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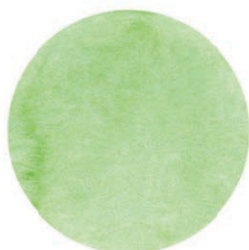
State Support Services

INSURANCE COVERAGE

MEDICAID WAIVER PROGRAMS

OTHER DHH SERVICES AND PROGRAMS

ACCESS TO HEALTH CARE SERVICES AND STATE PROGRAMS





State services represent an essential component of the ASD services/resources infrastructure. As a consequence, the prevalence of insurance coverage for health care services authorized to address the needs of patients with an ASD diagnosis is incredibly important to families with one or more members on the spectrum. In the U.S. health care system, health insurance coverage for any condition is dependent upon a recognized diagnosis and treatment order by a physician or other qualified (authorized) professional. Universally accepted numerical coding systems for diagnoses and ordered treatments/procedures are utilized by health care providers to document medical necessity and services delivered. The coding system for mental/behavioral health diagnoses is



The Diagnostic and Statistical Manual of Mental Disorders often referred to as DSM. The latest version of the DSM, DSM-5 was released in 2013. Health care insurers also utilize these coding systems to guide insurance payments.

Insurance coverage for most of the medical services that may be required by patients with ASD – such as physician and psychologist visits, diagnostic tests, inpatient and outpatient hospital services, physical therapy, speech therapy, and occupational therapy – is virtually universal given a valid diagnosis and authorized treatment orders. However, insurance coverage for Applied Behavior Analysis (ABA) therapy is not as universally available in the U.S. Compared to many states, insurance coverage for ABA therapy in Louisiana is quite strong, although, there are still some loopholes, in particular for large employers. Additionally, Louisiana's Medicaid State Plan provides that ABA therapy that is medically necessary and provided under the supervision of a behavior analyst who is currently licensed by the Louisiana Behavior Analyst Board, or a licensed psychologist or licensed medical psychologist is reimbursable. With plans underway in Louisiana to expand Medicaid, there is an opportunity for Louisiana's coverage mandate to have an even greater impact in helping families access an important early intervention tool.¹⁵⁸

Louisiana's favorable legal and regulatory climate for reimbursement of ABA therapy does not only benefit parents seeking to maximize early intervention services for their child. It also benefits therapy providers and school systems (both public and private) by providing a sustainable and reliable source of reimbursement for providing therapy to children who need it, either as part of their educational experience or in an after-school setting. As described in the **Pre-K-12 Education** section of this report, providers and school systems in the Capital Region can and should take greater advantage of these reimbursement funding streams.

¹⁵⁸ At the time of report production in June 2016, Medicaid expansion was well underway in Louisiana with the Louisiana Department of Health and Hospitals spearheading an enrollment effort with a services start date of July 1, 2016.



INSURANCE COVERAGE

COMMERCIAL INSURANCE COVERAGE

Today, Louisiana is one of 44 states that have some type of autism coverage mandate for state-regulated commercial health care insurers.¹⁵⁹ The Louisiana insurance coverage mandate was established in 2008 through legislation authored by Representative Franklin Foil of Baton Rouge.¹⁶⁰ This mandate was strengthened in 2012 and today includes “coverage for the diagnosis and treatment of autism spectrum disorders” in individuals up to age 21, with an annual maximum benefit of \$36,000.¹⁶¹ A health coverage plan may review proposed treatments of ASD according to medical necessity criteria that may be based in part on evidence of continued improvement as a result of the treatment. Specifically, treatment of ASD as outlined in the legislation includes the provision of habilitative or rehabilitative care, pharmacy care, psychiatric care, psychological care, and therapeutic care. This coverage mandate encompasses ABA therapy, since it is used to treat individuals with ASD. Unfortunately, self-funded health plans utilized by many large companies and a growing number of medium-sized companies are exempt from state mandates because they are regulated at the federal level under the Employee Retirement Income Security Act (ERISA). These health plans could include autism/ABA coverage (as each employer utilizing a self-insured plan so chooses) but are not currently required to provide such coverage under federal law.

MEDICAID STATE PLAN COVERAGE

As noted above, most medical services related to ASD are covered. Medicaid recipients under the age of 21 may be eligible for the following services:¹⁶²

- Doctor’s visits
- Hospital (inpatient and outpatient) services
- Lab and X-ray tests
- Home health care
- Prescription drugs
- Psychological evaluations and therapy
- Psychological and behavioral health services
- Medical, dental, vision, and hearing screenings
- Personal care services
- Necessary transportation: ambulance and non-ambulance transportation
- Appointment scheduling assistance
- Certified nurse practitioners
- Mental health rehabilitation
- Mental health clinic services

¹⁵⁹ <https://www.autismspeaks.org/state-initiatives>

¹⁶⁰ Act 648, Regular Session, 2008, (Louisiana, 2008), <http://www.legis.la.gov/legis/BillInfo.aspx?s=08RS&b=ACT648&sbi=y>.

¹⁶¹ Act 208, Regular Session, 2012, (Louisiana, 2012), <http://www.legis.la.gov/legis/BillInfo.aspx?i=220277>.

¹⁶² For a complete listing of available services, visit Louisiana Department of Health and Hospitals website at <http://new.dhh.louisiana.gov/index.cfm/page/322>.



REHABILITATION SERVICES

Many children with ASD will need rehabilitative services. If a child or youth wants rehabilitation services such as Physical, Occupational, or Speech Therapy, Audiology Services, or Psychological Evaluation and Treatment, these services can be provided at school, in an early intervention center, in an outpatient facility, in a rehabilitation center, at home, or in a combination of settings, depending on the child's needs. For Medicaid to cover these services at school (ages 3 to 21), or early intervention centers and EarlySteps (ages 0 to 3), they must be part of the IEP or Individual Family Service Plan (IFSP), described in more detail below. For Medicaid to cover the services through an outpatient facility, rehabilitation center, or home health, they must be ordered by a physician and be prior-authorized by Medicaid. There is no cap for this coverage, so long as all services are deemed medically necessary.

