

PROVISIONS OF LOUISIANA'S COMMUNITY AND FAMILY SUPPORT SYSTEM PLAN

Each section below contains service system provisions in Act 378 (in **bold**), original provisions in the plan (in plain text), and status updates (in *italics*).

Family Support Services

◁ **A cash subsidy of \$258 per month for families with children with severe disabilities.** The plan listed qualifying exceptionalities as: developmental delay for children between the ages of three through eight years, autism, mental disability/severe, mental disability/profound, deaf-blind, traumatic brain injury, multiple disabilities, other health impairment and orthopedic impairment and emotional disturbance as determined by the Department of Education (Bulletin 1506). The plan estimated 3,000 children would be eligible for the subsidy.

In 2011, the Cash Subsidy program was renamed the Flexible Family Fund and eligibility criteria changed from being based on automatic eligibility for some disability categories to the use of a universal screening protocol for all children identified with qualifying exceptionalities for severity of functional limitations. In 2012, Flexible Family Fund eligibility criteria were further tightened to include means testing (65% FPL) for families of children also receiving waiver services. These new eligibility limitations reduced the number of families receiving funds by 55. In 2017, the Council formed a workgroup to review program policies and practices and recommended the Louisiana Department of Health (LDH) changes that would increase access to the program and help ensure consistent policy implementation. LDH accepted all of the Council's recommendations and implemented new program policy May 1, 2019. Two additional qualifying exceptionalities were added: Intellectual Disability Moderate with a behavior intervention or individual healthcare plan and Intellectual Disability Mild with a behavior intervention or individual healthcare plan. Other key changes include additional methods for submitting an application (i.e. in-person, by mail, or by e-mail), removal of financial eligibility criteria for children participating in a home and community-based waiver, allowing a licensed professional evaluation as appropriate documentation for all qualifying exceptionalities, removal of the requirement that families provide their child is actively attending an approved education setting, and the continuation of the monthly stipend during the appeal process. A total of 2,182 families are currently receiving the monthly Flexible Family Fund. Approximately 2,117 children remain on a waiting list.

◁ **A flexible array of services should be developed throughout the state to support families of children with developmental disabilities.** Children from birth to age 18 with a developmental disability would be eligible for services. The services are those that enable a family to keep their child at home and include, but are not limited to: communication services, counseling services, crisis intervention, day care, dental and medical care, equipment and supplies, home and vehicle modifications, home health services, homemaker services, parent education and training services, personal assistance services, recreation services, respite care, service coordination, sitter services, specialized diagnosis and evaluation, specialized nutrition and clothing, specialized utility costs, therapeutic and nursing services, and transportation services. The plan estimated 4,500 children would be eligible for these services.

In 2007, the Family Opportunity Act began offering Medicaid coverage to children with disabilities in families up to 300% of the Federal poverty level. In 2019, Act 421 was passed which requires LDH, pending CMS approval, to begin a program to provide health care services via the state's Medicaid program to children in the TEFRA population no later than June 1, 2020.

As of 2019, family support services are being provided in a variety of ways.

- *Act 378 provides flexible funds for children who are not Medicaid-eligible or for goods or services not reimbursable through Medicaid. For children with developmental disabilities*

the program is called Individual and Family Support (IFS) and for children with behavioral health needs the program is called Consumer Care Resources (CCR). These programs are administered through the Human Services Districts/Authorities or Local Governing Entities (LGEs). In 2018, the Council formed a workgroup to review IFS and CCR policy and practices and recommended changes to LDH to address numerous concerns with state and regional policies/practices that were not aligned with Act 378. The recommendations were accepted by LDH and the process for editing program rule is underway.

- *The LGEs also have access to Mental Health Block Grant funds to provide individualized family supports to children with behavioral health needs.*
- *The Medicaid Children's Choice Waiver, administered by the Office for Citizens with Developmental Disabilities (OCDD), provides an array of services to children with developmental disabilities in their own homes. In 2018, as part of OCDD's transition to a tiered waiver system, children, now through age 20, will be eligible for the Children's Choice Waiver only as the New Opportunities Waiver (NOW) and Residential Options Waiver (ROW) are designated for adults. Children already receiving services through the NOW or ROW will continue to do so.*
- *The Medicaid Psychiatric Rehabilitation Option provides community supports to a limited number of children with severe emotional disturbance.*

While all of these programs are extremely effective in assisting families to care for their children at home, insufficient and inequitable funding causes variable access to statewide services and programs such as the Flexible Family Fund and Individual and Family Support. Act 73 of 2017 was passed to begin to address the inequities across the state by requiring each LGE to dedicate an amount equal to nine percent of its state general funds to Act 378 services for people with developmental disabilities. In addition to this mandatory minimum, Act 73 increased the representation of developmental disabilities on the boards of the LGEs. While Act 73 helped, full equal access will not exist until all of the LGEs are funded equitably per capita across the state. In 2019, additional funding for the two lowest funded LGEs per capita (Northwest LA and Florida Parishes) was included in the state's Fiscal Year 2020 budget.

