coverage: Chemotherapy Treatment." Report to California State Legislature April 17, 2009, revised June 26, 2009.

complications associated with administration; greater flexibility in timing, duration, and location of administration; and, often, fewer side effects.[23] In addition, oral medications may be less costly to administer since they do not require an office visit or nursing staff.[24] On the other hand, some cancer patients cannot assume the considerable responsibility of potentially complex treatment regimens, and health care professionals must invest significant time educating the patient and providing technical support. Although oral medications may offer many advantages, health benefit plans often require enrollees to pay higher out-of-pocket costs for them.[25]

By early 2009, the FDA had approved 40 oral anticancer medications for treatment of 54 different cancers. Of these medications, 28% had intravenous/injected substitutes and 23% had generic equivalents.[26] Since then, 11 more anticancer medications have been approved.[27]

With the exception of some limited benefit plans and small employer plans, chemotherapy is generally a covered expense, regardless of how it is administered. However, because of the historic evolution of these plans, oral anticancer medications are covered differently from intravenous or injected medications, often by entities that are separate. The key determinant is the site of administration. Cancer medications administered in a doctor’s office or hospital are covered under the plan’s medical provisions. Oral medications are generally covered under separate prescription drug plans.[28] As a result, benefits vary a great deal.

A plan’s “medical” benefit usually covers a higher percentage of eligible expenses than a plan’s pharmacy benefit since the medical benefit usually requires only a copayment for the chemotherapy visit (although some plans may have a coinsurance design for office visits, which may result in high cost sharing requirements). Pharmacy plans, in contrast, commonly have a tiered benefit design with expensive oral drugs often in the highest tier. Usually this tier is a high copayment tier for non-preferred brand name drugs, but in some

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[23] Texas Department of Insurance. “Patient Cost Disparity Between Orally and Intravenously Administered Chemotherapies.” Report on Senate Bill 1143, Section 3. 81st Legislature, Regular Session, 2009, August 2010.

[24] Texas Department of Insurance.

[25] Texas Department of Insurance.

[26] CHBRP.

[27] Centerwatch. “FDA Approved Drugs.”

[28] CHBRP.

plan designs, the highest tier is designated a "specialty drug tier" and carries a significant cost-sharing in the form of coinsurance.[29]

Traditional pharmacy benefit designs, with fixed copays, such as $10 per prescription for generic drugs, $25 for formulary brand drugs, and $40 for other brand drugs, do not impose large cost sharing for expensive drugs and, in fact, may cover a higher percentage of the costs of expensive oral medications than the typical medical benefit.[30] However, some plan designs (one estimate is 18% of all pharmacy benefit plans nationwide[31]) have unlimited coinsurance provisions, typically 20% for generic drugs, 25% for formulary brand drugs, and 35% for other brand drugs.[32] These can impose a significant cost sharing burden when the prescription costs thousands of dollars, as is often the case. (UnitedHealthcare reported that the average prescription costs of the more than two dozen oral anticancer medications covered in 2008 were $3,400.[33]) At this time it appears that insurance carriers in Maryland have not adopted unlimited coinsurance provisions for drugs as readily as other parts of the country, but this could change rapidly.[34]

Nine states and the District of Columbia have passed "chemotherapy equity" legislation, and others have similar legislation pending.[35] Many have "no less favorable" language similar to Maryland's bill. While the expectation is that carriers subject to these provisions will comply by reducing current cost-sharing requirements for oral anticancer medications to match the cost-sharing provisions applicable to intravenous drugs,[36] the legislation does not require that action. In today's climate, some carriers might choose to comply by raising the cost-sharing features of intravenous, et al, drugs to meet the arguably higher provisions of the oral medications.

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[29] K. Fitch, K. Iwasaki, and B. Pyenson. "Parity for Oral and Intravenous/Injected Cancer Drugs." Prepared by Milliman, Inc., NY, for GlaxoSmithKline. January 25, 2010.

[30] Fitch, et al

[31] Takeda Pharmaceuticals. "2009-2010 Prescription Drug Benefit Cost and Plan Design Report." Table 15: Trends in Common Plan Configurations 2007-2009.

[32] Watson Wyatt COMPARISON Database: 2008 Statistical Summary. Watson Wyatt, 2009.

[33] UnitedHealth Group. "Facts and Perspective on Legislation Mandating Certain Benefits for Oral Chemotherapy Agents." January 2010.

[34] 2009 Mercer Survey of Employer Sponsored Health Plans, Maryland Large Employers. This proprietary report shows that in 2009 only 8% of large employers (500 or more employees) in Maryland use coinsurance for one or more drug categories.

[35] Texas Department of Insurance.

[36] Texas Department of Insurance.

Medical Impact

In this section, we answer questions regarding chemotherapy coverage equity.

- **Does the medical community recognize oral anticancer medications as being essential and/or effective in slowing the growth of or eliminating certain forms of cancer?**

- **Are oral anticancer medications recognized as appropriate and necessary by the medical community, as evidenced by scientific and peer review of literature?**

- **Do treating physicians utilize oral anticancer medications?**

As previously mentioned, oral anticancer medications have been available for decades. However, the last few years have seen a proliferation of new oral anticancer medicines.[37] This trend is expected to continue. National Comprehensive Cancer Network (NCCN) experts estimate that the number of FDA-approved oral medications (currently 40) could easily triple in the next few years.[38]

There are three primary approaches to cancer treatment: anticancer drug therapy, surgical treatment, and radiation therapy. These approaches can be used individually or in combination, depending on the type of cancer, the stage of the disease, and the patient.[39]

Over 100 anticancer medications are currently in use, and they are administered in a variety of ways. They vary widely in their chemical makeup, the types of cancer they target, and their side effects.[40] There are three basic categories of anticancer drug therapy: cytotoxic agents, biologic/targeted agents, and hormonal agents.[41]

Cytotoxic agents are intended to kill cancer cells by impairing cell division in rapidly dividing cells. These agents generally do not discriminate, killing both cancer and healthy cells. Because of their side effects, they are usually administered intravenously in

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[37] Saul Weingart, Elizabeth Brown, Peter Bach, et al. "NCCN Task Force Report: Oral Chemotherapy." *Journal of the National Comprehensive Cancer Network*.6, Supplement 3. March 2008.

[38] Weingart, et al.

[39] Fitch, et al.

[40] University of Iowa Hospitals and Clinics. "Types of Chemotherapy." University of Iowa Health Care website. February 2004. Revised November 2006.

[41] CHBRP.

the maximum dose that the patient can tolerate.[42] However, in some instances, oral administration is an option.[43]

Biologic/targeted agents are targeted specifically at cell surface proteins or at pathways that are relatively specific to cancer biologic pathways.[44] These medications attack cells that contain mutated genes or cells that contain duplicates of a particular gene. These agents often have less systemic but unique side effects because they are targeted at cancer cells.[45] They may be taken orally and are most effective when administered on a regular and recurring basis. [46]

Hormonal agents are not chemotherapy in the strictest sense, as they do not directly kill or slow the growth of cancer cells. Instead, they interfere with the activity of hormones that can promote the development or growth of cancer cells.[47] These medications, typically less expensive than cytotoxic or targeted anticancer medications, may be administered orally, as an infusion, or as an injection.[48] Almost half of patients receiving chemotherapy use oral products only, and most of that usage is lower costing hormonal agents.[49]

Spending on oral chemotherapy drugs more than doubled between 2002 and 2006.[50] More attention is being given to the administration of oral chemotherapy as the availability of these agents has increased and many patients prefer oral options when they are available.[51]

NCCN publishes evidence-based treatment guidelines that are designed to improve the quality, effectiveness, and efficiency of oncology practice. The NCCN Clinical Practice

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[42] Fitch, et al.

[43] Weingart, et al.

[44] Weingart, et al.

[45] American Cancer Society. "Chemotherapy Principles: An In-Depth Discussion of the Techniques and Its Role in Cancer Treatment." 2009.

[46] Fitch, et al.

[47] CHBRP.

[48] Texas Department of Insurance.

[49] Fitch, et al.

[50] Weingart, et al.

[51] Kathryn Ruddy, MD, et al. "Patient Adherence and Persistence with Oral Anticancer Treatments." *CA: A Cancer Journal for Clinicians.* 2010.

Guidelines in Oncology are the recognized standard for clinical policy in oncology.[52] These guidelines provide recommended cancer treatment protocols based on the type of cancer and the stage of the disease.

Some NCCN guidelines recommend the administration of a single intravenous anticancer medication or a single oral anticancer medication. Other protocols call for various combinations. When a drug is available in both forms, the guidelines indicate that these drugs can be substituted for each other.[53] The choice largely depends on the preferences of the patient and the attending physician – and on the patient's ability to adhere to the treatment regimen.[54]

As indicated earlier, research has produced new, orally administered cancer drugs that are more targeted and better tolerated than the older injectables. These new drugs are causing a paradigm shift toward long-term maintenance use in an ambulatory setting, rather than the use of short-term cyclic treatments. These oral treatments are expensive – they frequently cost in the range of $5,000 to $10,000 for only a month of therapy. Many new cancer drugs are used on a long-term basis in addition to or sequentially with other treatments, so they can be significant drivers of utilization growth[55] and the related aggregate treatment costs.

The degree of compliance with the oral regimen is a concern. (The International Society for Pharmacoeconomics and Outcome Research (ISPOR) recently defined *adherence* as synonymous with *compliance* – that is, "the degree or extent of conformity to the recommendations about day-to-day treatment by the provider with respect to the timing, dosage, and frequency."[56] The ISPOR group distinguished *adherence* from *persistence*, which was defined as the "duration of time from the initiation to the discontinuation of therapy."[57]) Optimal adherence and persistence occur when a patient follows his or her prescribed treatment regimen exactly. A patient is optimally adherent if no doses are missed, no extra doses are taken, and no doses are taken in the wrong quantity or at the wrong time. A patient shows optimal persistence if he or she takes a medication as long as it is prescribed.

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[52] National Comprehensive Cancer Network. "About the NCCN Clinical Practice Guidelines in Oncology."

[53] NCCN.

[54] Weingart, et al.

[55] Medco. "2010 Drug Trend Report."

[56] Ruddy, et al.

[57] Ruddy, et al.

Non-adherence to oral therapies can result in adverse consequences. The oncologist may incorrectly assume that the agent is not effective if the cancer is still growing, when the true cause may be that the patient simply is not taking the full medication at the proper intervals. Rates of adherence to and persistence with oral cancer therapies have been documented to range between 16% and 100% in adult populations.[58] The 2010 study by Kathryn Ruddy et al. on patient adherence recommends that providers monitor adherence rates and ascertain the cause(s) for noncompliance (for example, is the regimen causing side effects or distress?). For patients who have difficulties adhering to the regimen, physicians will need to re-emphasize the importance of adherence. Providing pill boxes or medication diaries may help – and, where possible, discussions with pharmacists should be encouraged.[59]

To quantify the prevalence of oral chemotherapy, Milliman Inc. performed a detailed analysis of data from the Thomson Reuters Medstat database. This study found that 1.5% of the population with commercial insurance has a claim for cancer each year and 25% of these receive chemotherapy. Of this group, 48% receive oral treatment only, 35% receive intravenous treatment only, and 17% receive both.[60]

In a 2009 analysis of a similar mandate for California based on 2006 data, the California Health Benefits Review Program (CHBRP) estimated that 0.5% of the individuals covered by its mandate use anticancer medications each year. Almost 70% used oral medications only, 20% percent used intravenous or injected medications only, and 10% used a combination.[61]

In their survey response, one carrier questioned the medical appropriateness of singling out oral chemotherapy drugs for special coverage:

> *"Medically speaking, it would seem discriminatory in a broad sense to provide coverage for this condition, and not other, similar conditions. There are and will be many more diseases that have expensive treatments that include both the infusion route and pills. The concern is, what will this mandate cost in the future when other disease entities are included?"*

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[58] Ruddy, et al.