ABA THERAPY

In 2014, in response to a class-action lawsuit brought by parents of Medicaid-eligible children with ASD,¹⁶³ the Louisiana Department of Health and Hospitals (DHH) established coverage for ABA under Louisiana's Medicaid State Plan for recipients under the age of 21.¹⁶⁴ Medical necessity must be established through a comprehensive diagnostic evaluation (CDE) performed by a qualified health care professional. Additionally, a behavior treatment plan must be developed that identifies the treatment goals and provides instructions to increase or decrease targeted behaviors. There is no cap on the amount of therapy that may be covered, as long as the services are medically necessary and in accordance with an approved treatment plan. Services must be provided under the supervision of a behavior analyst who is currently licensed by the Louisiana Behavior Analyst Board, or a licensed psychologist or licensed medical psychologist. Services must be delivered in a natural setting, which includes home and community-based settings, clinics, and schools.

DHH issued a comprehensive ABA provider manual in October of 2014 that addresses covered services, recipient requirements, service authorization process, provider requirements, reimbursement/coding, and claims filing.¹⁶⁵

In 1997, a class of Medicaid beneficiaries eligible for Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services who sought home and community based treatment for autism and related disorders filed suit against the state Department of Health and Hospitals. A class was certified in 2001. Later that year, the court found the Medicaid agency violated provisions of the Social Security Act which require state Medicaid programs to provide any EPSDT services that could be covered by the Medicaid state plan and that are necessary to correct or ameliorate the conditions found during screening and diagnosis, whether or not the services are included in the state's Medicaid plan. The court ordered the agency to:

1. Cover the behavioral and psychological services of licensed psychologists;
2. Provide individuals eligible for EPSDT services with the behavioral services necessary to correct or ameliorate their condition as required by Soc. Sec. Act sec. 1905(r)(5); and
3. Establish 15 multidisciplinary teams in locations around the state to serve EPSDT beneficiaries with autism.

¹⁶³ A copy of the final order in this case, *Chisholm v. Kliebert*, Civ. No. 97-3274 (E.D. La., Apr. 1, 2014), http://new.dhh.louisiana.gov/assets/docs/BehavioralHealth/LBHP/2014_RFP_Procurement_Library/APPENDIX-H_CHISHOLMVKLIEBERT_STIPULATED-ORDER.pdf.

¹⁶⁴ Louisiana's Medicaid State Plan is available online at www.dhh.state.la.us/index.cfm/page/1718. A copy of the final rule covering ABA-based therapy services is available on pages 9-12 of the *Louisiana Register*, Vol. 41, No. 1 (January 20, 2015) at <http://www.doa.la.gov/osr/reg/1501/1501.pdf>.

¹⁶⁵ A copy of Applied Behavior Analysis Provider Manual, Issued October 21, 2014 is available through the Louisiana Department of Health and Hospitals website, www.lamedicaid.com/provweb1/Providermanuals/manuals/ABA/ABA.pdf.



DHH was ordered to make bimonthly reports to the court and counsel on the number of providers enrolled, their locations, and the number of beneficiaries receiving services. DHH was subsequently held in contempt for failing to comply with the order. Finally, in 2014, DHH took action. Today, as a result of the *Chisholm* court order, any child who is approved as eligible for Medicaid and on the New Opportunities Waiver (NOW) waiting list is a member of the *Chisholm* class. Any class member with a medical diagnosis for whom ABA therapy is deemed “medically necessary” can receive ABA therapy reimbursed by Medicaid during the school day, as long as the public school district, charter school or private school applies to become a Medicaid provider or contracts with a third-party Medicaid provider to supply the ABA therapy services.

More importantly, however, the final ABA therapy coverage rule adopted by DHH is broad enough to apply to all Medicaid eligible individuals under the age of 21, *regardless of whether the child is a member of the Chisholm class*. Thus, any school district can provide ABA therapy services and seek reimbursement, either through Medicaid or private insurance, as long as the services are deemed “medically necessary” by a qualified health care provider. Moreover, school districts are not just limited to providing ABA to K-12 students from 8:00 a.m. – 3:00 p.m. if the therapies are deemed medically necessary. The reimbursement system in place gives districts flexibility, for example, to integrate ABA and other therapies into Pre-K programs – a tool that could prove particularly beneficial given the evidence that early intervention is most effective – or to contract with ABA and other therapeutic providers for integrating therapy into after-school programs.

Shortly after DHH issued its final coverage rule in 2014, the Louisiana Department of Education (DOE), in its weekly newsletter to LEAs, notified LEAs that “[b]eginning immediately, LEAs will be able to submit claims for reimbursement of Applied Behavior Analysis (ABA) services provided to qualified students. This includes Medicaid eligible students who exhibit the presence of excesses and/or deficits of behaviors that significantly interfere with home or community

...any school district can provide ABA therapy services and seek reimbursement, either through Medicaid or private insurance, as long as the services are deemed “medically necessary” by a qualified health care provider.

activities (including school). Program requirements include a comprehensive diagnostic evaluation and a prescription for ABA-based therapy services ordered by a qualified health care professional (psychologist, psychiatrist, neurologist, or developmental pediatrician). Authorization for a school-based service is through the student’s IEP and services must be provided directly by behavior analysts licensed by the Louisiana Behavior Analyst Board.”¹⁶⁶

For the 2015-16 fiscal year, DHH designated \$24,512,388 million in Medicaid funds specifically for the provision of medically necessary ABA therapy, including ABA therapy provided in a school setting to ensure compliance with the *Chisholm* order. However, despite this substantial source of funding and Louisiana’s broad Medicaid and private insurance coverage formulas, currently neither EBR or any other Capital Region public school system or public charter school is taking advantage of these reimbursement mechanisms to offer ABA therapy for those students with a medical diagnosis of autism. Officials from both DOE, DHH, and local school systems acknowledged that there remain significant opportunities to leverage these reimbursement programs to a greater extent in order to provide ABA therapy and other ASD related services to a wider range of school-aged students.

