

RESOURCES FOR INDIVIDUALS AND FAMILIES OF CHILDREN LIVING WITH DISABILITIES

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Resources for Individuals and Families of Children Living with Disabilities

Introduction

This brochure focuses on the legal resources available in Louisiana for individuals and families of children with disabilities. The purpose is to advise you of your rights as well as to help you recognize opportunities to take advantage of resources and planning tools. It does not offer legal advice. All of the links and resources presented in this brochure are current as of the date of publication, but may change over time. If you have a specific question, please check the sources mentioned in this brochure or talk with an attorney.

What is a Developmental Disability?

According to Louisiana law, “Developmental Disability” means either (a) a severe, chronic disability of an individual that is attributable to an intellectual or physical impairment (or a combination of the two) which is manifested before the age of 22, is likely to continue indefinitely and results in substantial functional limitation to certain areas of major life activity but which is not attributed solely to a mental illness and which reflects a need for lifelong special services, treatment or care or (b) a substantial developmental delay or condition from birth through age 9 which, without special services, treatment or care, has a high probability of resulting in such functional limitations. (See *La. R.S. 28:451.2*)

Early Childhood: EarlySteps

EarlySteps is a comprehensive, family-based program designed to enhance the development of infants and toddlers with disabilities and minimize their need for special education. This program places emphasis on educating and supporting families in helping their child develop and learn. EarlySteps provides in-home services to infants and toddlers (up to age 3) who have or are likely to experience developmental delays. The cost for participation in EarlySteps is determined by family size and income. Through EarlySteps, children receive a variety of services including:

- *Physical Therapy*
- *Speech Therapy*
- *Visual and Audiological Services*
- *Psychological, Social, and Translation Services (foreign and sign language)*

EarlySteps is administered by the Office for Citizens with Developmental Disabilities (OCDD). To locate services or find a provider, visit <http://ldh.louisiana.gov/>.

Education

By law, your child is afforded certain rights with respect to education in Louisiana, regardless of disability or special needs. Legal provisions of particular

interest to families of those with special needs may include:

- *Public schools cannot require the disclosure of a student's medical information or special education needs prior to enrollment (See La. R.S. 17:154.2)*
- *Schools are required by law to protect a student's personally identifiable information, and schools can face financial penalties for improper disclosure of that information for any purpose, including commercial or marketing purposes (See La. R.S. 17:3914)*

The Individualized Education Program (IEP)

Under the Individuals with Disabilities Education Act (IDEA 2004), public schools must create an Individualized Education Program (IEP) for each student who is found to be eligible. The IEP must be designed to meet the unique educational needs of your child and will specify what additional services, accommodations and modifications will be provided to your child to help them achieve academic success. Parents are considered equal members of the IEP team along with the school staff.

For more information on IEP's in Louisiana, visit www.louisianabelieves.com/.

Graduation Pathways

Students with disabilities have four pathways to pursue a high school diploma: TOPS University, Jump Start TOPS Tech (career diploma), Act 833, and LAA 1. An appropriate pathway for a student is determined based upon the student's career interests and individual needs. Students on the **TOPS University** pathway are prepared to attend a 4-year college and can earn TOPS scholarships. Students completing the **Jump Start TOPS Tech** path graduate from high school with credentials for employment and may receive additional educational education after high school. Within the Jump Start TOPS Tech pathway are alternative routes to graduation for students eligible under Act 833 (2014), and students who take the LAA 1 assessment. The **Act 833** route provides an alternative *means* for graduation for students with disabilities, while the **LAA 1** route provides alternative *requirements* for graduation.

For more information on the graduation pathways for students with disabilities, visit: www.louisianabelieves.com/. The website's digital pamphlet resources include: "**Pathways to Graduation for Students with Disabilities**," "**Louisiana Special Education Guidance for High School Students**," and "**Louisiana Department of Education Graduation Requirements**."

