

2016

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Recommended Citation

DeRigne, LeaAnne (2016) "Government Programs for Disabled Children: A Practitioner's Guide to Policy and Programs in Florida," *Florida Public Health Review*: Vol. 13 , Article 7.

Available at: <https://digitalcommons.unf.edu/fphr/vol13/iss1/7>

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Government Programs for Disabled Children: A Practitioner's Guide to Policy and Programs in Florida

LeaAnne DeRigne, PhD, MSW

ABSTRACT

There are many government programs and benefits available to disabled children in the United States and include income-support programs, educational and therapeutic programs, and health services. This paper provides a practice/policy update for practitioners working with disabled children and their families. Doctors, nurses, counselors, and educators need to understand the rights of disabled children and their families. A short case scenario is presented followed by a summary of the federal and state policies that are available. Finally, sources of funding for each program are presented.

Florida Public Health Review, 2016; 13, 49-54.

BACKGROUND

Case Scenario

Michele Garcia gave birth to a little boy in the summer of 2013 at Hialeah Hospital in Miami, Florida. She was on public health insurance at the time of the birth of her son, Lorenzo. The little boy was born with the cord wrapped around his neck three times and he suffered hypoxic ischemic encephalopathy and was in Miami Children's Hospital for two months. He has been diagnosed with severe cognitive deficiencies, speech delays, and autism. His parents are legal residents of the United States (U.S.) from Cuba. His father is employed and earns between \$40,000 and \$50,000 annually. His mother stays home to manage his care, which includes speech therapy, occupational therapy, and physical therapy three times a week. There is one sibling at home who is in the 9th grade. A combination of income support, educational, and health policies apply to this case.

Income Support Programs

Social Security. There are two programs administered by the Social Security Administration (SSA) that provide cash benefits to disabled individuals. They are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Children are potentially eligible for either or both of these programs. Both programs are funded entirely by the federal government (social insurance/payroll taxes or general revenue) except for a small state supplement to SSI that is described further in this article. Payroll taxes (FICA) are

withdrawn from wages to fund the Social Security and Medicare programs. After 10 years of payments, individuals become eligible upon retirement age or disability for each program. FICA taxes are set-aside in the Social Security and Medicare Trust Funds are meant only to fund those programs. General revenue funding comes from all other sources of income that the federal government collects, including individual and corporate income taxes, duties, excise fees, etc. This revenue funds all the other programs of the federal government.

Social Security Disability Insurance (Title II of the Social Security Act) is funded through payroll taxes and provides benefits to adults (18-64) who have paid into the program for 10 years. Benefits are available to certain disabled dependents (0-18) of insured individuals as well. Supplemental Security Income is funded through general revenue and provides benefits to children and adults who have not paid into Social Security payroll taxes. It is considered a public assistance program as income and asset limits must be met to qualify for benefits.

Definition of Disability

The Social Security Administration makes disability determinations for children and adults. The definition of disability is the "inability to engage in any substantial gainful activity" (SGA) by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months (U.S. Social Security Administration, 2008a).

Florida Public Health Review, 13, 49-54.

<http://www.ut.edu/floridapublichealthreview/>

Page 49

Definition of Disability for Children

A child is considered disabled if he or she has a medically determinable physical or mental impairment or combination of impairments that causes “marked and severe functional limitations,” and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months (U.S. Social Security Act, 2008b).

Listing of Impairments

The Social Security Administration uses a listing of impairments that will automatically distinguish someone as disabled. The listing of impairments describes for each major body system, impairments considered severe enough to prevent an adult from SGA and in the case of children under age 18, severe enough to cause marked and severe functional limitations. The presence of an impairment that meets the criteria in the Listing of Impairments is usually sufficient to establish that an individual who is not working is disabled and that a child has marked and severe functional limitations (U.S. Social Security Administration, 2008). Lorenzo’s conditions would fall into the neurological impairments listing (section 111.00) under several categories.

Supplemental Security Income

The Supplemental Security Income (SSI) program was created in 1972 as Title XVI of the Social Security Act. SSI is a federal program administered by the Social Security Administration and funded through general revenue. It is meant to provide a guaranteed minimum income to disabled individuals. SSI is a means-tested public assistance program meaning you must be poor to qualify for SSI.