166

Louisiana Department of Education, *LDOE Weekly Newsletter*, “Medicaid Approves ABA Services for LEA Providers,” Nov. 18, 2014. A copy of the ABA Enrollment Form for LEAs was included in the Newsletter and is provided as [Appendix E](#) of this report.



EARLY AND PERIODIC SCREENING DIAGNOSTICS AND TREATMENT (EPSDT) HEALTH SERVICES

As a component of the Louisiana Medicaid Program, EPSDT provides children under the age of 21 enrolled in Medicaid with comprehensive and preventive health care services. These services are designed to provide a framework for routine health, mental health, and developmental screening of children from birth through age 20 plus evaluation and treatment for illnesses, conditions or disabilities. Medicaid eligible children ages birth through two years old may receive EPSDT Health Services through EarlySteps and Medicaid eligible children from three years through 20 years of age are eligible for EPSDT Health Services through a Local Education Authority. All EPSDT Health Services must be furnished through a child's Individualized Family Services Plan (IFSP) or Individualized Education Program (IEP) and must be included in the current IFSP or IEP.

Through the EPSDT program, families can receive the following services:

EPSDT Personal Care Services

All Medicaid recipients 0 to 21 years old not receiving Individual Family Support waiver services are eligible for EPSDT Personal Care Services. In addition, once a recipient receiving Individual Family Support waiver services has exhausted the limit of those services, they are then eligible for supplemental EPSDT Personal Care Services. Therefore, recipients of Children's Choice Waiver services can receive both PCS and Family Support Services on the same day; however, the services may not be rendered at the same time. A physician must write a prescription for services and they must be deemed medically necessary.

EPSDT Psychological and Behavioral Services

All Medicaid recipients under the age of 21 years old who meet the criteria for Pervasive Developmental Disorder (PDD) are eligible for these services. Recipients can receive psychological and behavioral services including necessary assessments, evaluations, individual therapy, and family therapy from an enrolled psychologist. For a list of providers in the Capital Region, contact the Specialty Care Resource line at 1-877-455-9955.

Covered Services include:

- Basic personal care-toileting and grooming activities,
- Assistance with bladder and/or bowel requirements or problems,
- Assistance with eating and food preparation,
- Performance of incidental household chores, only for the recipient,
- Accompanying, not transporting, recipient to medical appointments, and
- Does NOT cover any medical tasks such as medication administration or tube feedings.



LONG TERM – PERSONAL CARE SERVICES (LT-PCS)

The LT-PCS program provides help with activities of daily living for those who qualify for assistance. This program does not provide supports 24 hours a day. To qualify, recipients must receive Medicaid benefits, be at least 21 years old, meet nursing facility level of care, require at least limited assistance with one activity of daily living, independently or through a responsible representative, direct their care, and either live in a nursing facility and be able to be discharged if community-based services were available or be likely to require nursing facility admission within the next 120 days or have a primary caregiver who has a disability or who is at least 70 years old. Services available through this program include help with:

- Eating,
- Bathing,
- Dressing,
- Grooming,
- Moving from one surface to another,
- Walking or using a wheelchair,
- Toileting,
- Changing positions in bed,
- Light housekeeping,
- Preparing and storing meals,
- Shopping,
- Laundry,
- Reminders about taking medicines,
- Help with medical appointments, and
- Help finding transportation for medical appointments.

SUPPORT COORDINATION

Support Coordination (formerly known as case management) is a set of services designed to provide Medicaid eligible recipients assistance in gaining access to the full range of services (medical, social, educational, and other support services) available through the Office for Citizens with Developmental Disabilities (OCDD). Support Coordination develops person-centered plans, completes necessary tasks to ensure plan approvals and revisions are timely, assists in the development and coordination of community resources, and monitors plan implementation. Those on the waiver Request for Services Registry who are Medicaid eligible or any Medicaid recipient 3 through 20 years of age for whom support coordination is medically necessary can qualify for Support Coordination services. To access, call toll-free 1-800-364-7828.



MEDICAID WAIVER PROGRAMS

Louisiana's Medicaid program includes four home and community-based waiver programs that “allow Louisiana citizens to have greater flexibility to choose where they want to live, and the waiver services and supports that best suit their needs, while still receiving Medicaid State Plan benefits.”¹⁶⁷ These programs are administered through the Louisiana Department of Health and Hospitals, Office of Citizens with Developmental Disabilities (DHH, OCDD). Application and eligibility determinations are administered through the local human services districts/authority – the Capital Area Human Services District in Greater Baton Rouge.¹⁶⁸

The first step in accessing Medicaid waiver services is determining developmental disability (DD) eligibility. The eligibility determination is completed by the local health district/authority entry staff who conduct a face to face interview with the individual (and family), complete an interview and assessment of functioning, and review all available records from any appropriate professionals depending upon presenting diagnosis, school records, and any other available information about diagnosis and associated substantial functional limitations will be considered if presented. A diagnosis of ASD does not guarantee eligibility for the developmental disability waiver programs. An individual must show “substantial functional limitations” in noted life areas¹⁶⁹ (at least two life areas up to age 10 and at least three life areas if 11 years or older). At determination, the individual will be offered the opportunity to be placed on the Request for Services Registry (RFSR) which acts like a waiting list for each waiver program and determines the “protected date” for receiving

services. An individual becomes a recipient of a waiver program when his or her protected date is served.

Once the individual's protected date is served, the recipient is made an offer for waiver services that they qualify for and must accept in order to access these programs. At that time, the recipient can choose a Support Coordinator (formerly known as a case manager) who from multiple support coordination agencies in the regional area must contact the recipient within three days of the assignment. The Support Coordinator then has ten days to meet with the recipient to perform “person-centered discovery activities” and conduct a needs-based assessment. Through this initial meeting, the Support Coordinator works with the family to determine what support services the individual wants and needs. This assessment was added to the waiver process in recent years to better allocate resources in the face of budgetary constraints.