Financial Planning

Financial Assistance

The OCDD offers a program called **Flexible Family Funds**, which are monthly stipends to help families of children (up to age 18) with severe developmental disabilities meet extraordinary care costs. Funds may be used for medical expenses and equipment, child care, nutritional supplements, personal hygiene products, educational expenses and supplies, and community activities. There is no deadline for applying for the funds, but applications are processed in the

order they are received (based upon postmark date).

More information about Flexible Family Funds can be found at: <http://dhh.louisiana.gov>.

The OCDD also offers a program called **Children's Choice Waiver**, which offers supplemental support to children with developmental disabilities who currently live at home with their family or a foster family. It is offered to children from birth to age 18; children who reach the age of 19 while receiving the waiver are offered an appropriate waiver for adulthood if they remain eligible. Children's Choice Waivers assist by providing funding for:

- *Medical care*
- *Family support services*
- *Home or vehicle modifications*
- *Care-giving support*
- *Housing services*

Participants in the Children's Choice Waiver program must be under the age of 19 and must meet other eligibility criteria.

For more information about the Children's Choice Waiver and to apply, visit: <http://new.dhh.louisiana.gov>.

Tax Free Savings

The **ABLE** (Achieving a Better Life Experience) **Act** is a section of the Internal Revenue Service Code which creates tax-free savings accounts for individuals with disabilities. The ABLE Act supplements, but does not replace, benefits provided through private insurances, the Medicaid program, the supplemental security income (SSI) program, the beneficiary's employment and other sources. This means that individuals with disabilities who currently receive Medicaid and SSI benefits due to their disability will be able to utilize the ABLE Act account to save and build up a larger sum of money than the \$2,000 maximum currently allowed by SSI. Individuals with disabilities who receive SSI and Medicaid can set up an ABLE Act account and put up to \$14,000 (the annual allowable gift tax exclusion) per year and a maximum of \$100,000 before their SSI benefits will be affected. The actual maximum allowed in an ABLE Act account is determined by each individual state, based on what the maximum that state allows for 529 plans. In Louisiana, the maximum allowed to be held in an ABLE Act account is \$313,000 (as of 2016). Currently, only an individual who was designated by a physician (per the regulations for SSI and Medicaid) as disabled by the age of twenty-six (26) can utilize an ABLE Act account. Also, each individual with disabilities can only have one (1) ABLE Act account.

Although Louisiana has enacted the ABLE Act Legislation (in July of 2015), ABLE Act accounts are not yet available for use in Louisiana. The Louisiana Legislature must fund the program. Once funded, the ABLE Act will be under the administration of Louisiana Office of Student Financial Assistance (LOSFA). It is hoped that the ABLE Act legislation will be funded during the 2017 Legislative Fiscal Session.

Legal Planning

Powers of Attorney

A **power of attorney** (referred to in Louisiana law as a “mandate”) authorizes a third-party (“mandatary”) to act on behalf of the individual (“principal”). It can be limited to certain matters, such as financial or healthcare, or it can be general and cover essentially any matter. However, the authority to perform the following actions for the principal must be expressly stated in the instrument: (1) to alienate, acquire, encumber, or lease a thing or property; (2) to donate a thing, either outright or to a trust or to another custodial arrangement, and to impose conditions on the donation; (3) to accept or renounce a succession; (4) to contract a loan, acknowledge or make remission of a debt, or become a surety; (5) draw or endorse a promissory note or negotiable instrument; (6) to enter into a compromise or refer a matter to arbitration; (7) to make healthcare decisions; (8) to prevent or limit reasonable communication, visitation, or interaction between the principal and a relative by blood, adoption, or marriage within the third degree, or any other individual with strong affection for the principal; and (9) to enter into a contract with the principal when acting as the principal’s mandatary. The power of attorney does not remove the principal’s ability to make decisions for themselves; rather, it only authorizes another individual to also make decisions for the principal. Additionally, the principal can revoke the power of attorney at any time. The power of attorney instrument is not required to be in any particular form; however, if the underlying action the mandatary is performing requires a particular form, such as a donation of real estate is required to be in authentic form, then the power of attorney instrument must also be in that form. (*See La. C.C. arts. 2985-3032*)