[59] Ruddy, et al.

[60] Fitch, et al.

[61] CHBRP.

Social Impact

In this section, we address the following questions:

- **To what extent will the proposed change generally be utilized by a significant portion of the population?**
- **To what extent is the insurance coverage already available?**

- **To what extent does the lack of coverage result in individuals' avoiding necessary health care treatments?**
- **To what extent does lack of coverage result in unreasonable financial hardship?**

- **What is the level of public demand for these services?**

- **How interested are collective bargaining agents in negotiating privately for including this coverage in group contracts?**

- **To what extent is the proposed health insurance service covered by self-funded employers in the state with at least 500 employees?**

The Department of Health and Mental Hygiene reports the following incidence rates of all types of cancer and compares them to the national incidence rates. Please note that these incidence rates cover all ages, including those over age 65.

Table 1:

All Cancer Sites Incidence Data* By Gender and Race, Maryland and the United States, 2004-2006[62]

	Total	Males	Females	Whites	Blacks	Other
2004						
MD New Cases (count)	25,419	12,460	12,942	18,780	5,677	795
MD Incidence Rate	462.6	524.4	421.5	469.8	444.4	344.9
US SEER Rate††	464.6	545.4	408.9	471.7	501.6	314.7
2005						
MD New Cases (count)	25,513	12,765	12,719	18,756	5,719	877
MD Incidence Rate	457.4	528.3	409.0	466.4	434.9	362.9
US SEER Rate	456.4	527.5	407.9	465.3	480.9	306.2
2006						
MD New Cases (count)	24,203	12,246	11,895	17,629	5,391	903
MD Incidence Rate †	426.3	495.6	376.9	434.3	395.7	353.1
US SEER Rate	450.5	521.9	401.0	458.1	467.3	299.7

* Rates are per 100,000 and are age-adjusted to 2000 US standard population
† 2006 Maryland case counts and incidence rates are lower than actual due to case underreporting for Montgomery and Prince George counties (See Appendix C, Section A.1)
†† Surveillance Epidemiology and End Results

Total includes cases reported as transexual, hermaphrodite, unknown gender, and unknown race

Sources:
Maryland Cancer Registry (MD incidence data), National Cancer Institute SEER statistics (US SEER 17 rates)

Please note that, as defined by the table above, "incidence" measures a person only once – in the year that the cancer was initially diagnosed. If a person received treatment over a period of years, he or she would not be counted in any of the subsequent years. Thus, this definition of "incidence rate" significantly understates the number of individuals receiving care for cancer in any single year.

The current estimate of individuals in the US diagnosed with cancer is 5,700,000, or about 15 in 1,000 [63] based on a population estimate of 380,000,000.[64] This rate is about three times the incidence rate in the previous table. We would expect the number of individuals with cancer in any given year to be significantly higher than the number of individuals newly diagnosed. Approximately 25% of these cancer patients (or 4 per

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[62] Maryland Department of Health and Mental Hygiene. "Cancer Report 2009."

[63] Fitch, et al.

[64] Robert Schlesinger. "US Population, 2010: 308 Million and Growing." *US News and World Report.* Politics & Policy Blog. December 30, 2009.

1,000) receive chemotherapy;[65] approximately 65% of these individuals utilize oral medications.[66]

In 2008, The Hilltop Institute reported in its "Overview of the Existing Insurance Market in Maryland" that there were 3,590,609 individuals with private insurance in Maryland.[67] Based on this estimate of the covered population and the incidence rates reported above, there are approximately 13,500 insured Marylanders receiving chemotherapy annually; 65% of these (or 8,500 to 9,000 individuals) utilize oral anticancer medications to some extent. In California, 98% of covered individuals had coverage for oral anticancer medications.[68] In Texas, the estimate was closer to 82%.[69] No comparable number for Maryland is currently available. However, based on feedback from the carriers, we would expect the percentage to be similar to California's. In the Maryland small group market, all carriers must offer some type of drug coverage. The 2010 Kaiser/HRET Employer Health Benefits Survey shows that 99% of covered workers in employer-sponsored plans have prescription drug coverage.[70]

Almost all Maryland medical plans cover chemotherapy, regardless of how it is administered. Few, however, cover oral and injectable/infused medications in the same way. Table 2 summarizes information provided by the health plans responding to the survey:

Table 2: Coverage of Anticancer Medicines

Health Plan	Coverage of Infused/Injectable Anticancer Medicines	Coverage of Oral Anticancer Medicines
A	Medical plan	Pharmacy benefit
B	Major medical benefit	Prescription benefit
C	Medical plan	Pharmacy benefit
D	Medical plan	Medical plan
E	Medical benefit	Pharmacy benefit
F	Medical benefit	Pharmacy benefit

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[65] Fitch, et al.

[66] Texas Department of Insurance.

[67] Charles Milligan. "Overview of the Existing Insurance Market in Maryland." The Hilltop Institute. University of Maryland, Baltimore County. August 2010.

[68] CHBRP.

[69] Texas Department of Insurance.

[70] Kaiser Family Foundation/Health Research & Educational Trust (HRET). "Employer Health Benefits 2010 Annual Survey." September 2010.

One carrier indicated that 95% of its insured plans in Maryland have the same cost-sharing provisions and out-of-pocket dollar limits for cancer chemotherapy regardless of how it is administered. Others indicated that medical and pharmacy benefits differ.

Maryland carriers treat cancer chemotherapy differently depending on where and how the chemotherapy is administered. This reflects the nationwide trend. Express Scripts reports that 81% of drug chemotherapy occurs in the medical benefit while 19% occurs in the drug benefit.[71]

However, this pattern is changing. Medco reports that currently, more than 800 new cancer drugs and new indications for existing cancer drugs in clinical development.[72] New, more specialized and better tolerated orally administered cancer drugs are prompting a trend toward long-term maintenance use of these drugs in an ambulatory setting, rather than the use of short-term cyclic intravenous or infused treatments.

Out-of-pocket costs for all treatment regimes are becoming a concern to oncologists. In a recent survey, 84% of oncologists indicated that their decisions regarding the type of treatment to prescribe are influenced by patients' out-of-pocket expenses. While 67% of oncologists in the survey believe that every US citizen should have access to effective cancer treatments regardless of costs, 56% indicated that the cost of new cancer drugs influenced their treatment recommendations. In addition, 58% indicated that patients should have access to effective cancer treatments only if the treatments provide "good value for the money" or are cost effective.[73] The challenging questions, of course, are: who determines whether a treatment provides good value for the money and what comparative effectiveness or pharmacoeconomic evidence is available to guide that determination?

The out-of-pocket costs for oral chemotherapy and intravenous/injectable chemotherapy for individuals vary depending on their medical plan design and their prescription drug plan design.

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[71] Express Scripts. "2009 Drug Trend Report." April 2010.

[72] Medco. "2010 Drug Trend Report."

[73] Peter J. Neumann, Jennifer A. Palmer, Eric Nadler, ChiHui Fang, and Peter Ubel. "Cancer Therapy Costs Influence Treatment: A National Survey of Oncologists." *Health Affairs* 29, Issue 1. Jan. 2010.

One carrier analyzed its own claims for similar legislation in other states and found that requiring parity for chemotherapy treatments would actually increase out-of-pocket costs for some individuals.[74] Details are as follows:

- 75% of affected members would be favorably impacted by approximately $150 annually
- 18% would be unfavorably impacted by approximately $165 annually
- 7% would be unfavorably impacted by approximately $1,600 annually

Of the 7% that would be unfavorably impacted by approximately $1,600, 40% would incur an additional out-of-pocket cost of $2,700 due to the proposed mandate. [We are assuming that, for these individuals, the oral chemotherapy drug benefit (which currently has copays) would be changed to reflect the medical benefit (which, for these individuals, has higher front-end deductibles, a coinsurance cost sharing requirement, and higher out-of-pocket limits).] This carrier indicated that currently, it only has drug benefits with a maximum of three tiers of copayments, and that it does not subject any of the drugs under the non-integrated drug plans to coinsurance cost sharing without out-of-pocket maximums.

For individual employees enrolled in plans that use coinsurance for a high-cost or specialty tier of medicines without any out-of-pocket limit, the costs for oral chemotherapy can be substantial.[75] For example, a 25% coinsurance provision for a $100 drug is a manageable $25 for an employee, but the same provision for a $10,000 prescription would be $2,500, a substantial burden.

None of the surveyed health plans in Maryland indicated that they classify oral chemotherapy medications separately for their insured plans. A recent survey reported that, nationwide, 14% of large employers have drug plans with coinsurance,[76] but others are considering implementing coinsurance in light of prescription drug cost trends. The 2009 Mercer survey shows that only 8% of large groups in Maryland use coinsurance for one or more drug categories.[77]

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[74] UnitedHealth Group.

[75] Fitch, et al.

[76] The Pharmacy Benefit Management Institute. "Prescription Drug Benefit Cost and Plan Design Online Report." 2008-2009 Edition.

[77].Mercer. "2009 Mercer Survey of Employer Sponsored Health Plans, A Special Report: Maryland Large Employers." 2009.

We surveyed health plans in Maryland to ascertain the current level of copays for oral chemotherapy drugs. Table 3 illustrates the results.

Table 3:
Maryland Health Plan Copays for Oral Chemotherapy Drugs

Carrier	**Copays for Oral Chemotherapy Drugs (Per 30-day Supply)**
A*	$200
B	$20 to $25
C	$0 to $60
D	$20 to $75
E	$0 to $50
F	$25 to $30

** Carrier A was the only carrier reporting a unique copay for oral chemotherapy drugs. All the other carriers reported that these drugs are considered the same as any other drug, meaning that some of these drugs qualify as generic (and are subject to the generic copay), some qualify as preferred brand-name drugs (and are subject to the preferred brand -name drug copay) and some may be classified as non-preferred brand-name drugs (and would be subject to the non-preferred brand-name drug copay). With the exception of Carrier A, the carriers indicated that they did not base their classifications of chemotherapy drugs on costs, and that many were available under both generic and preferred brand-name drug tiers.*

Maryland carriers reported that almost all of the large self-insured plans that they administer treat chemotherapy expenses the same way the insured plans treat chemotherapy expenses, and that when a self-insured plan elected a coinsurance design for a specialty tier, the cost sharing per prescription would usually be capped at an amount commonly between $75 and $200.

The Milliman study indicates that plan provisions affect anticancer drug use. In particular, the study demonstrates that higher cost sharing for oral chemotherapy medicines is associated with lower utilization of these drugs.[78] Data shows an inverse relationship between the percentage of cost sharing and the number of claims per patient. “These data suggest that oral/intravenous/ injected chemotherapy parity will increase drug utilization, which will increase cost.”[79]

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[78] Fitch, et al.

[79] Fitch, et al.