Following this preliminary meeting, the Support Coordinator holds a planning meeting with key participants in a recipient's support plan such as provider agencies, vocational agencies, and family members. The Support Coordinator should also discuss with families all other state programs and services besides the waiver program for which the individual might be eligible and that might help meet the individual's needs, such as Family Support Services or rehabilitative services. However, anecdotal evidence collected through this report suggests this does not happen universally, leaving families with incomplete information about the full array of state services and supports that might be available to help their child or young adult.

¹⁶⁷ Louisiana Department of Health and Hospitals, Office of Citizens with Developmental Disabilities, <http://www.dhh.state.la.us/index.cfm/page/142>.

¹⁶⁸ Capital Area Human Services District serves Ascension, East Baton Rouge, East Feliciana, Iberville, Pointe Coupee, West Baton Rouge and West Feliciana parishes. Florida Parishes Human Services Authority serves Livingston Parish.

¹⁶⁹ These life areas can include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Additional information can be found on Office of Citizens with Developmental Disabilities' website at <http://new.dhh.louisiana.gov/index.cfm/page/1920/n/166>.



Following the needs assessment, the Support Coordinator works with this collective group of family members and providers to develop a support plan, which must then be approved by the local human services district. Once the support plan is approved, the Support Coordinator forwards the approved support plan to the participant within two calendar days or by the next business day so that the participant may start receiving services. Once a recipient starts receiving care, they maintain continued contact with their Support Coordinator to ensure a recipient's needs are met. The Support Coordinator must contact the participant to assure adequateness and appropriateness of services within 10 business days following the initial support plan approval. If a parent is not satisfied with the support plan approved by the agency, he or she may file an appeal.

The services provided under the waiver programs are focused on day to day assistance and support needs. Nonetheless, families interviewed as part of this report consistently stressed the importance of the waiver

...waiver programs do not provide therapy services, such as ABA therapy, occupational therapy, speech therapy or physical therapy.

programs to their child's overall support infrastructure. However, as the below descriptions reveal, long waiting lists make access to the waiver programs an impossible goal for most families. Through the creation of this report, current and former policymakers reiterated a need to improve the allocation of funding within the waiver system. In addition, both policymakers and parents repeatedly echoed that the wide range of different services offered in each of the waivers

programs and different eligibility requirements for each result in confusion among families about what program is the right program for their child, which waiting list or lists the child should be on, and what is necessary to qualify for each program.

It is also important to note that waiver programs do not provide therapy services, such as ABA therapy, occupational therapy, speech therapy or physical therapy. Because these services are covered through the state's Medicaid State Plan as described earlier in this report on page 220, there is no need for them to be offered through a Medicaid "waiver" program. Additionally, several other OCDD services are described later in this section that often better fit a family's needs or can help supplement services offered through the waiver programs.

The following are summary descriptions of the four home and community-based waiver services offered in the Capital Area by the Capital Area Human Services District (CAHSD).



CHILDREN'S CHOICE WAIVER PROGRAM

The Children's Choice Waiver Program is designed to offer supplemental support to children aged birth through age 18 with developmental disabilities who live at home with their families. To be eligible, applicants must meet Louisiana's definition of developmentally disabled¹⁷⁰ and meet the ICF/DD¹⁷¹ level of care for medical and/or psychological criteria. Participants receive all medically necessary Medicaid services, including Early Periodic Screening, Diagnosis, and Treatment (EPSDT) screenings. In addition, funding from this waiver program can be used for:¹⁷²

- **Support Coordination** assists families in planning for the child's medical, social, educational, and other services.
- **Family Support Services** are provided directly to the child that enable a family to keep the child at home and that enhance family functioning. The Self-Direction option was added to Family Support Services.
- **Center-Based Respite Care** includes services provided on a short-term basis to children unable to care for themselves due to the absence or need for relief of the parents or to others who normally provide care and supervision provided in a licensed respite care facility.
- **Family Training** includes training and education services provided to the recipient's family by a professional organization.
- **Environmental Accessibility Adaptations** include physical adaptations to the home or vehicle necessary to ensure health, welfare, and safety of the child, or which enable the child to function with greater independence in the home. The adaptations are limited to individuals for whom without additional supports, institutionalization would be required.
- **Specialized Medical Equipment and Supplies** are specified devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live.
- **Aquatic Therapy** uses the resistance of water to rehabilitate an individual with a chronic illness, poor or lack of muscle tone or a physical injury/disability.
- **Art Therapy** is used to increase awareness of self and others, cope with symptoms, stress and traumatic experiences; enhance cognitive abilities and as a mode of communication and enjoy the life-affirming pleasure of making art.
- **Hippotherapy/Therapeutic Horseback Riding** is used to promote the use of the movement of the horse as a treatment strategy in physical, occupational, and speech-language therapy sessions for people living with disabilities. The movement of the horse provides physical and sensory input which is variable, rhythmic, and repetitive. Equine movement coerces the client to use muscles and body systems in response to movement of the horse.

¹⁷⁰ Louisiana Developmental Disability Law, LA RS 28:451.1-28:455.2.

¹⁷¹ ICF/DD – Intermediate Care Facility for the Developmental Disability.

¹⁷² Service listing from the Louisiana Department of Health and Hospitals, Children's Choice Waiver, <http://www.dhh.state.la.us/index.cfm/page/218>.