Interdiction

If your child is unable to execute a power of attorney, then an interdiction may be necessary. An **interdiction** is a legal proceeding in which a judge determines if an individual cannot consistently make reasoned decisions regarding the care of his person and/or property, or communicate those decisions, due to an infirmity (disability), and his interests cannot be protected by less restrictive means. There are two types of interdictions: limited and full. A limited interdiction applies when it affects the care of the individual’s person or property, or any aspect of either. A full interdiction applies when it affects the care of both the individual’s person and property. If the court is satisfied that the need for interdiction exists, then the court will appoint a third-party (“curator”) to represent the individual (“interdict”) in all legal acts, and to otherwise care for the interdict’s person and affairs. The court will also appoint another individual (“undercurator”) to act as a check on the curator and ensure he is properly performing his duties. In most matters, the curator must get the concurrence of the undercurator and approval of the court prior to performing an action for the interdict. Also, the curator is required to file an annual accounting to the court. Unless disqualified as provided in law, the court will consider the following individuals in order of preference when selecting the curator: (1) the individual designated by the interdict when he had sufficient ability to communicate his preference; (2) the

spouse of the interdict; (3) the parent of the interdict; (4) an individual with whom the interdict has resided for more than six months prior to initiating the interdiction proceeding; or (5) any other individual. (*See La. C.C. arts. 389-399 and La. C.C.P. arts. 4541-4570*)

Continuing Tutorship

If parents know their child with special needs will not have the requisite capacity to execute a power of attorney upon turning eighteen, another option is a continuing tutorship. A **continuing tutorship** is a legal proceeding in which a judge determines if a minor child with special needs will be unable to care of his person and manage his affairs upon turning eighteen. If the court is satisfied that the need for continuing tutorship exists, then the child will continue to remain under the authority of his parents indefinitely, even after turning eighteen. In other words, the child continues to be treated as a minor, even though he may be an adult. To be eligible for a continuing tutorship, (1) the minor child must be above the age of fifteen, (2) possess less than two-thirds the intellectual functioning of persons of the same age with average intellectual functioning as evidenced by standard testing procedures, and (3) obtain the concurrence of the local coroner. Proof of the child’s limit functioning can usually be found in school or medical records. A continuing tutorship is oftentimes more favored than an interdiction because it is a much simpler (and economical) process. However, it is important to be mindful of the timeframe during which parents may institute a continuing tutorship proceeding. (*See La. C.C. arts. 354-362*)

Special Needs Trusts

For individuals living with disabilities, problems with Medicaid or SSI eligibility often arise when parents or other relatives leave an inheritance to the individual living with a disability or that individual comes into possession of a large sum of money from a legal settlement. These large sums of money (more than \$2,000) very well may prevent individuals who are receiving government benefits for their disability from continued receipt of federal and/or state aid. Fortunately, the law allows for these assets to be placed into a trust for the individual living with a disability while still preserving their eligibility for federal and/or state benefits.

Essentially Special Needs Trusts allow for the assets in trust to be used for certain needs of the individual living with a disability. The assets in trust will go toward supplementing government benefits rather than replacing them. Certain terms and restrictions must be included in the trust, however, to ensure that eligibility parameters are met. Common restrictions on the Special Needs Trusts include provisions that prevent trust assets from being given directly to the Special Needs Trust Beneficiary. Another restriction placed on Special Needs Trusts is that the assets from the Trust must be used only for the benefit of the Special Needs Trust Beneficiary. Also worth noting, if the individual with the disability receives SSI in addition to Medicaid, using assets/funds from the Special Needs Trust to pay for housing can, and most likely will, cause a reduction in the SSI benefit the individual receives.