It is difficult to estimate the financial burden for individuals. Only three carriers provided any information on the average cost sharing for oral chemotherapy drugs paid through the pharmacy benefit versus cost sharing for chemotherapy paid through the medical benefit. Even this information was inconsistent with one carrier reporting higher cost sharing for chemotherapy claims under the medical benefit: one carrier reporting higher cost sharing for chemotherapy paid under the drug benefit; and one carrier indicating the cost sharing are the same. Therefore, cost-sharing comparisons based on Maryland-specific data are not possible with the information we received.

We would like to have obtained more information from more carriers, but the other carriers indicated this information was not available.

Maryland's unions are generally in favor of this proposed mandate, but some cited concerns about how it would be administered. Union spokespeople indicated that the provision was not currently a part of most contracts.

Financial Impact

In this section, we estimate how much it would cost to enact the proposed mandate. We compare our estimates with those of other sources, including Maryland health carriers.

Mercer asked six major carriers in Maryland to estimate how adopting this mandate would affect claims costs. Five carriers provided estimates.

The following table summarizes the carriers' responses.

Table 4
Carriers' Estimates of Proposed Mandate's Cost Impact

Carrier	$ per Member per Year	% of Claims
1	$13.14 to $17.08	0.4% to 0.6%
2	$0.00	0.00%
3	$0.00 to $6.20	0.0% to 0.2%
4	$0.00	0.0%
5	$0.03	0.0%

The Maryland Department of Legislative Services prepared a Fiscal and Policy Note estimating the cost of this proposed benefit at $10.77 per member per year.[80] This is

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[80] Department of Legislative Services, Maryland General Assembly. 2010 Session. "Fiscal and Policy Note for House Bill 626." February 2010.

within the range that we observe from the survey of carriers, although it is toward the high end.

Mercer completed an independent estimate. Because of the carriers' incomplete survey responses regarding incidence rates and the utilization of oral chemotherapies for the currently insured population, we had to rely on public data. We were able to use Maryland carrier data for information on copays for drug programs. We used the following assumptions:

- The incidence rate of members seeking cancer care for the commercial population varied from a low of 0.5 per thousand members[81] to a high of 1.5 per thousand members.[82]
- The percentage of individuals with cancer-seeking chemotherapy ranged from 25%[83] to 33%.[84]
- The percentage of chemotherapy patients that use oral chemotherapy ranges from 65%[85] to 80%.[86]
- The average number of prescriptions for oral chemotherapy per patient per year is 26.[87]
- The average copayment per prescription in Maryland as a whole ranges from $15 to $50. This range is based on the carriers' responses, which are then weighted based on their percentage (based on premium) of the Maryland group market. We are also assuming that those who are undergoing chemotherapy will have satisfied any out-of-pocket cost sharing under the medical plan via other benefits. This is a conservative assumption.[88]
- Compliance with this mandate will be achieved by eliminating the cost-sharing provisions under the drug program. We have not provided for any decrease in benefit resulting from this proposed mandate.

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[81] CHBRP.

[82] Fitch, et al.

[83] Fitch, et al.

[84] CHBRP.

[85] Fitch, et al.

[86] CHBRP.

[87] CHBRP.

[88] As Table 5 shows, the estimated range of the full cost of this mandate is immaterial, so the conservativeness attributable to this assumption is immaterial.

Table 5
Estimates of Full Costs

	Low	High
Rate of members seeking cancer treatment in any year	5/1,000	15/1,000
% of members seeking cancer treatment that use chemotherapy	25%	33%
% of members using chemotherapy that use oral chemotherapy	65%	80%
# scripts per year	26	26
Copay per script	$15	$50
$PMPY	$0.32	$5.20
Members/EE	1.827	1.827
$PEPY	$0.58	$9.50
% of claims	0.0%	0.2%

The carriers estimating no impact on premium represent 70% of the group medical premium in Maryland. Based on this statistic, we assume a marginal cost of 30%.

Table 6
Estimates of Full and Marginal Costs

	Full Cost	Marginal Cost
Estimated cost as a percentage of average cost per group policy	0.0% – 0.2%	0.0% – 0.1%
Estimated cost as a percentage of average wage	0.00% – 0.02%	0.01% – 0.01%
Estimated annual per- employee cost	$0.58 – $9.50	$0.17 – $2.85

Please note that these estimates do *not* include any provision for additional administrative costs. Several carriers expressed concerns regarding the costs of administering this benefit. These concerns were also expressed during a discussion with the medical directors of several of the carriers.

Since the medical benefits and the drug benefits are often administered under entirely different systems – and sometimes by different entities – the cost of integrating these systems for one subset of benefits would be very high. Several carriers questioned whether these additional costs were justified, given the limited number of insureds who would benefit from this change (and also given the fact that some might actually experience an increase in cost sharing). None of the carriers provided any dollar estimates for implementation costs.

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3

Expansion of Habilitative Services – Financial Impact Analysis

Background

In 2007, a proposed mandate requiring coverage of habilitative services, regardless of age was introduced but did not pass. Mercer, the Commission's consulting actuary, prepared an evaluation of the proposed mandate, as presented in a report dated December 20, 2007.

As presented, HB 1192/SB 944 (2007) would have required a health insurer, nonprofit health service plan, Medicaid managed care organization, or HMO (further referred to as a "carrier") to provide coverage for habilitative services for persons of all ages who suffered "congenital or genetic birth defects," including but not limited to autism spectrum disorder (ASD) or cerebral palsy (CP). Guidance from the Maryland Department of Legislative Services (DLS) indicated that the intent of this proposed mandate was *to limit services to individuals who suffered developmental disabilities resulting from these conditions*. As defined in the proposed legislation, habilitative services are occupational, physical, and speech therapy (OT, PT, and ST) treatments that enhance the functioning ability of a person with the prescribed conditions. Mercer used this interpretation and definition for its analysis.

The state of Maryland currently mandates coverage of these services for children who are developmentally disabled by birth defects, ASD, or CP through age 18. This proposed mandate would have extended coverage to affected persons from 19 through 64 years of age.

Introduction

In a letter dated March 11, 2010, the Senate Finance Committee (Committee) of the State of Maryland requested that the Commission examine the impact of a new proposed mandate very similar to the earlier proposal in 2007. This new proposed mandate, introduced as SB 445 of 2010, and before that as SB 564 of 2009, would require health insurers in the State to cover habilitative services up to age 25. The Committee has requested this additional analysis due to the potential cost impact of these bills on health insurance plans in the State.

The Committee has also requested that the Commission examine the potential cost impact to health insurance plans of a gradual phase-in of the requirement (i.e., up to and including age 19 in the first year after enactment of such a mandate, up to and including age 20 in the second year, and so on, until age 25, at which time coverage for the services would end).
In the conduct of the cost analysis, Mercer assumed (at the Commission's direction) that the only difference between this proposed mandate and the 2007 proposed mandate is the ages to which the covered services would be provided.

If either the parameters for the services to be provided or the population to whom these services would be extended differed significantly from those assumed, these estimates would not be appropriate.

A discussion of the financial impact of this proposed mandate follows. Mercer was not asked to address the medical or social impact of the proposal, as those aspects of the proposed mandate were covered in the 2007 report.

Recap of 2007 Cost Estimates – Expansion of Coverage to Ages 19 to 64

Below is a summary of the 2007 cost estimates for ages 19 to 64. Mercer included this summary in this report for reference, as these results and the underlying pricing approach have been used, in part, in determining cost estimates for the 19 to 24 age group under the new proposal (discussed later in this report).

As background, it was noted in the 2007 report that statistics on the incidence and costs associated with habilitative services were not readily available for ages 19 through 64. Below are examples of statements to that effect from the 2007 report.

> *"Although there are many studies and articles about the positive outcomes of the various therapies, the studies and articles do not access the cost of these therapies nor the cost benefit that results."*

> *"Data that track the use of these services by treating physicians for the target population were not available."*
>
> *"Efforts to use data from the Maryland Medicaid program as a proxy proved problematic because claims data focus on the primary diagnosis being treated, not any underlying conditions that may have been present at birth. Therefore, a search of the claims data by diagnosis would yield a very modest return, especially for services rendered to adults. There is no clear identifier or reasonable proxy for sorting the Medicaid claims data."*
>
> *"Statistics for incidence and costs of habilitative services for adults disabled by birth defects, ASD and CP are not readily available."*

However, in the 2007 report, Mercer did note the various sources of information available to determine the extent to which habilitative services were generally utilized by a portion of the population. Mercer had considered all of those sources and estimated that the prevalence of developmentally disabling birth defects, ASD, and CP among people age 19 to 64 was between 1% and 2%. Mercer stated: *"due to the low prevalence rates, it can be presumed that only a small portion of the population generally uses these services."*

Mercer had also surveyed four major carriers in Maryland in 2007, asking them to provide financial estimates as to how rates would be affected. Responses include the following:

- ***Carrier A** – "It is very difficult to anticipate premium increases, but, in addition to costs of care, we anticipate programming and operational changes costing in the 10's of millions of dollars."*

- ***Carrier B** – "This company's actuaries indicated that there was no way to estimate the increase in premium based on the language in the proposed mandate. With no defined scope of services, and with the wide variety of possible conditions and treatments, they felt they could not begin to quantify that information."*

- ***Carrier C** – "Removing age limits would require a rate increase of between $4.00 and $8.00 PMPM. Our calculations indicate that this equates to 2% to 3% of premium."*

- ***Carrier D –** "This carrier estimated that premiums would increase by 0.7%."*

Because of the very limited data available regarding the use and cost of habilitative services for adults who suffer from developmental disabilities associated with congenital or genetic birth defects, Mercer had provided a range of cost estimates using two different methods, as illustrated below in Table 1. These cost estimates reflected three primary sources, including 1) various sources of information cited in the 2007 report; 2) responses from the carrier surveys, and; 3) Medicaid data in other states.

Table 1
Claim Cost Estimates for Habilitative Services – Ages 19 to 64
December 20, 2007 Report
(Excluding Potential Increases in Administrative Costs)

	Approach A		Approach B	
	Low	**High**	**Low**	**High**
Estimated cost as a percentage of average cost per Maryland policy	0.8%	5.1%	0.9%	1.9%
Estimated cost as a percentage of average wage	0.1%	0.4%	0.1%	0.2%
Estimated annual per-employee cost for Maryland's policies	$39	$261	$50	$100

Financial Impact – Expansion of Coverage to Ages 19 to 24 (Current Proposal)

Health Plan Medical Directors' Input

To help assess potential financial and administrative concerns about the current proposed mandate, MHCC invited the medical directors of several of Maryland's larger health plans to provide insight. Several issues were raised during these discussions.

One carrier expressed difficulty in defining habilitative versus rehabilitative services. This carrier also expressed concern about being responsible for administering any treatment plans that may be associated with habilitative services.

A second carrier expressed concern over whether there would be enough provider capacity for the necessary habilitative services (occupational, physical, and speech therapy).

A third carrier stated that the mandate could be very costly and cited several concerns, as follows: 1) The mandate does not address the need for any required plan of care or continued need for care. 2) What would stop the age cap from being extended beyond age 25? 3) Had any analysis ever proved that these services improved patient outcomes? 4) Any "creep" in scope and diagnosis of services would potentially add to the cost.

The general conclusion from these interviews was that, while carriers were concerned with the costs and issues that could arise during the proposed mandate's implementation and ongoing administration, at the time of these discussions no carrier had quantified the potential cost impact.