◀ A system of independent service coordination (case management) to assist families in accessing needed services and supports.

While this was a funded service for several years in the early nineties as a result of Act 378, independent support coordination is available only to Home and Community-Based Waiver recipients and infants and toddlers eligible for Part C services under the Individuals with Disabilities Education Act. As a result of the Chisolm court settlement with DHH (now LDH), all Medicaid eligible children on the waiver registry are eligible to receive support coordination and other services available through EPSDT.

◀ A designated agency in each region to provide information to families in need. Each of these agencies will be widely publicized in its region and will have a toll-free number to facilitate easy access.

In response to the Community & Family Support System Plan, the Developmental Disabilities Council initiated funding of nine Families Helping Families Resource Centers to provide information and referral, education and training, and peer support to families throughout Louisiana. In addition to the Developmental Disabilities Council, these centers currently receive funding from their regional LGE, Children's Special Health Services, the Department of Education and others. In 2007, a tenth Families Helping Families Center opened to serve families living in St. Bernard, Orleans, and Plaquemines parishes. These parishes were previously included in a combined Greater New Orleans Center.

Community Support Services for Adults

◁ **A range of supports to assist adults with disabilities live in their own homes and communities.** These supports include, but are not limited to communication services, companion and/or roommate services, counseling services, crisis intervention, dental and medical care, equipment and supplies, home and vehicle modifications, home health services, homemaker services, personal assistance services, recreation services, respite care, service coordination, specialized diagnosis and evaluation, specialized nutrition and clothing, specialized utility costs, therapeutic and nursing services, transportation services and vocational and employment services.

The plan estimated 600 adults with developmental disabilities would receive services through supported living over a three year period. It called for these supports to be provided in the following manner:

◁ The Office for Citizens with Developmental Disabilities would implement 23 pilot projects over a three year period for adults with developmental disabilities. In addition, supports would be provided to 300 adults with developmental disabilities who choose to remain at home with their family, or already have a home and need additional supports to remain there.

Actually, supported living in Louisiana has developed a little differently than the plan specified. Since supported living services are financed through the Medicaid Home & Community Based Waivers, the Office for Citizens with Developmental Disabilities (OCDD) was not able to limit supported living providers to a small group. Providers who agreed to receive training and technical assistance and participate in a supported living network through a Developmental Disabilities Council grant were awarded Act 378 funds to assist individuals with non-Medicaid reimbursable costs associated with setting up their home. These funds are now available to any individual in supported living, regardless of their provider, through the Individual and Family Support program. The Individual and Family Support program is also available to adults who choose to remain with their families, but need supports to do so.

While the waiver and Individual and Family Support are both extremely effective in keeping people at home and as participating members of their communities, a lack of funding has limited access to these programs for many. Fortunately, beginning in 2017, steps were taken to improve an individual's ability to access services and have their needs met. During the 2017 legislative session, Act 73 passed requiring each LGE dedicate an amount equal to nine percent of its state general funds to Act 378 services for people with developmental disabilities.

Then in 2018, after years of planning with stakeholders, OCDD transitioned to a tiered waiver delivery system allowing people on the waiting list with the most urgent needs to receive a waiver that best supports their needs. Through prioritization of the waiting list, for the first time in nearly 25 years, people with unmet needs will receive a waiver offer immediately instead of a number on a waiting list. As of June 2019, OCDD has made waiver offers to all individuals identified as having urgent or emergent needs. No one remaining on what has been historically called the waiting list is waiting for a service they need now, so the Council is comfortable referring to the list as the Request for Services Registry.

At the request of the Council, LDH initiated the ROW 50 pilot program in 2016 to offer a ROW slot to 50 individuals from Intermediate Care Facilities for Persons with Developmental Disabilities (ICF/DD) on the waiver waiting list. For various reasons OCDD has had difficulty getting ICF/DD residents to accept a ROW offer. As of August 2019, all 50 slots have not been filled.

◀ Louisiana Rehabilitation Services would administer three pilot projects implemented over a three year period for adults whose severe disability occurred before the age of 55.

Louisiana Rehabilitation Services (LRS) served adults with adult-onset disabilities in two supported living programs through Resources for Independent Living in New Orleans and Baton Rouge. In 1998, the Developmental Disabilities Council received Act 378 funding to replicate this program in another area of the state. In 2010 Council funds and LRS funds were transferred over to the Office of Adult and Aging Services (OAAS) to consolidate resources and enable better oversight over services. In 2015 OAAS combined this program and funding with the State Personal Assistance Services program. As of June 2019, forty-five individuals were receiving a variety of person centered Supporting Living services through a contract with the Arc of Louisiana. There are 84 people on the waiting list for this program.