Children under the age of 18 with a medically determined physical or mental impairment that causes “marked and severe functional limitations that have lasted or are expected to last at least 12 months qualify (U.S. Social Security Administration, 2016a).” About one-fifth of both children and adults (aged 18 to 64) receiving SSI have intellectual disabilities. To qualify for benefits parents’ incomes and assets must meet certain requirements (in 2016 assets must be less than \$2000 for an individual and \$3000 for a couple). Countable income must be lower than the maximum federal SSI payment (\$733 for 2016) (U. S. Social Security Administration, 2016b). Individuals who qualify for SSI also qualify for Medicaid, the joint federal-state health insurance program for low-income individuals. Medicaid benefits are discussed later in this article.

Florida Supplement to SSI

States have the option to provide additional cash assistance called a state supplement to SSI recipients.

Florida is one such state and those benefits are funded 100% by state general revenue. The supplement is paid only if an individual is living in a community care setting, assisted living facility, or Medicaid facility. The supplement brings the total payment up to \$776.40 a month (state portion is \$78.40) (U.S. Social Security Administration, 2011). There is currently no lifetime benefit limit meaning SSI payments can continue throughout an individual’s lifetime.

When children become 18 they are re-evaluated for SSI eligibility, meaning it will be determined whether the child continues to be disabled and their income and assets will be counted. If a child was ineligible for SSI due to parents’ income and asset levels they may now qualify for SSI because when children turn 18 they are disconnected from their parents’ income and asset levels.

Over the lifetime Lorenzo also could qualify for Social Security Disability when one of his parents reaches retirement age or becomes disabled. Under SSDI there are three categories of eligible beneficiaries:

- A disabled insured worker under full retirement age
- An individual disabled since childhood (before age 22) who is a dependent of a parent entitled to Title II disability or retirement benefits or was a dependent of a deceased insured parent.
- A disabled widow or widower, age 50-60 if the deceased spouse was insured under Social Security.

To collect SSDI as a child, the parent must be deceased, retired, or disabled. A child could collect if he/she was:

- a minor (under age 18),
- adult disabled before the age of 22,
- or a high school student under the age of 19 (U.S. Social Security Administration, 2016c).

The benefit for the dependent child would be 50% of the total benefit of the parent. There is a maximum amount a family can collect which is typically between 150% and 180% of the worker’s total SSDI benefit.

Education Policy

Individuals with Disabilities in Education Act. The original federal definition of developmental disabilities appeared in the Developmental Disabilities and Facilities Construction Act of 1970 and was expanded in the Developmental Disabilities Assistance and Bill of Rights Act of 1975. The current federal definition of developmental disabilities is found in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000. According to this Act: “Developmental

disabilities are severe, life-long disabilities attributable to mental and/or physical impairments that manifest themselves before the age of 22 years and are likely to continue indefinitely.” They result in substantial limitations in three or more of the following areas:

- Self-care
- Comprehension and language
- Skills (receptive and expressive language)
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency
- Ability to function independently without coordinated services.

The definition is functionally oriented and does not restrict services only to persons with specific diagnoses (U.S. D.H.H.S., 2000).

The Individuals with Disabilities Act (IDEA) states that every child with a disability is entitled to a “free appropriate elementary and secondary education” (U.S. Dept. of Education, 2010). Part B of IDEA covers children aged 3-22 and Part C covers birth to age 3. Most children are served in regular public schools. If a child must be placed in a private school by the local education authority to obtain an appropriate education, this service must be provided at no cost to the child’s family. Other services, including transportation and special devices, must also be provided. In 1997, IDEA was reauthorized with various amendments including provisions to expand mediation services when parents and schools disagree on what a child needs and will receive.

Children with disabilities are assessed and an individualized educational plan (IEP) is created. IDEA ensures the student receives all needed services identified on the IEP at no cost to the parent. Therapies including speech, occupational and physical therapy can be included on a child’s IEP as necessary related services and in a frequency as needed by the student’s disability. In Florida, children with disabilities have a right to a free and appropriate education until they are 22 years old if they do not receive a standard diploma by age 18 (Florida Dept. of Education, 2012). If a child’s local school cannot offer the needed services and placements they can look to another local school public district or a private school to provide the services. All services and transportation would still have to be offered at no cost to the parent (Florida Dept. of Education, 2012).

Because Lorenzo is already nearing age 3 his educational services would be provided through his local school district beginning in the Fall of 2016 and continue through age 22. He will have care including needed therapies (frequency determined by need)

during normal school hours (roughly 6 hours per day, Monday-Friday) at his local public school.