2010 Carrier Survey

To supplement the interviews with the carriers' medical directors, Mercer conducted a written survey of several of the major carriers in Maryland, as was done in 2007. The purpose was to determine 1) the extent to which carriers already cover habilitative services up to age 25; 2) the cost of those services; 3) the services' estimated impact on premium; and 4) other administrative issues that the carriers might foresee with the proposed mandate. Five carriers answered the Mercer survey, and their responses suggested a wide range of possible outcomes. Key results are as follows:

- **Current Coverage:** Based on our interpretation of the carriers' survey responses, carriers are providing habilitative services up to age 19 only, and no carrier is currently providing the benefits of the proposed mandate up to age 25.

- **Claim Costs:** Claim cost estimates for habilitative services for the existing mandate vary widely by carrier, as noted in the following:

    - **Carrier # 1: $22.36 PMPY**
    - **Carrier # 2: $50.09 PMPY**
    - **Carrier # 3: $79.90 PMPY**
    - **Carrier # 4: $174.15 PMPY**
    - **Carrier # 5: The average cost ranged from $9,100 to $18,200 per year for people who utilize habilitative services. No PMPY cost was provided.**
    - **Average: $81.63 PMPY, excluding Carrier # 5.**

- **Premiums:** Carriers were asked to estimate the impact on premium for this proposed mandate. Responses varied across a wide range of possible outcomes, as follows:

    - **Carrier #1: 0.02% of premium**
    - **Carrier #2: 0% (This carrier said there would be no impact on premium)**
    - **Carrier #3: 0.4% to 1.1% of premium, depending on plan design**
    - **Carrier #4: $.03 PMPM premium, or $0.36 PMPY**
    - **Carrier #5: Did not quantify, but qualified their estimate as a "moderate" to "significant" impact on premium**

These results show that the carriers have widely varying estimates for the reasons given above related to the broad and non-specific nature of the proposed mandate.

Results of the annual small group health plan premium survey conducted by MHCC show that the average annual premium per policy (for all lives covered under the policy) was approximately $7,100 in 2009. Mercer estimates this to be a reasonable proxy for the average combined premium of group (small and large) and individual plans. Using the estimates from the carriers above, this would result in an average premium for habilitative services for the age group 19 to 24 ranging from $0 to $78. The high end of the range of $78 represents 1.1% (from Carrier #3 above) of $7,100. This range of premium estimates could be even greater, as Carrier #5 did not provide a specific estimate, but indicated that the premium impact could be significant.

- **Administrative issues:** Only one carrier (Carrier #1) expressed concern in the survey over potential administrative issues or additional related administrative costs associated with the proposed mandated benefit. This differed from the 2007 survey results, in which several carriers raised concern over certain potential administrative issues and their potential costs. This also differed from the opinions that the carriers' medical directors conveyed during the telephone interviews this year (as noted above). The survey response from Carrier #1 was as follows:

  > *"Habilitative care is repetitive in nature and often delivered by non- licensed persons. We are concerned with the educational and license status of several of the behavioral and other types of therapists who deliver habilitative services. Our estimated cost assumes no expansion in the current scope of covered habilitative services (only the increase in age); any "creep" in scope could considerably increase costs."*

Although the new carrier surveys revealed more details on potential cost estimates than were available in the 2007 surveys, the results that are discussed above reveal that potential costs and premiums could vary across a relatively wide range of estimates.

A summary of this carrier information is outlined in Table 2 below. As illustrated, no direct correlation appears to exist between the costs for habilitative services at ages 0 to 18 and the range of premium estimates for ages 19 to 24.

Table 2
Estimated Cost and Premium for Habilitative Services
Summary of 2010 Carrier Surveys

Carrier	**Estimated PMPY Cost Current Mandate (Ages 0 – 18)**	**Estimated PMPY Premium Proposed Mandate (Ages 19 – 24)**
# 1	$22.36	$1.42 *
# 2	$50.09	$0
# 3	$79.90	$28.40 – $78.10 *
# 4	$174.15	$0.36
# 5	*Not available*	“Moderate” to “Significant”
Average All Carriers	$81.63	$7.55 – $19.97
Range	$22.36 – $174.15	$0 – $78.10

** Based on an assumed average annual premium of $7,100*

Independent Mercer 2010 Cost Estimates – Expansion of Coverage to Ages 19 to 24 - (Methods A and B)

While the carrier surveys serve as one resource for determining the proposed mandate’s potential cost, Mercer has developed two other methods for estimating the potential costs of extending habilitative services up to age 25.

Method # 1: Indirect Method – Ages 19 to 24 Relative to Ages 19 to 64

The first method provides a proxy for the cost of the 19 to 24 age group relative to the cost for the 19 to 64 age group. This method uses two primary sources of information: 1) an update to the results from the 2007 study for ages 19 to 64, using the same approaches (Approach A and Approach B) from that study, and 2) new information Mercer obtained from the Maryland Medicaid program for both age groups 19 to 24 and 19 to 64.

Mercer updated the cost estimates for ages 19 to 64 using the most recent 2010 cost information and trends available from several of the same sources used in the 2007 study. These estimates, shown below in Table 3, are updates of the estimated costs presented above in Table 1 from the 2007 study.

Table 3
2010 Claim Cost Estimates for Habilitative Services – Ages 19 to 64
Update to 2007 Study
(Excluding Potential Increases in Administrative Costs)

	Approach A		**Approach B**	
	Low	**High**	**Low**	**High**
Estimated cost of mandated benefits as a percentage of average cost per Maryland policy	0.66%	4.46%	1.20%	2.39%
Estimated cost as a percentage of average wage	0.08%	0.53%	0.14%	0.28%
Estimated annual per-employee cost of mandated benefits for Maryland's policies	$39	$266	$71	$143

Using the cost estimates in Table 3 for ages 19 to 64 and the new Maryland Medicaid data, Mercer estimated the costs for habilitative services for the 19 to 24 age group.

Mercer obtained the new Maryland Medicaid data from the Department of Health and Mental Hygiene (DHMH)[89] and The Hilltop Institute of the University of Maryland, Baltimore County (UMBC)[90]. This data was instrumental to Mercer's analysis as it contained complete medical service records as well as cost and utilization information for calendar years 2006 through 2009 for enrollees using habilitative services. This level of detail and completeness in the data was not available at the time of the 2007 study. Mercer wishes to thank the DHMH and UMBC for their help in preparing this data. Under this method, Mercer used summary information for the Maryland Medicaid data for age groups 19 to 24 and 19 to 64. While not without limitation, the data enabled Mercer to estimate the cost of habilitative services for the 19 to 24 age group relative to the cost for these same services for the 19 to 64 age group. These cost relativities are presented in Table 4.

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[89] Maryland Department of Health and Mental Hygiene.

[90] The Hilltop Institute at the University of Maryland, Baltimore County.

Table 4
Average Annual Maryland Medicaid Amounts 2006 to 2009 for Enrollees Receiving Habilitative Services

	Ages 19 – 24	**Ages 19 – 64**	**Ratio**
Number of Enrollees	350	785	45%
Medicaid Allowed Charges	$7,096,526	$33,097,088	21%
Number of Services	44,803	192,915	23%
Services per Enrollee	128	246	52%
Services/Enrollee/Week	2.5	4.7	52%
Charge per Service	$158.39	$171.56	92%
Charge per Enrollee	$20,305	$42,189	48%

Table 4 illustrates that the average annual number of enrollees, number of services per enrollee, and allowed charges per enrollee over the four-year period of 2006 through 2009 for the 19 to 24 age group are approximately half of those for the 19 to 64 age group. However, the ratio for the overall number of services and allowed charges is only slightly more than 20%, suggesting that providing these services for the 19 to 24 age group costs approximately one-fifth as much as it does for the 19 to 64 age group.

Applying the 21% cost ratio in line 2 of Table 4 to the estimated cost values in Table 3 for ages 19 to 64 yields a cost estimate for habilitative services for the 19 to 24 age group. Results are presented in Table 5.

Table 5
2010 Cost Estimates for Habilitative Services – Ages 19 to 24: 21% of the Estimated Cost for Ages 19 to 64 in Table 3
(Excluding Potential Increases in Administrative Costs)

	Approach A		**Approach B**	
	Low	**High**	**Low**	**High**
Estimated cost of mandated benefits as a percentage of average cost per Maryland policy	0.14%	0.94%	0.25%	0.50%
Estimated cost as a percentage of average wage	0.02%	0.11%	0.03%	0.06%
Estimated annual per-employee cost of mandated benefits for Maryland's policies	$8	$56	$15	$30

Method # 2: Direct Method – Cost Estimate for Expansion of Coverage to Ages 19 to 24 (Approach C)

Under this second method, Mercer utilized detailed service records for each individual enrollee aged 19 to 24 from the Maryland Medicaid data cited above for calendar years 2006 through 2009, along with publicly available Maryland Medicaid enrollee data, to directly estimate the cost of habilitative services for the 19 to 24 age group. The Medicaid service records exclude all personal information that could be used to identify the person receiving the services. Mercer adjusted this cost analysis for trend and anticipated reimbursement levels in the commercial market. Table 6 presents the results of Mercer's analysis (labeled as Approach C) compared with the results from Method #1 above (Approach A and Approach B) from Table 5.

Table 6
2010 Direct Cost Estimates for Habilitative Services – Ages 19 to 24
(Approach C)
(Excluding Potential Increases in Administrative Costs)

	From Table 5				Approach C	
	Approach A		Approach B			
	Low	High	Low	High	Low	High
Estimated cost of mandated benefits as a percentage of average cost per Maryland policy	0.14%	0.94%	0.25%	0.50%	0.49%	0.82%
Estimated cost as a percentage of average wage	0.02%	0.11%	0.03%	0.06%	0.06%	0.10%
Estimated annual per-employee cost of mandated benefits for Maryland's policies	$8	$56	$15	$30	$29	$49

Given that the Maryland Medicaid data appears to be the most complete and credible source available, Approach C represents Mercer's best estimate of the costs under the proposed mandate. The range of cost estimates under Approach C is somewhat higher than the range under Approach B, but within the range of Approach A. Also, the estimated annual per-employee costs under all three approaches fall within the estimated PMPY premium range of $0 to $78 from the carrier surveys in Table 2 above.

Phase-In of Proposed Mandate

As requested, Mercer also estimated the cost impact of phasing in the proposed mandate over a six-year period. Under this approach, habilitative services would be covered for only age 19 during the first year of implementation, ages 19 and 20 during the second year, and so on, until mandated habilitative services for ages 19 through 24 were covered during the sixth and later years after the mandate's implementation.

Table 7 below presents cumulative cost estimates at the end of each year of the proposed phase-in period based on 2010 dollar levels. The year six values are the same as illustrated above for Approach C in Table 6. Note that this distribution assumes that costs, premiums, and wages will all trend at the same rate each year. To the extent that any one or all three of these items trend at different rates or inflate beyond the 2010 dollar level, the distribution of anticipated costs in this table could differ from what is shown.