- **Music Therapy** is used to help recipients improve their cognitive functioning, motor skills, emotional and affective development, behavior and social skills, and their quality of life.
- **Sensory integration** is used to improve the way the brain processes and adapts to sensory information as opposed to teaching specific skills. Sensory integration involves activities that provide vestibular (balance/motion), proprioceptive (visual/sight), and tactile (touch) stimuli which are selected to match specific sensory processing deficits of the recipient.
- **Housing Stabilization Transition Services** enable participants who are transitioning into a Permanent Supportive Housing (PSH) unit, including those transitioning from institutions, to secure their own housing, and provides assistance at any time the participant's housing is placed at risk (e.g., eviction, loss of roommate or income).
- **Housing Stabilization Service** enables waiver participants to maintain their own housing as set forth in the participant's approved POC. Services must be provided in the home or a community setting.

This waiver program is capped at approximately \$16,410 per year per child and the average cost per child is \$10,588.¹⁷³ The program currently services 1,273 children at a total cost of \$11.7 million from both state and federal funding sources as of fiscal year 2014-2015. The demand for Children's Choice Waiver services exceeds state supply. The size of the current waiting list requires a typical wait of approximately ten years. Approximately 7,460 individuals are waiting to receive this waiver program service on the Request for Services Registry.

Once a child who is on a Children's Choice Waiver turns nineteen and continues to meet the eligibility criteria, the child is transferred to an appropriate adult waiver, such as the New Opportunities Waiver or Residential Options Waiver. The Louisiana Department of Health and Hospitals' webpage for the Children's Choice Waiver provides additional information about this program.¹⁷⁴

173 Louisiana Department of Health and Hospitals, Children's Choice Waiver Fact Sheet, available online at www.dhh.state.la.us/index.cfm/page/218.
174 For more information about the Children's Choice Waiver, visit the Louisiana Department of Health and Hospitals' website titled "About the Children's Choice Waiver" online at www.dhh.state.la.us/index.cfm/page/218.



NEW OPPORTUNITIES WAIVER (NOW) PROGRAM

The NOW program includes a wide array of services that assist individuals to live as independently as possible in the community. To qualify, an applicant must be at least three years old,¹⁷⁵ meet Louisiana's definition of developmentally disabled¹⁷⁶ and meet the ICF/DD¹⁷⁷ level of care for medical and/or psychological criteria. While there is no age cap for eligibility, an applicant's disability must have occurred at or before age 22. Services include:¹⁷⁸

- Center-based respite,
- Community integration and development,
- Day habilitation and transportation,
- Employment related training,
- Environmental accessibilities adaptations,
- Housing stabilization services,
- Housing stabilization transition services,
- Individualized and family support (IFS) service day and night,
- One-time transitional services,
- Personal emergency response system,
- Professional services,
- Self-direction option,
- Skilled nursing services,
- Specialized medical equipment and supplies,
- Substitute family care,
- Supported employment and transportation, and
- Supported living.

¹⁷⁵ Early Steps providers interviewed as part of this assessment project refer clients to the waiver eligibility determination process at age two years and nine months.

¹⁷⁶ Louisiana Developmental Disability Law, LA RS 28:451.1-28:455.2.

¹⁷⁷ ICF/DD – Intermediate Care Facility for the Developmental Disability

¹⁷⁸ Services listed on Louisiana Department of Health and Hospitals, Office of Citizens with Developmental Disabilities, <http://www.dhh.state.la.us/index.cfm/page/283>



Current annual benefits average \$52,718 per recipient, although there is no cap for individual benefits. NOW slots are offered on a first-come, first-served basis – with the exception of people who qualify for the NOW through emergency placement or other designated placements.¹⁷⁹ An individual's priority is based on the individual's "protected date," which is the date when an individual or his or her guardian signs and submits the application.

The program currently serves 8,713 individuals at a total program cost of \$429.8 million from state and federal sources as of fiscal year 2014-2015. The demand for NOW services exceeds state supply. The size of the current waiting list requires a typical wait of approximately 12 years, and there are currently approximately 13,826 individuals on the waiting list.¹⁸⁰ Interested citizens can add their names to a waiting list called the Request for Services Registry (RFSR).

179 Louisiana Department of Health and Hospital, NOW Provider Manual, available online <http://www.lamedicaid.com/provweb1/Providermanuals/manuals/NOW/NOW.pdf>

180 Louisiana Developmental Disabilities Council, End the Wait!, <http://www.laddc.org/Initiatives.cfm?aid=6&id=31>.





The following is a brief summary of waiver funding in recent years compiled by the Louisiana Developmental Disabilities Council.

Between Fiscal Year (FY) 2010 and FY 2014, funding was appropriated for only 150 new NOW slots so the waiting list and the ten year wait continued to grow every day. The 2014 Legislature approved FY 2015 funding for an additional 200 NOW slots and funding to fill approximately 1,000 waiver slots for people with developmental disabilities that were vacated but not refilled. Unfortunately, 772 waiver slots for people with developmental disabilities (155 NOW, 204 Children's Choice, and 413 Supports) were frozen as a part of the Governor's FY 2015 Mid-Year Deficit Reduction Plan. As a result of the Council's advocacy efforts, the 2015 Legislature appropriated funding to fill these frozen slots beginning the first day of FY 2016. Unfortunately, 324 waiver slots were once again frozen as part of the Governor's FY 2016 Mid-Year Deficit Reduction Plan.¹⁸¹

The NOW is the most desired waiver program due to the significant level of benefits offered. During this assessment project, several stakeholders discussed the reluctance of some families to accept other available waiver choices that become available to them, such as the Children's Choice Waiver, for fear of losing a more coveted NOW slot. However, those who accept a Children's Choice Waiver are placed in the NOW waiver when they age out at 19 years old or when their original NOW protected date is reached on the waiting list, whichever comes first. The Louisiana Department of Health and Hospitals' webpage, About the New Opportunities Waiver, provides additional information about the program and waiver waiting lists.¹⁸²

¹⁸¹ ibid

¹⁸² For more information about the New Opportunities Waiver, visit the Louisiana Department of Health and Hospitals' webpage titled "About the New Opportunity Waiver" online at www.dhh.state.la.us/index.cfm/page/283.