◀ The Office of Mental Health would administer a pilot project for adults with severe mental illness.

Project Life was first funded in 1991 in Shreveport to serve individuals transitioning out of state hospitals into the community. The Office of Mental Health, now Office of Behavioral Health, received additional Act 378 funding in 1997 to serve individuals in three regions of the state transitioning out of state hospitals. A total of five LGEs currently have Act 378 funds to assist individuals with behavioral health needs remaining in the community. Two hundred and seventy-four individuals were served in State Fiscal Year 2019.

Evaluation and Performance Indicators

Methods to generate feedback from those individuals receiving services were included in the Community and Family Support System Plan as follows:

◀ **Regional and state family support advisory councils.** These councils were to provide assistance to the Department of Health and Hospitals on the implementation of family support services.

Regional councils were initiated but disbanded after several years due to lack of participation and need. The State Family Support Advisory Council/Work Group continued to evaluate family support services and develop family support policy for recommendation to the Community & Family Support System Task Force through 2001. The DD Council assumed direct oversight of the Community and Family Support System in 2002 through its Act 378 Sub-Committee. In 2016, the Council formed a Community and Family Support System Task Force to develop recommendations to address funding and other issues preventing the system from meeting the needs of Louisianans with disabilities and their families. These recommendations were submitted to the Governor, LDH Secretary and Deputy Secretary, Assistant Secretaries, LGE Executive Directors, and legislators. Many of these have been implemented, but much work remains.

◀ **A state advisory council on supported living.** This council was to provide assistance on the implementation of supported living programs.

This council was short-lived, but the implementation of supported living was continuously monitored by the Supported Living Work Group of the Community & Family Support System Task Force through 2001. The DD Council assumed direct oversight of the Community and Family Support System in 2002 through its Act 378 Sub-Committee.

◀ **An annual evaluation based on consumer satisfaction and performance indicators.**

A consumer satisfaction survey on the cash subsidy program was conducted by the Developmental Disabilities Council through a third party evaluator. Results were overwhelmingly

positive. A third party evaluation on implementation of the Community and Family Support System was conducted by the Human Services Research Institute in 2000. The report is available through the D.D. Council office. Another survey was conducted in 2010 by the Council. Results indicate these programs provide vital support to families of or individuals with developmental disabilities. Results of this study are available on the Council website.

Funding

Implementation of the Community and Family Support System Plan requires a combination of flexible state funds and various Medicaid options. Recommended funding mechanisms for components of the Plan are the following:

Cash Subsidy/Flexible Family Fund - There is no Medicaid source for subsidy payments to families. Funds for the cash subsidy program are state generated.

The LGEs have been able to increase the amount of funding available for this program by utilizing the LINCCA program.

Flexible Services - Services for children with developmental disabilities can be funded in a variety of ways.

Through the regular Medicaid program and EPSDT, eligible families can access traditional Medicaid services. The New Opportunities Waiver, Children's Choice Waiver, and Residential Options Waiver offer services for children such as respite care, attendant care, and environmental modifications. (Beginning in 2018, children through age 20 are only eligible for Children's Choice, but those already receiving services through the NOW or ROW continue to do so.) Additionally, children receiving waiver services also receive regular Medicaid state plan services. Children with emotional/behavioral health needs are eligible for services through Medicaid Psychiatric Rehabilitation. In 2007 Louisiana expanded Medicaid coverage to children with disabilities living in middle- income families through the Family Opportunity Act, a Medicaid buy-in program. Flexible state funds should always be available for necessary services that are not accessible through Medicaid and for those children not eligible for Medicaid. In 2019, Act 421 was passed which requires LDH, pending CMS approval, to begin a program to provide health care services via the state's Medicaid program to children in the TEFRA population no later than June 1, 2020.

Independent Service Coordination - The Community and Family Support System Plan calls for state funds to cover independent service coordination for families not eligible for Medicaid funded case management.

Medicaid offers support coordination only to families receiving Medicaid waiver services, Medicaid eligible children on the Request for Services Registry, and to infants and toddlers eligible for Part C services. Limited support coordination is available from the LGEs for people receiving individual and family support services.

Designated Agencies in Each Region - State funds are necessary to fund these regional points of entry into the service system.

The Families Helping Families Regional Resource Centers are funded by state dollars provided by the Developmental Disabilities Council, the LGEs, the Office of Public Health and the Department of Education. The LGEs also use the LINCCA mechanism to maximize the funding available for the FHF contracts.

Supported Living - A combination of Home and Community Based Waiver services, Medicaid state plan services, and the Psychiatric Rehabilitation Option are required to fund support services

to adults living on their own. Additionally, flexible state funds are necessary to purchase those supports that are not reimbursable through Medicaid for adults living with their families or in their own homes and for those who do not meet the eligibility requirements for the above Medicaid programs.

All of these funding options are available.