Table 7
Estimated Distribution of Habilitative Costs Over a Six-Year Phase-In Period: Cost Estimates Under Method # 2, Approach C

2010 Dollar Levels		Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
		Age 19	Ages 19–20	Ages 19–21	Ages 19–22	Ages 19–23	Ages 19–24
% Total Cost		**20%**	**38%**	**63%**	**78%**	**88%**	**100%**
Cost as % Pure Premium/Cert	**Min**	0.10%	0.18%	0.31%	0.38%	0.43%	0.49%
	Max	0.16%	0.31%	0.51%	0.64%	0.72%	0.82%
Cost as % Wage	**Min**	0.01%	0.02%	0.03%	0.04%	0.05%	0.06%
	Max	0.02%	0.04%	0.06%	0.08%	0.09%	0.10%
Average Cost/Cert per Year	**Min**	$6	$11	$18	$23	$26	$29
	Max	$10	$18	$31	$38	$43	$49

The cost pattern shown above would be replicated for estimates using the other two cost approaches. By this, we mean that 20% of the ultimate costs would be expected in the first year, 38% of the ultimate costs would be expected in the second year, and so on as shown in the table above, until 100% of the costs would be expected by the sixth year.

The relative complexities associated with healthcare reform (PPACA), particularly with respect to the timing and interaction of the various anticipated changes over the next several years, make it difficult to project the potential cost impact of this proposed mandate beyond 2010. Therefore, these cost estimates are based upon the market prior to any potential effects of PPACA. For example, PPACA requires extension of benefits to children up to age 26 as well as guarantee issue for children under age 19, among other benefit modifications.[91] These two changes in particular could result in an increase in membership of children who need habilitative services, and therefore these cost estimates may be aggressive (i.e., understated). While it is expected that the small group and large group market segments will see increases in the number of children due to the extension of dependent coverage up to 26, the individual market segment is probably most susceptible to anti-selection, especially for those carriers offering child only policies. The small group and large group markets have more members over which to spread these

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[91] Maryland already required coverage to dependents to age 25 prior to PPACA, but had more restrictive eligibility standards than PPACA.

additional costs than the individual market and minimize selection by employer contributions to the cost of insurance. This is not the case in the individual market, where parents/custodians must fund the entire premium and may elect to defer coverage for healthy children until they need insurance, but will have financial incentives to purchase insurance immediately for higher cost children, such as those that would use this benefit.

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Maryland Department of Health and Mental Hygiene. http://www.dhmh.state.md.us/

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Coverage for Treatment of Spinal Muscular Atrophy

House Bill 1557, entitled “Health Insurance – Coverage for Treatment of Spinal Muscular Atrophy”, introduced during the 2010 legislative session, outlines proposed coverage of certain nursing services for the treatment of spinal muscular atrophy (SMA). The bill would have required carriers to provide coverage for private duty nursing services as recommended by the treating physician for the treatment of SMA but the carrier would not be required to provide coverage exceeding 12 hours per day.

According to the Spinal Muscular Atrophy Foundation, SMA is a rare, inherited disease characterized by muscle atrophy and loss of motor function, caused by the absence of or defect in the Survival Motor Neuron 1 (SMN1) gene. This gene is responsible for a protein that is crucial to the health and survival of the nerve cells in the spinal cord that control muscle contraction. As these neurons become unhealthy due to the reduced SMN1 levels, muscles weaken and become atrophic.[92]

Clinically, the disease is classified into four types, by degree of severity (as shown in Table 1).

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[92] Spinal Muscular Atrophy (SMA) Foundation. “Frequently Asked Questions.” Accessed July 2010.

Table 1

Clinical Classification of Spinal Muscular Atrophy (SMA)			
SMA Type	**Age of Onset**	**Highest Function**	**Natural Age of Death**
Type 1 (severe)	0 - 6 months	Never sits	< 2 years
Type 2 (intermediate)	7 - 18 months	Never stands	> 2 years
Type 3 (mild)	> 18 months	Stands and walks	Adult
Type 4 (adult)	Second or third decade	Walks during adult years	Adult

There are many differences among the types but, for classification purposes, clinicians have focused on the age at onset, the highest function, and the typical age at death.[93] Type 1, also called Werdnig-Hoffmann disease, is the most severe and the most prevalent. About 60% of SMA patients have this form.[94] Type 1 patients display signs of SMA during their first six months of life, or in some instances, in utero. These patients are never able to sit and rarely survive beyond the age of two. They do maintain normal intellectual and emotional development, as do patients in the other three classifications.[95]

Type 2 patients (approximately 27% of SMA patients) have an intermediate form of the disease. Onset generally occurs within seven to 18 months after birth, and patients may survive into adulthood. During this time, patients may be able to sit unassisted, but they are never able to stand or walk.

Type 3, also called Kugelberg-Welander or Juvenile Spinal Muscular Atrophy, is considered a mild form of SMA. Symptoms appear after 18 months, and these patients often survive well into adulthood. They can stand and walk with limited assistance during much of their lives.

Little information exists on Type 4, an adult form of the disease. This less common form involves a slower progression of symptoms that typically affect walking. Symptoms begin to show during the second or third decade of life.

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[93] C.H. Wang, R.S. Finkel, E.S. Bertini, M. Schroth, A. Simonds, B. Wong, A. Aloysius, L. Morrison, M. Main, T.O. Crawford, A. Trela, and Participants of the International Conference of SMA Standard of Care. "Consensus Statement for Standard of Care in Spinal Muscular Atrophy." *Journal of Child Neurology* 22, No. 8 (August 2007).

[94] SMA Foundation. "Frequently Asked Questions."

[95] SMA Foundation. "Frequently Asked Questions."

Medical Impact

This section, we address questions regarding coverage of private-duty nursing services for SMA patients.

- **Does the medical community consider private-duty nursing essential and/or effective in treating SMA patients?**
- **Does the medical community consider private-duty nursing to be appropriate and necessary, as evidenced by scientific and peer review of literature?**
- **Is private-duty nursing available to and utilized by treating physicians?**

According to the International Standard of Care Committee for Spinal Muscular Atrophy (the Committee), care for SMA patients should be determined by current functional status rather than original classification of disease type.[96] The current classifications include (1) non-sitters, or patients who cannot sit independently, (2) sitters, including those who can sit independently but cannot walk, and (3) walkers. In seeking to develop a consensus statement, the Committee focused on five care areas:

- diagnostic/new interventions
- pulmonary
- gastrointestinal/nutrition
- orthopedics/rehabilitation
- palliative care.

Consensus was achieved in many areas, and these have become the basis for standards of care for SMA. The Spinal Muscular Atrophy Foundation summarizes the Committee's recommendations as follows:

- **Confirm the diagnosis –** Verify the diagnosis with a simple genetic blood test, to help medical professionals plan for and provide patient-specific care.
- **Manage breathing –** Respiratory problems are cited as the top cause of illness and the most common cause of death among children with SMA types 1 and 2. The goal is to educate patients and families on how to (1) manage breathing and employ techniques to maintain clear airways, (2) take measures to prevent respiratory problems, and (3) learn how to minimize the impact of respiratory infection.
- **Manage eating and nutrition –** Patients with SMA are susceptible to both over- and under-nutrition problems. Families and health care professionals work together to monitor growth and closely follow personal nutrition plans.

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[96] C.H. Wang, et al.

- **Muscle movement and daily activities –** Maintaining function of trunk, arm, leg, and neck muscles helps patients achieve their highest level of function and independence. Health care professionals design individual physical therapy plans and recommend assistive devices, tools and exercises to help slow or prevent complications of SMA.

- **Prepare for illness –** Families are encouraged to develop plans for the inevitable medical emergencies and to share the plans with all health care professionals involved in the patient's care.[97]

The "standard of care" literature for SMA makes no explicit reference to private-duty nursing services. Nevertheless, treatment for SMA types 1 and 2 is care intensive and draws on the skills of numerous health professionals who participate in the assessment, contribute to the chronic care plan, monitor the patient's status, adjust the plan as necessary, and respond as circumstances warrant. Chronic management requires discussion of the family's goals, including balancing caring for the child at home for as long as possible, long-term survival, quality of life and comfort, the availability of resources, and the illness's potential burden on the family.[98]

Experts note that there is a wide range of care for SMA patients. A reasonably comprehensive plan may draw on the skills of medical doctors, physical therapists, occupational therapists, nutritionists, respiratory therapists, and/or hospice professionals. Disparity in family resources, medical practitioners' knowledge, and regional and cultural standards contribute to variations in care plans even when severity is similar.[99] One example is pulmonary care for Type 1 children and the use of mechanical ventilation. Some patients and their families are not offered any form of respiratory support, while others are routinely treated with a full array of respiratory assistance and supportive care.[100] Certain treatments, such as invasive mechanical ventilation, may lead to extensive nursing care.[101] [102]

Much of the ongoing care that is provided under the direction of these professionals is highly technical but can be provided by family caregivers. Indeed, as will be reported in the next section, some carriers specifically allow the skilled nursing benefit when the

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[97] SMA Foundation. "Frequently Asked Questions."

[98] C.H. Wang, et al.

[99] C.H. Wang, et al.

[100] M.K.M. Hardart, R.D. Truog. "Spinal Muscular Atrophy – Type 1 – The Challenge of Defining a Child's Best Interests." *Archives of Disease in Childhood* 88 (2003).

[101] M.K.M. Hardart, et al.

[102] There is a wide range of care for SMA patients. Literature indicates that ventilation in the US is less common than it is in other parts of the world, e.g., Japan, and that invasive ventilation is even rarer, in part because of its significant expense in relation to non-invasive measures.

services involve teaching family members how to deliver the needed care. However, the emotional and financial[103] burden on caregivers can be substantial. As a result, private-duty nurses may play important roles in providing hands-on care to SMA Type 1 and 2 patients in relief of family caregivers.

In addition to a review of the literature, Mercer participated in a conference call with the medical directors of the major carriers to discuss the medical aspects of several proposed mandates including SMA.

During the call, concern was expressed regarding this benefit. Several medical directors questioned why this particular condition should be given special treatment when there are other conditions as severe that would not enjoy the benefit. Concern was also expressed regarding “diagnosis creep” – specifically that the mere availability of private duty nursing services increases the demand for and cost of private duty nursing services and hinders development of a “circle of need” for care and may prevent or discourage caregivers from learning how to care for members with this condition.

It should be noted that carriers often provide private duty nursing services as a respite for family members when a physician indicates that the respite care is necessary.

It is particularly important to note the impact of the proposed mandate on the carriers. According to the Maryland Insurance Administration, those carriers that exclude private duty nursing coverage would need to modify their plans to cover these services. In addition, those carriers that do not exclude the coverage but instead apply their own medical necessity criteria to determine coverage would be required to defer to the treating physicians’ recommendations. In effect, the proposed mandate removes any opportunity for anyone other than the attending physician to review the clinical necessity and appropriateness of these services. [104]

Social Impact

In this section, we address the following questions:

- **To what extent will the proposed change generally be utilized by a significant portion of the population?**
- **To what extent is the insurance coverage already available?**
- **To what extent does the lack of coverage result in individuals’ avoiding necessary health care treatments?**

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[103] David Greenberg. “A Cost-Benefit Analysis of Maryland’s Medical Child Care Centers.” Maryland Institute for Policy Analysis and Research. University of Maryland, Baltimore County. December 2008.

[104] Assistant Attorney General. Maryland Insurance Administration. January 2011.