SUPPORTS WAIVER PROGRAM

The Supports Waiver is designed to provide options and meaningful opportunities for citizens who are 18 years or older to better achieve vocational and community inclusion. To qualify, an applicant must meet Louisiana's definition of developmentally disabled and meet the ICF/DD¹⁸³ level of care for medical and/or psychological criteria. Services all medically necessary, Medicaid services and:

- Support coordination (required case management),
- Supported employment,
- Pre-vocational services,
- Day habilitation,
- Respite,
- Habilitation,
- Permanent supportive housing stabilization transition,
- Permanent supportive housing stabilization, and
- Personal emergency response system.

This waiver program averages approximately \$7,945 per year per person. The program currently serves 1,817 individuals at a total program cost of \$12 million from state and federal sources as of fiscal year 2014-2015. The demand for Supports Waiver services exceeds state supply. The size of the current waiting list requires a typical wait of approximately two to three years with approximately 1,426 people on the Request for Services Registry waiting list. The Louisiana Department of Health and Hospitals' webpage, About the Supports Waiver, provides additional information about the program.¹⁸⁴

¹⁸³ ICF/DD - Intermediate Care Facility for the Developmental Disability

¹⁸⁴ For more information about the Supports Waiver, visit the Louisiana Department of Health and Hospitals' website titled "About the Supports Waiver" online at www.dhh.state.la.us/index.cfm/page/1828.



RESIDENTIAL OPTIONS WAIVER (ROW)

The Residential Options Waiver is designed to support a move from an intermediate care facility for the developmentally disabled (ICF/DD) or nursing facility to the community. There is no age restriction for eligibility; however, citizens must meet the Louisiana definition of developmentally disabled¹⁸⁵ and meet the ICF/DD¹⁸⁶ level of care for medical and/or psychological criteria. Covered services include:

- Support coordination,
- Community living supports,
- Host home services,
- Companion care services,
- Shared living,
- Respite care/out of home,
- Personal emergency response system,
- One time transition services,
- Environmental accessibility adaptations,
- Assistive technology/specialized medical equipment and supplies,
- Transportation-community access,
- Professional services,
- Nursing services,
- Dental services,
- Supported employment,
- Prevocational services, and
- Day habilitation.

There is currently no waiting list for ROW services that result in a determination of eligibility. The program currently serves approximately 25 individuals at a total program cost of \$834,000 in state and federal sources as of fiscal year 2014-2015. The current average benefit is \$27,886 per person. Caps for the ROW waiver program are instituted based on a recipient's Inventory for Client and Agency Planning score which determines a recipient's plan of care. The upper-limit of the cap is currently \$61,753.99. The Louisiana Department of Health and Hospitals' webpage, About the Residential Options Waiver, provides additional information about the program.¹⁸⁷

¹⁸⁵ Louisiana Developmental Disability Law, LA RS 28:451.1-28:455.2.

¹⁸⁶ ICF/DD - Intermediate Care Facility for the Developmental Disability

¹⁸⁷ For more information about the Residential Options Waiver, visit the Louisiana Department of Health and Hospitals' website titled "About the Residential Options Waiver" online at www.dhh.state.la.us/index.cfm/page/1875.



COMPARATIVE TABLE OF WAIVER PROGRAMS

| | Children's Choice | NOW | Supports | ROW |
|-------------------------------|--|--|--|--|
| Age | 3 to 19th birthday | Age 3 and over* | Age 18 and over | No age restriction |
| Eligibility Criteria | <ul style="list-style-type: none"> Meet LA definition of developmentally disabled Meet the ICF/DD level of care for medical and/or psychological criteria | <ul style="list-style-type: none"> Meet LA definition of developmentally disabled Meet the ICF/DD level of care for medical and/or psychological criteria | <ul style="list-style-type: none"> Meet LA definition of developmentally disabled Meet the ICF/DD level of care for medical and/or psychological criteria | <ul style="list-style-type: none"> Moving from an intermediate care facility for the developmentally disabled (ICF/DD) or nursing facility to the community |
| Select Covered Services | <ul style="list-style-type: none"> Support coordination Family support services Center-based respite Family training Specialized therapies, including aquatic, art, therapeutic horseback, music, and sensory integration therapy | <ul style="list-style-type: none"> Support coordination Center-based respite Day habilitation Employment-related training Supported employment Supported living Adult companion care Community integration and development Individual and family support One-time transitional services Personal emergency response systems Professional services Remote assistance Substitute family care | <ul style="list-style-type: none"> Support coordination Day habilitation Habilitation Prevocational services Supported employment Personal emergency response system | <ul style="list-style-type: none"> Support Coordination Host home services Respite services Day habilitation Supported employment Shared living services Companion care Community living supports One-time transitional services Transportation – community access |
| Protected Date Serving | 6-20-2006 (10 year waiting list) | 8-18-2004 (12 year waiting list) | 12-31-2014 (1.5 year waiting list) | Current |
| Average Annual Benefit or Cap | \$16,410 (cap) \$10,588 (average) | \$52,718 (average) | \$7,945 (average) | \$27,886 (average) |
| Total # Slots Allocated | 1,475 | 9,032 | 2,050 | 210 |
| Total # Vacant Slots | 179 | 257 | 121 | 184 |

* disability must have occurred at or before age 22



OTHER DHH SERVICES AND PROGRAMS

A variety of non-waiver services and programs that can benefit some citizens with an ASD diagnosis are offered by DHH through the Office for Citizens with Developmental Disabilities (OCDD) following a determination of eligibility for Louisiana Developmental Disability Services. Each program includes specific eligibility criteria and covered services. The following is a summary of relevant programs and services provided through OCDD.

EARLYSTEPS

EarlySteps is Louisiana's Individuals with Disabilities Education Improvement Act (IDEA) - Part C *Early Intervention program*. In Louisiana, the Part C program is under the leadership of the Department of Health and Hospitals, Office for Citizens with Developmental Disabilities.