Current estimates are that the federal government funds 16.0% of what it costs to serve students with disabilities (National Education Association, 2015). The remaining costs fall upon state governments and local municipalities. When IDEA was passed the federal government promised to pay up to 40% of the costs of educating children with disabilities. Funding at the federal level is from general revenue. The state and local municipalities provide the remaining funding for K-12 education (41.71% from state, 45.93% from local sources, and 12.36% from federal government) (Florida Dept. of Education, 2015).

Florida’s Early Steps Program

Florida offers an early intervention program for families of children with developmental delays (regardless of income or asset levels). Services are provided from birth to age 3 years at no charge to families. The child’s needs are assessed and an Individualized Family Educational Plan (IFEP) is developed within 45 days. The plan will outline the services that are needed and the outcomes that are desired (Florida Dept. of Education, 2016a). The Early Steps program is mandated through Part C of IDEA (F.S. 393). Funding is shared between the federal and state government from general revenue sources. Medicaid and or private insurance may reimburse the provider for medically necessary services. All eligible children must be served. IDEA part B also provides services to disabled preschoolers at no charge to families. Services are provided at public schools. Lorenzo has been receiving speech, occupational and physical therapy services through Early Steps since he was six months old. Funding for Early Intervention programs (IDEA Part C) and for First Steps in Florida has been in place since 1986.

No Child Left Behind

The No Child Left Behind Act of 2001 minimally affects students with disabilities. States are now held more accountable for the progress of students with disabilities. NCLB requires that all students, including those with disabilities, perform proficiently on reading, math, and science tests. States must report these data. Passage of NCLB was the first time federal law required public schools to demonstrate how well they are serving children with disabilities due to concern that schools were simply warehousing disabled children during the day. Concerns about how to assess students with severe cognitive abilities led to allowing “alternative forms” of assessment appropriate for a student’s learning level (Cortiella, 2010).

Healthcare

Medicaid. Medicaid is a jointly funded federal-state program that provides health insurance and long-term care to needy and disabled individuals. It was enacted in 1965 through amendments to the Social Security Act. Applicants must meet income and asset requirements to qualify. Asset limits generally cannot exceed \$2000 (Florida Dept. of Children and Families, 2016). Each state administers its own Medicaid program so programs vary by state. Medicaid services in Florida are administered by the Agency for Healthcare Administration. At the federal level the Center for Medicare and Medicaid Services oversees state administration of the program.

Though benefits and eligibility can vary state-by-state the federal government requires states to cover the following groups: pregnant women, children, adults with dependent children, people with disabilities, and seniors. The federal government also requires that states cover certain mandatory benefits but states can then choose to provide additional optional benefits. Medicaid programs are required to cover:

- Inpatient and outpatient hospital services;
- Physician, midwife, and nurse practitioner services;
- Laboratory and x-ray services;
- Nursing facility and home health care for individuals age 21+;
- Early and periodic screening, diagnosis and treatment for children (EPSDT) under age 21;
- Family planning services and supplies; and
- Rural health clinic/federally qualified health centers (Paradise, 2015).

Under EPSDT, children are entitled to all medically necessary treatment services including speech, occupational, and physical therapies and long-term in-home care up to 24 hours of nursing care per day. Cost sharing with parents is strictly regulated and cannot exceed 5% of monthly family income (Paradise, 2015). The frequency of therapeutic services such as speech, occupational and physical therapy is not limited to a set number of visits but rather driven by diagnosis and need. Thirty-two states (including Florida) and the District of Columbia automatically provide Medicaid to those eligible for a cash benefit through the Supplemental Security Income Program (U.S. Social Security Administration, 2016d).

Funding for Medicaid is a joint effort between the federal and state government. The federal match rate is a formula based on state per capita income. In Florida the match rate was 61.10% in FY 2017 (U.S. D.H.H.S., 2016). Medicaid funding is drawn from general revenue funds at the state and federal level.