- **To what extent does lack of coverage result in unreasonable financial hardship?**

- **What is the level of public demand for these services?**

- **To what extent is the mandated health insurance service covered by self-funded employers in the state with at least 500 employees?**

It is estimated that one in 6,000 to one in 10,000 live births are affected with SMA, making it one of the most common lethal genetic diseases.[105] Over 60 percent of these babies have the most severe form[106] and generally do not survive beyond their second birthday.[107] Others with Types II and III SMA generally live into adulthood and could have normal life expectancy.[108]

Maryland health plans that were surveyed as part of this study indicated limited incidence among their covered populations, ranging from a low of 0.01 cases per 1,000 member years to a high of .1 per 1,000 members years. The majority of companies reported incidences of .01 per 1,000 member years to .05 per 1,000 member years.

The estimates of the surveyed health plans are generally supported by national figures. The SMA Foundation in its "Introduction for SMA Families" estimates that there are 25,000 SMA patients in the US.[109] Based on an estimated national population of 380,000,000 in 2010[110], there are six to seven SMA patients per 100,000 Americans nationally. If this rate were mirrored among Maryland's covered population of 3,590,609[111], there would be 215 to 251 patients in the state distributed among insured, self–funded, and public programs.[112]

Although many covered individuals already have coverage for SMA nursing services, others do not. Table 2 summarizes the responses of the health plans responding to the survey.

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[105] B.C. Hendrickson, C. Donohoe, V.R. Akmaev, E.A. Sugarman, P. Labrousse, L. Boguslavskiy, K. Flynn, E.M. Rohlfs, A. Walker, B. Allitto, C. Sears, and T. Scholl. "Differences in SMN1 allele frequencies among ethnic groups within North America." *Journal of Medical Genetics* published online June 21, 2009.

[106] B.C. Hendrickson, et al.

[107] M.K.M. Hardart, et al.

[108] SMA Foundation. "Frequently Asked Questions."

[109] "Spinal Muscular Atrophy: Introduction for SMA Families." SMA Foundation, New York, New York. February 2010.

[110] Robert Schlesinger. "U.S. Population, 2010: 308 Million and Growing." *U.S. News and World Report* Politics & Policy Blog. December 30, 2009.

[111] Charles Milligan. "Overview of the Existing Insurance Market in Maryland." The Hilltop Institute. University of Maryland, Baltimore County. August 2010.

[112] The differences between the rate of live births with SMA and the population incidence rates reported by the carriers is in large part attributable to the high mortality among Type I patients during the first two years following birth.

Table 2

Health Plan	Coverage of SMA Private Duty Nursing Services
Carrier 1	Most fully insured plans exclude; some self-insured plans have limited coverage
Carrier 2	No insured plans cover but there is an approved endorsement available, although to date no one has purchased the endorsement
Carrier 3	All plans cover, subject to certain guidelines and limitations
Carrier 4	All plans cover
Carrier 5	Limited coverage for certain home health services; none for unskilled, or custodial, supportive nursing care

When services are covered, there often must be specific conditions. For example, Kaiser's covered home health care services are limited to evaluating, implementing, and teaching skilled nursing services to family care providers following a change in status. CIGNA covers services if they (1) are provided in lieu of institutionalization or (2) are established by a physician as part of an approved treatment plan.

Likewise, benefits may be limited. Aetna reports that, when home health care visits are covered, they are routinely limited to 120 days per year. CIGNA's contract options include duration limits of 40 to "unlimited" days. Of course, the cost will depend on the option selected.

All of the surveyed health plans limit or exclude coverage for services that are custodial in nature, and it appears that certain services contemplated by the proposed legislation fit the definition of custodial care. Table 3 illustrates.

Table 3

Health Plan	Custodial Care Definition
Aetna	Services and supplies that are primarily intended to help [the patient] meet personal needs… It may involve artificial methods such as feeding tubes, ventilators, or catheters. Examples … include: ▪ Routine patient care, such as changing dressings, periodic turning and positioning in bed, administering medications; ▪ Care of a stable tracheostomy (including intermittent suctioning); ▪ Care of a stable colostomy; ▪ Care of a stable gastrostomy/jejunostomy/nasogastric tube (intermittent or continuous) feedings; ▪ Care of a stable indwelling bladder catheter (including emptying/changing containers and clamping tubing); ▪ Watching or protecting [the patient]; ▪ Respite care, adult (or child) day care or convalescent care; ▪ Institutional care, including room and board for rest cures, adult day care and convalescent care; ▪ Help with daily living activities, such as walking, grooming, bathing, dressing, getting in or out of bed, toileting, eating, or preparing foods; ▪ Any services that a person without medical or paramedical training could be trained to perform; and ▪ Any service that can be performed by a person without any medical or paramedical training.
CareFirst	Any care that would not require a licensed health care professional. Private-Duty Nursing means skilled nursing care services, ordered by a physician that can only be provided by a licensed health care professional, based on a plan of treatment that specifically defines the skilled services to be provided as well as the time and duration of the proposed services. If the proposed services can be provided by a caregiver, or if the caregiver can be taught and demonstrates competency in the administration of same, then Skilled Nursing Care is not medically necessary. Skilled Nursing Care excludes services for performing the Activities of Daily Living including but not limited to bathing, feeding, or toileting.

Table 3 (continued)

Health Plan	Custodial Care Definition
CIGNA	Any services which are not intended primarily to treat a specific injury or sickness (including mental health and substance abuse). Custodial services include but are not limited to: ▪ Services related to watching or protecting a person; ▪ Services related to performing – or assisting a person in performing – any activities of daily living, such as (a) walking, (b) grooming, (c) bathing, (d) dressing, (e) getting in or out of bed, (f) toileting, (g) eating, (h) preparing foods, or (i) taking medications that can be self-administered; and Services not required to be performed by trained or skilled medical or paramedical personnel.
Coventry	Care that is primarily for meeting personal needs. For example, custodial care includes help in walking; getting in and out of bed; bathing; dressing; shopping; preparing and eating meals; performing general household services; taking medicine; or providing other home services mainly to help people in meeting personal, family, or domestic needs, to include extraordinary personal needs created by the illness of a family dependent. If no skilled need is identified, then the service would be classified as “custodial.”
Kaiser	Any care and/or service which is not medically necessary and required for treatment of a condition or illness.

The timing of services can also be important. Certain private-duty nursing services that are rendered immediately after a change in status (such as after acute illness requiring hospitalization) may be covered, but only for a limited time. Examples of these services include evaluating, implementing, and teaching skilled nursing services to family care providers. At other times, these same services would not be covered.

Survey responses indicate that large self-insured plans are very similar to smaller insured plans with respect to these services. Insurers such as CIGNA and Coventry, which indicated that these services are covered if certain conditions are met, reported that the self-insured plans they administer generally cover them on the same basis. Health plans such as Aetna and Kaiser, which do not generally cover these services for their insured customers, were not providing them to any of the self-insured plans that they administer. Finally, CareFirst reported that no self-insured plans had adopted its optional coverage endorsement.

Surveys of organized labor also indicated that this benefit is included in few, if any, contracts. The unions are mixed on supporting this particular mandate. Some thought it was a valid issue, while others were concerned that it would be subject to abuse and be difficult to administer properly. Unions are very concerned about the cost of health benefits in general and recognize that they must be selective of the mandates they are willing to support, as money spent on health benefits is not available for salaries or pension funding.

It is important to note that in the literature we reviewed, there is no evidence that patients are foregoing necessary care because their plan fails to cover certain private-duty nursing services. There is occasional reference to quality-of-life decisions with regard to SMA care.[113] Likewise, family life considerations are raised. Finally, there is also the infrequent report of major financial hardship.[114] Since most of the uncovered services that are addressed in the proposed legislation can be readily provided by family caregivers (albeit often at great inconvenience), little is written about foregone care.

That is not to say that the financial burden on those who choose to retain private-duty nurses to provide much of the custodial care is not substantial. A study of the cost-effectiveness of medical child care centers in Maryland estimated the private-duty nursing costs in 2008 to be $19.20 – $46.20 per hour.[115] Based on 12 hours a day for 365 days, this amounts to $84,096 –$202,356 in 2008 dollars. We would expect that private duty nursing services in the home setting would be more expensive than in a medical child care setting. Of course, there is a good chance that the patient may be hospitalized at some point(s) during the year so it is unreasonable to assume that these services would be provided for 365 days.[116] It is also important to reiterate that many of these services can be – and currently often are – provided by family caregivers.

Financial Impact

In this section, we estimate the cost of enacting the proposed mandate and compare the results of our analysis to those of other sources, including the estimates submitted by health carriers in Maryland.

Mercer surveyed six major carriers in Maryland to obtain information on current practices regarding providing private-duty nursing services for members with spinal muscular atrophy. Mercer also asked these carriers to provide incidence rates and estimates as to how premium would be affected if coverage were mandated for private-duty nursing services up to 12 hours per day with no other annual limit.

We received responses from five of the six carriers. Of the responding carriers, two indicated that they did not cover this benefit for fully insured plans (although one did

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[113] M.K.M Hardart, et al. and C.H. Wang, et al.

[114] William S. Ehart. “NY Insurance Company Ends Program Rather Than Pay Out Big.” *The Washington Times.* October 14, 2009.

[115] David Greenberg.

[116] David Greenberg, et al. study showed that 73.2% of the children of survey respondents (who attend one of the two centers) were hospitalized during any given year. Note that this data includes children with many different serious medical conditions, not just SMA.

offer a rider), two indicated that they covered private-duty nursing services under certain circumstances subject to annual limits, and one indicated that it would cover these services if a formal plan of care is submitted and it is deemed medically necessary. The following table summarizes the results of the proposed benefit's financial impact.

Table 4

Carrier	$ per Member per Year	% of Claims
1	$12.48	0.4%
2	$10.80	0.3%
3	$2.17	0.07%
4	$31.50	1.0%
5	$6.20 – $12.40	0.2% – 0.4%

The Department of Legislative Services completed a Fiscal and Policy Note of this proposed benefit. Its estimate was a cost of $0.57 $PMPM, or $6.84 per member per year. This is within the range that we observe from the survey of carriers.

Mercer completed an independent estimate. We employed the following assumptions:

- Incidence rates reported by the responding carriers ranged from one per 100,000 to five per 100,000. (We discounted the one respondent reporting 10 per 100,000 because the rate was so much higher than those provided by the other respondents and in the literature).

- We had two carrier sources for costs per day for private duty nursing services, ranging from $600 per 12-hour day ($50 per hour) to $1,000 per 12-hour day ($83 per hour).

- We estimated that 87% of individuals diagnosed with spinal muscular atrophy would need this type of care, based on the medical literature.

- We assumed there would be no cost sharing, as members with this type of condition would have met any out-of-pocket maximum on other services.

Table 5

	Low	High
Incidence	1/100,000	5/100,000
Cost per Day	$ 600	$1,000
Days/Year	365	365
Cost per Year	$ 219,000	$ 365,000
% Needing PDN	0.87	0.87
$ per Year	$ 190,530	$ 317,550
$PMPY	1.91	15.88
Members/Employee	1.827	1.827
$PEPY	$ 3.48	$ 29.01
% of Claims	0.1%	0.5%

While most carriers indicated that private duty nursing services would be covered under very specific circumstances, most indicated that the majority of the services anticipated under this proposed mandate would not currently be provided. We estimate that about 10 percent of the services covered under this mandate are currently being provided. This would cover the types of circumstances described earlier in this paper. This is a very rough estimate, as these statistics are not readily available. Table 6 shows estimated costs.