The EarlySteps program is designed to serve families with a child aged birth to three years old who has a developmental delay or a medical condition likely to result in a developmental delay. EarlySteps services are designed to assist the family in their efforts to enhance the child's development, including:

- Assistive technology,
- Audiology,
- Health services (family education, assistance with other EarlySteps services only),
- Medical services (evaluation only),
- Nutrition services,
- Occupational therapy services,
- Physical therapy services,
- Psychological services,
- Service coordination,
- Social work services,
- Special instruction,
- Speech language pathology,
- Translation interpreter services (foreign language and sign language),
- Transportation (to and from an EarlySteps service only), and
- Vision services.



Louisiana currently serves approximately 8,000 children per year and has approximately 4,300 active children at any given time. Following referral, EarlySteps determines a child's eligibility based on an assessment process. A service plan, the Individualized Family Services Plan or IFSP is developed based on child needs and family concerns, priorities and resources related to their child. Service delivery is individualized to the child and family based on these needs. Each child in the program is screened for ASD at 18 months and 24 months and prior to exit at age 3. Results of the screening to date indicate that approximately 35% of the children screen positive for ASD and are then referred for a comprehensive diagnostic evaluation if the family is interested in determining if the child may have an ASD diagnosis.

In 2010, EarlySteps received additional funding to develop and implement the "Connect Model" Program. Every child who screens positive for ASD is offered this service. In this model, families are taught how to work with their child themselves. Teams of different and appropriate providers consisting of social workers, psychologists, occupational therapists, physical therapists, and speech-language pathologists, meet with families to teach them how to turn everyday tasks into appropriate learning and engagement activities. There are currently three active teams in the state with the demand for more teams to meet the needs. The model is based on evidence-based practices shown to support young

children at risk for an autism diagnosis. For example, demand from the Capital Region could support four Connect Model teams.

After a child ages out of EarlySteps, EarlySteps refers children to the appropriate service systems:

1. The developmental disabilities services system (Capital Area Human Services District for East Baton Rouge Parish) where the family is offered an array of support based on their needs, including Medicaid waiver services. Currently this means placement on the waiver registry (waiting list) in addition to other state-funded services for which the family may qualify.
2. Pre-school special education programs through the family's local school system.
3. HeadStart and/or child care.

For more information, visit the EarlySteps website - <http://www.earlysteps.louisiana.gov>. The website has referral information specific to the region where the family lives as well as their regional EarlySteps coordinator. To make a referral in the Baton Rouge region, call 225-925-92426. The website also includes Parent's Frequently Asked Questions for reference as well as family-to-family contact persons called Community Outreach Specialists on the EarlySteps "Parent Page" of the website.



FLEXIBLE FAMILY FUNDS

The Flexible Family Funds program provides a monthly stipend of approximately \$258 per month to families of eligible children aged birth to age 18 with severe or profound developmental disabilities to help the families meet extraordinary costs. Checks are mailed directly to families from a fiscal agent contracted by the regional human services district/authority. Eligibility is verified annually for this program and is determined by a global screening tool provided by OCDD and administered by the local human service district/authority. These stipends are offered on a first-come, first-served basis, and families apply through their regional human services district/authority. There is currently a waiting list for this benefit in the parishes served by the Capital Area Human Services District (CAHSD) which has resulted in the funding of the highest priority levels of recipients. Approximately 225 individuals were deemed eligible in FY 2014-2015 in the CAHSD catchment area. Finally, it is possible to receive this service with other services, like state waiver programs.



INDIVIDUAL AND FAMILY SUPPORT

Individual and Family Support services “provide assistance not available from any other resource [such as private and commercial insurance or Medicaid] that allows citizens with developmental disabilities to live in their homes or with their families in the community.”¹⁸⁸ Services are provided through contractual agreements by private provider agencies or through individualized agreements with individuals and families who obtain their own service providers. Services include:¹⁸⁹

- Respite care,
- Personal assistance services,
- Specialized clothing,
- Dental and medical services,
- Equipment and supplies,
- Communication services,
- Crisis intervention,
- Specialized utility costs,
- Specialized nutrition, and
- Family education.

In Fiscal Year 2014-15, the Capital Area Human Services District (CAHSD) was allocated an additional \$500,000 to their budget which was used for this program. Funding requests for services were prioritized 1 to 4 and only priority 1 requests were fully funded at 100%. Priorities 2, 3, and 4 requests were funded, but at less than 100%.

¹⁸⁸ Louisiana Department of Health and Hospitals, Office of Citizens with Developmental Disabilities website, <http://www.dhh.state.la.us/index.cfm/page/136/n/138>.

¹⁸⁹ *ibid*



ACCESS TO HEALTH CARE SERVICES AND STATE PROGRAMS

The addition of coverage for ABA therapy in 2014 by the Louisiana's Medicaid program represents a significant new resource for Medicaid recipients with an ASD diagnosis. This new Medicaid coverage along with Louisiana's relatively new ASD coverage mandate for state-regulated commercial health care insurers offers many in Louisiana reasonable access to early intervention services. Interviewees participating in this assessment project recognize the value of this "new" coverage for ABA therapy in Louisiana. However, many therapy providers and school district officials expressed hesitancy to tap into these reimbursement programs because of concerns about the administrative resources (both time and financial) required and low reimbursement rates.

Interviewees also expressed significant frustration and concern regarding the array of different programs and service offerings available through DHH's Office for Citizens with Developmental Disabilities. The sheer number of different programs and service offerings that potentially eligible individuals are confronted with, all with different eligibility requirements and covered services, can easily confuse and discourage anxious families in need of support services.

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...approximately 12-year waiting list for the New Opportunities Waiver (NOW). Across the board, interviewees were outraged by such a desperately long waiting time.

Families can potentially qualify for and access Medicaid State Plan services, waiver programs, and other programs as described in this report like the Flexible Family Fund, EPSDT, and Support Coordination.