Children's Health Insurance Program (CHIP)

The CHIP was enacted as a part of the Balanced Budget Act of 1997 and created expanded health insurance coverage for children in households with higher incomes. Programs vary by state. Florida's CHIP program (called KidCare) provides medical coverage for children between ages 1 and 18 with household incomes up to 215% of the federal poverty level or FPL (Kaiser Family Foundation, 2016). Parents are responsible for monthly premiums. Most families pay just \$15 to \$20 per month in premiums. There are low co-pays of \$5 for most services. For families over 215% of FPL they are able to purchase the insurance at full pay (Healthy Kids, 2016). In this case scenario Garcia's income was stated to be somewhere between \$40,000 and \$50,000 a year which would fall under 215% of the FPL for a family of four (in 2016 100% of FPL for a family of four was \$24,300) (Healthcare.gov, 2016).

The state and the federal government share the cost of CHIP. The federal government provides a higher match rate (15% higher) under CHIP than under Medicaid program (Center for Medicare Services, 2016). All funds are from general revenue.

Children's Medical Services

Children with special healthcare needs that require healthcare and related services beyond that required of a typical child may qualify for Florida's CMS program and are qualified for Medicaid or KidCare in Florida. A full range of care is provided including early intervention, primary and specialty care, and long-term care for medically complex fragile children, speech, occupational therapy, and physical therapy (frequency determined by diagnosis and recommendations of patient's doctors). CMS provides a case manager (either a nurse or a social worker or both) for each family. They are responsible for coordinating care among all the providers (Florida Dept. of Health, 2016b). Services are provided by an approved network of providers that are specially qualified to provide treatment to children with special health care needs. Funding is 65% federal and 35% state, both drawn from general revenues (Florida Dept. of Health, 2016).

The Affordable Care Act

Healthcare reform (Patient Protection and Affordable Care Act) enacted in March 2010 and implemented through 2014 impacts Americans with disabilities in several ways including:

- Expands Medicaid coverage to 133% of the FPL in the 39 states that expanded (Florida is still considering expansion of Medicaid).
- Prohibits insurance companies from denying children coverage based on pre-existing conditions. Also prohibits companies from

charging a person more based on medical history.

- Creates state-based health insurance exchanges to provide more consumer choice when purchasing health insurance. Provides tax credits to those who cannot afford coverage.
- Eliminates lifetime and annual limits on how much insurance companies will cover.
- Expands options for long-term care in non-institutional settings (home and community based services) under Medicaid.
- Plans in the new exchanges and all new plans have a cap on what insurance companies can require beneficiaries to pay in out-of-pocket expenses such as co-pays and deductibles (The White House, 2014).

Under the Affordable Care Act the maximum health insurance premiums a family is expected to pay is based on income and is capped at a set percentage of income. For a family of four with an income near \$50,000 a year (which would be somewhere in the 200% to 250% of FPL range) the premium contributions would be no more than 6.3% to 8.05% of income which calculates to a premium of \$3150-\$4025 annually (Kaiser Family Foundation, 2013). The federal government is subsidizing the actual cost of health insurance for low-income families.

Respite Care

Florida's Medicaid program provides respite care for caregivers of children with developmental disabilities including autism through several Medicaid waiver programs (Development Disabilities Waiver, and the Florida Model Waiver).

FL Developmental Disabilities Individual Budgeting (0867.R01.00)

"Provides residential habilitation, respite, support coordination, adult dental services, occupational therapy, physical therapy, respiratory therapy, skilled nursing, specialized medical equipment and supplies, specialized mental health counseling, speech therapy, transportation, behavior analysis services, behavior assistant services, dietician services, environmental accessibility adaptations, life skills development, personal emergency response system, personal supports, private duty nursing, residential nursing, special medical home care, supported living coaching for individuals w/autism, Intellectual Disabilities, Developmental Disabilities ages 3 - no max age" (Center for Medicare Services, 2016).

FL Model Waiver (40166.R05.00)

"Provides respite, assistive technology and service evaluation, environmental accessibility adaptations,

transition case management, for medically fragile individuals ages 0 – 20" (Center for Medicare Services, 2016). Income limits are \$2130 for an individual and \$4260 for a couple. There are long waiting lists though for services under the Medicaid waivers for Developmental Disabilities estimated at 7 years in length (Medicaid Waivers, 2016).

Conclusion

Families of children with disabilities contend with many hardships and challenges. Practitioners who work with these families need to know which policies and programs have been implemented to support these families. The income support programs can provide valuable financial support. Educational services can provide not only needed therapy services at public schools but also give parents a six-hour block of time to work or get needed respite from caregiving responsibilities. Finally health insurance programs provide coverage for needed medical care services. Together this group of public policies can go a long way to making the lives of families with children with disabilities a little bit more manageable.

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