Table 6

	Full Cost	Marginal Cost
Estimated Cost as a Percentage of Average Cost Per Group Policy	0.1% – 0.5%	0.1% – 0.4%
Estimated Cost as a Percentage of Average Wage	0.01% – 0.06%	0.01% – 0.06%
Estimated Annual Per Employee Cost	$3.48 – $29.01	$3.13 – $26.10

Since few of the services required by this mandate proposal are currently covered by large, self-insured plans - the reference point for the essential benefits package - there is some likelihood that the state would have to fund these mandated services for policies delivered through the Maryland health benefits exchange after January 1, 2014.

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Wang, C.H., R.S. Finkel, E.S. Bertini, M. Schroth, A. Simonds, B. Wong, A. Aloysius, L. Morrison, M. Main, T.O. Crawford, A. Trela, and Participants of the International Conference of SMA Standard of Care. "Consensus Statement for Standard of Care in Spinal Muscular Atrophy." *Journal of Child Neurology* 22, No. 8 (August 2007). https://smaregistry.iu.edu/Links/Downloads/ICC_SMA_SoC_Consensus_Statement_EN.pdf

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Coverage of Preventive Physical Therapy Services for Patients Diagnosed with Multiple Sclerosis

Baltimore County Delegate Shirley Nathan-Pulliam is considering introducing legislation that would require carriers to include coverage of preventative physical therapy services for patients diagnosed with multiple sclerosis (MS). She envisions that the bill will closely follow a similar mandate adopted by the State of Illinois. Key provisions of that legislation are as follows:

- "A group or individual policy of accident and health insurance or managed care plan … must provide coverage for medically necessary preventative physical therapy for insureds diagnosed with multiple sclerosis."
- For this purpose "preventative physical therapy" means "physical therapy that is prescribed by a physician licensed to practice medicine in all of its branches for the purpose of treating parts of the body affected by multiple sclerosis, but only where the physical therapy includes reasonably defined goals, including but not limited to, sustaining the level of function the person has achieved, with periodic evaluation of the efficacy of the physical therapy against those goals."
- Such coverage will be subject to "the same deductible, coinsurance, waiting period, cost sharing limitation, treatment limitation, calendar year maximum, or other limitations as provided for other physical or rehabilitative therapy benefits covered by the policy."[117]

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[117] Illinois Public Act 094-1076, Sec. 10, adding Sec. 365z.8 to the Illinois Insurance Code.

According to the National Multiple Sclerosis Society, MS is a chronic, unpredictable disease of the central nervous system (the brain, optic nerves, and spinal cord). It is thought to be an autoimmune disorder; the immune system incorrectly attacks the person's healthy tissue. It can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness, and other complications. These problems may be permanent or may come and go.[118] Approximately 400,000 Americans have MS.[119]

Most people with MS are diagnosed between the ages of 20 and 50, although individuals as young as two and as old as 75 have developed it. It is not considered fatal, and the vast majority of afflicted people live a normal life span. Quality of life is a different issue, though. Most people with MS have difficulty living as productively as they would like, often facing increasing limitations.[120]

At least two to three times more women than men are diagnosed with MS. Studies suggest that genetic factors make some individuals more susceptible than others, but there is no indication that MS is directly inherited. The disease occurs in most ethnic groups but is more common in Caucasians of northern European ancestry.[121]

Medical Impact

In this section, we answer questions regarding coverage of preventive physical therapy (PT) for MS patients.

- **Does the medical community recognize physical therapy as being essential and/or effective in preventing the progression of the effects of MS?**

- **Does the medical community recognize preventive physical therapy as being appropriate and necessary, as evidenced by scientific and peer review of literature?**

- **Is preventive physical therapy utilized by treating physicians?**

We will begin by, summarizing the course of illness and outlining the National Multiple Sclerosis Society's recommended care for persons diagnosed with MS. We then examine

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[118] National Multiple Sclerosis Society. "Multiple Sclerosis: Just the Facts." Nov. 2009.

[119] "Multiple Sclerosis: Just the Facts."

[120] "Multiple Sclerosis: Just the Facts."

[121] "Multiple Sclerosis: Just the Facts."

physical therapy services as they relate to treating MS. Specifically, we examine the types of physical therapy services and distinguish between those generally covered by the carriers, which focus on restoring function, and those that are not, which focus on maintaining function and preventing a deterioration of function. Finally, we will point out the challenges of determining what is preventive and what is not and touch on evidence supporting the efficacy of preventive PT.

Course and treatment of the disease

There are four courses of MS, each of which may be mild, moderate, or severe. They are:

- **Relapsing-Remitting MS –** Clearly defined attacks of worsening neurological function. Attacks – sometimes called "relapses," "flare-ups," or "exacerbations" – are followed by partial or complete recovery periods, during which no disease progression is apparent. Approximately 85% of those afflicted by MS are initially diagnosed with relapsing-remitting MS.

- **Primary-Progressive MS –** Characterized by slowly worsening neurological function from the beginning, with no distinct relapses or remissions. The rate of progression may vary over time, with occasional plateaus and temporary minor improvements. Approximately 10% of people with MS are diagnosed with primary-progressive MS.

- **Secondary-Progressive MS –** After an initial period of relapsing-remitting MS, the disease worsens more steadily with or without occasional flare-ups, minor recoveries, or plateaus. Before disease-modifying medications became available, approximately 50% of people with relapsing-remitting MS developed this form within 10 years.

- **Progressive-Relapsing MS –** Steadily worsening from the onset, with clear attacks of worsening neurological function along the way. People may experience some recovery, but the disease continues without remission. Approximately 5% are diagnosed with progressive-relapsing MS.[122]

Most patients with MS initially have a "relapse-remitting" experience, meaning that they experience a period of time when the symptoms manifest themselves (very often with increasing magnitudes) followed by periods of partial or total remission. About 30% to 50% have periods of progressive symptoms within the first 10 years of diagnosis.[123] Relapse rates vary widely (0.1 to 1 attack per year), and patients with higher relapse rates

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[122] National Multiple Sclerosis Society. "What Is Multiple Sclerosis? The Four Courses of MS."

[123] Judith A. O'Brien et al. "Cost of Managing an Episode of Relapse in Multiple Sclerosis in the United States." BMC Health Services Research. 2003.

in the first two years have been observed to be at greater risk of more rapid progression to a severe level of disability.

There are wide variations in the severity and duration of relapses, which can include sensory loss, optical neuritis, and weakness of the limbs – leading to fatigue, disturbance of gait, and loss of dexterity. Some relapses can last up to several months.[124]

According to the National Multiple Sclerosis Society, recommended care for individuals diagnosed with MS includes:

1. Treatment with one of the FDA-approved "disease modifying" drugs as soon as possible after diagnosis. Drug therapy is recommended after an episode that places the individual at high risk for subsequently developing clinically definite MS.
2. For patients with secondary-progressive, progressive-relapsing, or worsening relapsing-remitting MS, an FDA-approved chemotherapeutic agent might reduce disability and/or the frequency of attacks. (This drug has a lifetime dosage limit to prevent heart damage.)[125]

There are additional therapies for many MS symptoms including spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness, and cognitive problems.[126]

PT as rehabilitation

Rehabilitation is an important part of health care delivery for people with MS. In a clinical bulletin devoted to PT in MS rehabilitation, the National Multiple Sclerosis Society summarizes, "With the advent of disease modifying agents to prolong time between attacks and slow disease progression, OT [occupational therapy] and PT interventions are more important… than ever before. Interventions have the potential to last longer and have greater impact on improving quality of life.".[127] Many people are at the peak of their career or their childrearing years when they are diagnosed with MS.[128]

The role of physical therapy varies across the disease's course. Given of the variable nature of the illness, rehabilitation practices often vary. In Europe, there appears to be

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[124] O'Brien, J., et al.

[125] "Multiple Sclerosis: Just the Facts."

[126] "Multiple Sclerosis: Just the Facts."

[127] R. Kalb, ed. "Multiple Sclerosis: Focus on Rehabilitation." New York National Multiple Sclerosis Society. 2001.

[128] P.G. Provance. "Physical Therapy in Multiple Sclerosis Rehabilitation." National Multiple Sclerosis Society. Clinical Bulletin: Information for Health Professionals. 2008.

general consensus that physical therapy services have an important place.[129] There is little if any documentation of similar consensus in the United States. As noted, interventions focus on helping the patient achieve and maintain "optimal functional independence, safety and quality of life."[130] In the entire rehabilitation process, PT is but one part. As members of multi-disciplinary teams dedicated to the patient's care, physical therapists are concerned with:

- "Promoting the health and wellbeing of individuals and society through physical activity and exercise",
- "Preventing impairments, activity limitations, participatory restrictions and disabilities" in at-risk individuals,
- Providing treatments to "restore the integrity of body systems essential to movement, maximize function and recuperation, minimize incapacity, and enhance the quality of life…" among impaired individuals, and
- "Modifying environmental, home and work access and barriers to ensure full participation in one's normal and expected societal roles."[131]

The goal of MS rehabilitation is to reduce the consequences of the disease on function, personal activity, and social participation to allow patients as much independence as possible with the highest possible quality of life. However, its effectiveness is difficult to evaluate for a number of reasons:

- The disease course varies greatly between and among individuals and is difficult to predict in the different forms of the disease,
- Triggers of relapses and progression are not well-defined and the pathological processes may not be heterogeneous and can be discriminated accurately with standard neuro-radiological techniques, and
- It is hard to find a homogeneous patient group which satisfies scientific requirements for evaluating the efficacy of therapeutic interventions.[132]

As a result, there are few studies that effectively measure the effects of rehabilitative measures in MS. Earlier studies were uncontrolled, and most were retrospective

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[129] K. Rasova, P. Feys, T. Henze, H. van Tongeren, D. Cattaneo, J. Jonsdottir, A. Herbenova. "Emerging Evidence-based Physical Rehabilitation for Multiple Sclerosis – Towards and Inventory of Current Content across Europe." Health and Quality of Life Outcomes. October, 2010.

[130] Provance.

[131] "Description of Physical Therapy." World Confederation for Physical Therapy. 2007.

[132] J. Kesselring, S. Beer. "Rehabilitation in Multiple Sclerosis." ACNR. Vol 2 Number 5. November/December 2002.

observations on small, heterogeneous patient groups. Still, there have been a few controlled trials published.[133] [134] [135]

These demonstrate the efficacy of rehabilitation but indicate both that physiotherapy alone or other specific therapies may lead to some improvement in mobility and reduction of disability and that the effects are often relatively short-lived. There are long-term benefits but these are apparently attributable to improved compensation, adaptation and reconditioning and better use of personal and social resources. Rehabilitation measures seem to have no direct influence on the ongoing disease process and the progression of the disease and the benefits of physical therapies are temporary.[136]

Preventative PT

Because restorative physical therapy is typically covered by the carriers and preventive PT is often not, it is important to differentiate between the two. The goal of the former is the restoration of function and usually involves strengthening and retraining muscles as well as adapting to decreased function with new techniques. Restorative rehabilitation is especially useful following an exacerbation or acute attack of MS symptoms. Preventative PT, in contrast, seeks to prevent or slow functional decline and unnecessary complications before they occur.[137] Provance suggests that there are many potential preventative physical therapy interventions that may be appropriate during the course of the disease. For example:

- **At the time of diagnosis,** patients may benefit from education, support, and a baseline evaluation by an experienced PT professional.