However, the loudest complaint registered by interviewees was the existence of waiting lists – most significantly, the approximately 12-year waiting list for the New Opportunities Waiver (NOW). Across the board, interviewees were outraged by such a desperately long waiting time.

It is unreasonable for developmentally disabled citizens to wait two, three, or four, much less ten years to gain access to support programs for which they qualify. This problem is difficult to solve but relatively easy to understand. The solution is to find the political will to make these programs a high enough priority so as to eliminate the present multi-year waiting lines.



In 2005, OCDD began a stakeholder driven initiative to look at sustainability of the NOW waiver program and evaluate implementation of a needs-based assessment. Resolutions passed by the State Legislature in 2008 required that the ongoing work continue and that OCDD follow through with implementation of sustainability measures. In 2009, OCDD implemented the Guidelines for Support Planning and Resource Allocation System in the NOW program, based on the work of the stakeholder group from 2005 to 2008. At the completion of implementation in 2011-12, the NOW program grew in participation by 8.26%. Through this process, the average cost of the NOW waiver has been reduced from approximately \$65,000 per person per year in 2009 to approximately \$51,000 at program completion and has held steady at approximately \$52,000 today.

As part of the continuous quality improvement efforts, OCDD initiated on its own a Systems Transformation Stakeholder group in 2012 to look at all parts of the system and work collaboratively to address issues.¹⁹⁰ This workgroup is facilitated by the OCDD Executive Team and consists of self-advocates, family members, and advocacy group representatives. Through this workgroup, OCDD has implemented several improvements including an extensive study of the Request for Services Registry (RFSR). Phase 1 of the study was a review of all individuals on the RFSR and what if any services they may access outside of the waiver program. This analysis revealed that over 1/3 of the individuals were receiving other Medicaid long-term support and services or comparable services, and over 88% of the individuals were Medicaid eligible and could qualify for other services, but were not accessing them.

OCDD then undertook a direct-contact survey of over 400 individuals and families and discovered that many individuals and families were asking for services that they should already be able to access, and a small percentage even noted they would not request any additional services beyond what they currently receive. Based on the information from these two components, OCDD then worked with the core stakeholder group and developed a proposal for RFSR prioritization which would screen for urgency of need for waiver support. OCDD is currently piloting this tool with individuals receiving the Supports Waiver and on the NOW RFSR and will be completing a pilot for individuals currently receiving no services in the 2016-2017 fiscal year.

Despite all of the continued efforts of OCDD to increase access and improve efficiencies within the waiver programs, there is still much work to be done. Both current and former policymakers believe there are still many individuals on one or more waiting lists for services they do not necessarily need, often times because they do not fully understand each of the programs or the available non-waiver services and are worried they will miss out on services if they do not get on each and every list. And the fact remains, multi-year waiting lists continue to exist, rendering important support services unattainable for many children in need.

The Capital Region delegation of the state legislature is one of the largest in the state – representing one of the most populous regions in the state. An organized and committed effort by this delegation would have a substantial impact on convincing the full legislature and administration to take action to eliminate the waiting lines for our citizen's with developmental disabilities. At the same time, OCDD must also take a more proactive role in informing the State Legislature and the public of its work done to date and steps being taken to eliminate waiting lists as soon as possible.

¹⁹⁰ For more information, visit the Department of Health and Hospitals website
<http://new.dhh.louisiana.gov/index.cfm/page/1731>.



07

RECOMMENDATIONS

STATE SUPPORT SERVICES



ASD is an expensive lifelong condition often requiring financial resources well beyond the means of most families. Louisiana has established an array of financial support programs to help mitigate these lifelong costs. However, many of these programs are limited in terms of how many individuals can be served, denying access to needed services and/or exposing many families to multi-year waiting lists and financial hardship.

1. OCDD, leveraging the work done to date through its System Transformation Initiative, should take actionable steps to eliminate the waiting list for services through the waiver program. OCDD must also take a more proactive role in informing the State Legislature and the public of its work in this area. Potential actionable steps can include:
 - a. DHH's OCDD should create a registry of developmental disability service recipients and potential recipients in order to keep track of participants' needs and proactively determine community-wide level of support necessary. Through this system, OCDD can determine the level of need of each participant. Based on this information, OCDD should request additional funding or programmatic support from the State Legislature for those presenting with urgent and emergent needs.
 - b. OCDD and local human services district/authorities should examine existing waiting lists to determine if potential waiver recipients could have their needs met through other existing programs.
 - c. OCDD should examine a potential overhaul of the waiver program to achieve better and more efficient allocation of resources and provision of services. Preliminary discussions among policymakers and the System Transformation Work Groups have explored the creation of a single, consolidated waiver in place of the existing four home and community-based waiver programs. Within this consolidated waiver, continuing needs assessments would determine a recipient's level of support. OCDD should continue to study this option, as well as others, and be prepared to make a recommendation to the State Legislature by the 2017 legislative session.
2. Currently, not all allocated waiver slots are in use and vacant slots are unfunded and frozen such that DHH and OCDD are limited in who they can offer waiver slots to from the Request for Services Registry. This means that when a waiver slot becomes available, the spot is left vacant, and waiting lists continue to grow. The Louisiana Legislature should appropriate funds to fill vacant home and community-based waiver slots for people with developmental disabilities.
3. Anecdotal evidence suggests that Support Coordinators are not consistently providing families with comprehensive information about the array of supports and services available, both within and outside of the state waiver programs. DHH and local human services districts, including Capital Area Human Services District, should provide greater oversight of the delivery of case management services by Support Coordinators. Additionally, training by DHH, OCDD, and local services districts/authorities for Support Coordinators should include:
 - a. Specialization of Support Coordinators to serve specific populations which could potentially include specializations by age and disability.
 - b. Knowledge of all available state-funded programs so that Support Coordinators can develop a single Plan of Care that includes all available services offered by the state and that reduces the fragmentation of care delivery.