- **As the disease progresses,** the focus is on support, resourcing, avoiding deconditioning, maintaining safety, and maximizing health and independent function. This includes assessing the need for mobility aids now and in the future. Patients

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[133] J. A. Freeman, DW Langdon, JC Hobart, et al. "The Impact of Inpatient Rehabilitation on Progressive Multiple Sclerosis. Ann Neurol. 1999.

[134] A. Solari, G Filippini, P Gaasco, et al. "Physical rehabilitation has a positive effect on disability in multiple sclerosis patients." Neurology. 1999.

[135] CM Wiles, RG Newcombe, KJ Fuller, et al. "Controlled randomized crossover trial of the effects of physiotherapy on mobility in chronic multiple sclerosis." *Journal of Neurology, Neurosurgery & Psychiatry*. 2001.

[136] Ibid.

[137] L. Bain with R. Schapiro. "Managing MS Through Rehabilitation." National Multiple Sclerosis Society. April 2009.

transitioning from relapsing-remitting MS are unable to return to baseline due to the disease's progression, and they demonstrate a slow decline in function.

- **During advanced MS,** patients have significant disease burden, are non-ambulatory, and are at risk for secondary health conditions. The focus of PT at this stage is on seated trunk positioning and control, transfers, upper extremity strength, respiratory function, and equipment needs.[138]

It should be noted that some of the PT services described above, such as PT services provided for a short period of time following onset of a remission, may be considered rehabilitative and as such would be currently covered.

Carriers have various requirements for determining when a PT service is "rehabilitative." Generally there is a requirement that there be "significant improvement" of the person's condition within a short period of time (such as 60 days) or that the services will return a person to their usual state of functioning. Some carriers provide coverage for PT services as long as they are for a medical condition and they are restorative in nature and not for maintenance care; some plans require a pre-authorization plan even for rehabilitative PT.

But in general, PT that is intended to maintain function or prevent complications would not be covered, in part because it is impossible in a given situation to determine whether PT is having any beneficial effect on the course of a disease that in inherently variable. Similarly, because of this variability, it is very difficult to demonstrate in well-controlled trials a benefit for preventative PT, so the evidence base supporting the proposed mandate is weak.

In meetings with the medical directors of the largest plans, concern was expressed regarding this benefit. Several plans had conducted research and could find no evidence-based studies that support the use of preventive physical therapy for the treatment of MS. Several questioned why this particular condition should be given special treatment when there are other conditions as severe that would not receive a similar benefit.

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[138] Provance.

Social Impact

In this section, we address the following questions:

- **To what extent will the proposed change generally be utilized by a significant portion of the population?**
- **To what extent is the insurance coverage already available?**
- **To what extent does the lack of coverage result in individuals' avoiding necessary health care treatments?**
- **To what extent does lack of coverage result in unreasonable financial hardship?**
- **What is the level of public demand for these services?**
- **How interested are collective bargaining agents in negotiating privately for including this coverage in group contracts?**
- **To what extent is the proposed mandated health insurance service covered by self-funded employers in the state with at least 500 employees?**

The current estimate of individuals in the US with MS is 400,000,[139] or about 1 in 1,000 based on a population estimate of 380,000,000.[140] Maryland carriers surveyed as part of this study indicated similar incidence among their covered populations, approximately 1.4 to 1.5 per 1,000 members.

In 2008, The Hilltop Institute reported in its "Overview of the Existing Insurance Market in Maryland" that there were 3,590,609 individuals with private insurance in Maryland.[141] Based on this estimate of the covered population and the incidence rates reported above, Maryland insurance plans cover about 5,000 to 5,400 individuals diagnosed with MS.

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[139] "Multiple Sclerosis: Just the Facts."

[140] Robert Schlesinger. "US Population, 2010: 308 Million and Growing." *US News and World Report.* Politics & Policy Blog (December 30, 2009).

[141] Charles Milligan. "Overview of the Existing Insurance Market in Maryland." The Hilltop Institute. University of Maryland, Baltimore County. August 2010.

Table 1 summarizes the carrier's survey responses for preventive physical therapy for coverage of MS.

Table 1

Health Plan	Coverage of MS Preventive Physical Therapy Services
1	Not currently covered. Policies require that there be an expectation of "significant improvement" of the person's condition within 60 days from the date therapy begins. PT aimed at slowing or preventing further deterioration of a body function is not generally covered. Only services rendered for the treatment of delays in speech development – unless resulting from disease, injury, or congenital defect – are covered.
2	No insured plans cover.
3	All plans cover for any medical condition as long as it is restorative in nature and not for maintenance care, subject to certain guidelines and limitations. Plan does not distinguish between preventive and other physical therapy. Prior authorization is required.
4	All plans cover. Plan does not distinguish between preventive physical therapy and other physical therapy. Prior authorization is required.
5	Not currently covered. All PT services must meet the criteria for rehabilitation, which is defined as returning a person to the usual state of functioning. PT is limited to restoring an existing or recently existing physical function.

When PT services are covered, there are usually limits as to the annual number of visits, ranging from 20 to 60 (for all therapy services – PT, occupational, and speech – combined). One carrier indicated that employers can purchase unlimited visits but reported that very few do. Two carriers require prior authorization for PT services. One carrier provided the following description of its administration of PT services:

> *"All PT services require pre-authorization and must include physician prescribed goals to improve environmental safety, restore activities of daily living (ADLs) and independent activities of daily living (IADLs) or rehabilitate for function, usually ambulation. A plan of care is usually written during the first therapy evaluation visit, based on input and demonstration from the patient and caregiver, and plans out exercises and functional adaptations in measured steps towards the primary goal(s). Often home and functional safety evaluations require only one session. Here, the therapist provides recommendations, adaptations, and exercises, but if no rehabilitative or restorative goals are identified, the services terminate after the initial evaluative session."*

Only three carriers responded to the question regarding the dollar amount of claims denied in 2009 attributable to physical therapy for MS patients. One reported $0 claims denied; a second reported $465, and the third carrier indicated that there were "approximately three physical therapy denials per week."

Survey responses indicate that large self-insured plans are very similar to smaller insured plans with respect to these services.

The literature we reviewed showed no evidence that patients are forgoing necessary care because some plans do not cover these services. Among the carriers, there was a wide range in the percentage of members with MS that utilize the covered physical therapy benefit, from a low of 7% to a high of 69%. For the carriers responding to this question, an average of about 30% of all MS patients used PT in a given year. This is consistent with a broader study focusing on middle-aged and older adults with MS, which reported that:

1. 36% of those surveyed reported never using physical therapy services,

2. 33% reported using PT services within the past year, and

3. 31% reported using PT services more than a year prior.[142]

It is difficult to estimate the financial burden of not covering preventive PT for MS patients. According to the Maryland affiliate of the National Multiple Sclerosis Society, many survey respondents who have MS indicate that physical therapy services have not been covered.[143] That information is inconsistent with the responses of the carriers surveyed, several of which cite few limitations. The apparent disconnect lies in 1) the definition of "preventative" in the language of the proposed mandate and 2) the nature of the illness, where physical therapy does not restore one's condition but instead allows the patient to maintain a given level of activity rather than deteriorate further. This therapy, probably intended to be covered in the proposed mandate, can easily be considered as "maintenance" and excluded.

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[142] M. Finlayson, et al. "Use of Physical Therapy Services Among Middle-Aged and Older Adults with Multiple Sclerosis." *Physical Therapy Journal*. August 26, 2010.

[143] Telephone conversation with M. Viel, Director of Public Policy, Maryland Affiliate, National Multiple Sclerosis Society. November 1, 2010.

It is often said that no two MS cases are alike[144] – and the need for preventive PT services varies as a result. A patient might require PT services several times a week for an entire year, or a patient might require little or no physical therapy. In the former case, assuming a visit rate of $95, the financial burden could be as high as $14,820 annually (52 weeks x three visits a week x $95), most of which might be excluded as maintenance. As noted, however, the vast majority of MS patients do not utilize PT services.

Maryland's unions are mixed in support of this potential mandate. It is not specifically mentioned in most bargaining agreements. Some unions expressed concern that it could be subject to abuse and challenging to administer.

Financial Impact

In this section, we estimate the cost of enacting the proposed mandate and compare the results of our analysis with those of other sources, including the estimates submitted by carriers in Maryland. We also include a discussion of any administrative concerns the carriers have expressed.

Mercer surveyed six major carriers in Maryland to obtain information on current practices regarding providing preventive PT for MS patients.

We received responses from five of the six carriers. Of the responding carriers, only one currently covers this benefit.

The following table summarizes the results of the proposed benefit's financial impact.

Table 2

Carrier	$ per Member per Year	% of Claims
1	$3.28 to $4.93	0.1% to 0.2%
2	$4.08	0.2%
3	$0.00 to $6.20	0.0% to 0.2%
4	0.00	0.0%
5	$6.20	0.2%

Mercer developed an independent estimate using the following assumptions:

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[144] "Multiple Sclerosis: Just the Facts."

- Incidence rates reported by the responding carriers ranged from 1.12 per 1,000 to 4.2 per 1,000. The majority of the incidence rates were within the 1.12 per 1,000 to 1.5 per 1,000 range. We used this as the range.
- We had three carrier sources for costs per PT session, ranging from $95 to $108.
- The number of sessions in a year varied between 30 and 45, the general range of the annual limits of therapy sessions indicated by the carriers.
- We assumed a range in cost sharing from zero (assuming that individuals with MS would meet their out-of-pocket limits with other services) to $15, the median copayment for office visits for large employers in Maryland.[145]

Table 3

	Low	High
Incidence	1.12/1000	1.5/1,000
Cost per PT Session	$ 95	$108
Cost Sharing	0	15
Sessions/Year	$ 30	$ 60
Cost per Year	$ 2,850	$ 5,580
Annual Cost per Member	$ 3.19	$ 8.37
Members/Employeer	1.827	1.827
$PEPY	5.83	15.29
% of Claims	0.1%	0.3%
% of Wages	0.01%	0.03%

Only one carrier indicated that it currently covers preventive PT for MS patients. This carrier represented about 5% of the entire group medical premium in Maryland, based on 2009 statutory reports. Thus, we assumed that the marginal cost would reflect about 95% of the full cost.

Table 4

	Full Cost	**Marginal Cost**
Estimated Cost as a Percentage of Average Cost Per Group Policy	0.1% – 0.3%	0.1% – 0.3%
Estimated Cost as a Percentage of Average Wage	0.01% – 0.03%	0.01% – 0.03%
Estimated Annual Per-Employee Cost	$5.83 – $15.29	$5.54 – $14.53

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[145] Mercer. "2009 National Survey of Employer-Sponsored Health Plans." 2010.

Only one carrier identified *administrative* concerns (as opposed to the medical concerns discussed in the previous section) associated with the proposed mandate:

The body of administrative services to support physical therapy would require reengineering and oversight. All services would require redefinition, and training would be required for all therapists to provide:

- Therapies to maintain functions that have not actually declined;
- Therapies to maintain optimal functioning, which is not measurable because the progressive path of MS is so variable;
- Care plans without measurable goals (since the targeted functions already exist);
- New preventive muscle- and nerve-preserving therapies, which are differentiated from both rehabilitative therapies and those exercises that a person with MS can perform independently on a daily basis;
- A large increase in the number of visits for each member with MS because preventive therapies for MS patients would be, by definition, daily exercises.

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OLIVER WYMAN

411 East Wisconsin Avenue, Suite 1600
Milwaukee, WI 53202-4419
1 414 223 7989