There are several types of Special Needs Trusts:

- *Self Settled/ First Party Funded Trusts* - This Trust is set up and funded by the *individual living with a disability* using their own assets.
- *Third Party Funded Trusts* - This Trust is set up and funded by a third party who does not have an obligation to provide for the special needs individual.
- *A 42 U.S.C. 1396 (p)D4a or D4c Trust* - This Trust is set up under the rules provided for in 42 U.S.C. 1396 (p)D4a or D4c. Under the provisions of the aforementioned statute, a parent, guardian or the court can set up a Trust for the *individual living with a disability* using funds from a party who does have a legal obligation to provide for the individual.

One very important requirement to note about Special Needs Trusts is the payback provision. If the Special Needs Trust is either a Self Settled/ First Party Funded Trust or a 42 U.S.C. 1396 (p)D4a or D4c Trust, then there is a requirement that Medicaid be listed as the secondary beneficiary. This means that once the individual with the disability is no longer able to be a beneficiary of the Trust, due to death or no longer meeting the necessary requirements for a disability, then Medicaid becomes the beneficiary, at least up to the amount of benefits paid by Medicaid for the individual's medical care.

Employment

Training

Louisiana Rehabilitation Services is an organization which helps individuals with disabilities to obtain or maintain employment and/or achieve independence in their communities by providing rehabilitation services and working cooperatively with businesses and other community resources. One program offered by Louisiana Rehabilitation Services is the Vocational Rehabilitation Program which provides services including:

- *Finding job leads*
- *Filling out job applications*
- *Writing a resume*
- *Practicing for a job interview*
- *Providing computer access to search internet job banks*

For more information visit the **Louisiana Rehabilitation Services – Vocational Rehabilitation Program** through www.laworks.net.

Another program offered by Louisiana Rehabilitation Services is the Blind Services Section, which provides rehabilitation and independent living services to eligible individuals who are blind or visually impaired. This section also offers a specialized program for qualified individuals in the food services field.

For more information visit **Louisiana Rehabilitation Services – Blind Services** through www.laworks.net.

Other options for employment opportunities include:

Disability Employment Initiative: <https://dei.workforcegps.org/> and www.dol.gov

Work Pays: <http://work-pays.org/>

Protection from Discrimination at Work

There are federal and state laws that protect individuals with disabilities and make it unlawful to discriminate in employment situations, including hiring, firing, training and promotion. Employers are also required to make reasonable accommodations to individuals with a disability under certain circumstances.

If you believe you are being discriminated against in your workplace because of a disability or if you have requested a reasonable accommodation, but your employer has refused, you can file a charge with the EEOC. For more information and to locate an office, visit: www.eeoc.gov. You can also reach out to the Louisiana Commission on Human Rights (“LCHR”), which can be found at: <http://gov.louisiana.gov/>.

Housing

Both the federal government and the state of Louisiana provide resources and programs to assist families with children living with disabilities and adults living with disabilities to find housing and independent living arrangements.

Permanent Supportive Housing

This is a program administered by the Louisiana Department of Health, Office of Aging and Adult Services which links affordable rental housing to people with severe and complex disabilities and enables them to live in a community. The program allows individuals who would otherwise be at risk of being homeless or institutionalized the ability to live independently.

For more information, visit <http://new.dhh.louisiana.gov>.

New Opportunities Waiver (NOW)

Another program offered by the Louisiana Department of Health, the NOW includes an array of services aimed at assisting people to live as independently as possible. In order to qualify for the NOW, individuals must be over the age of 3, have a developmental disability, meet certain levels of care, and certain income limits. The services offered by NOW include:

- *Individualized and family support services*
- *Skilled nursing services*
- *Substitute family care*
- *Environment accessibility adaptations*
- *Supported living*

For more information about NOW, visit <http://new.dhh.louisiana.gov>.

Certain Development Vouchers

The U.S. Department of Housing and Urban Development offers certain development vouchers to non-elderly families having a person with disabilities who do not currently receive housing assistance in certain developments where

owners establish preferences for, or restrict occupancy to, eligible families to obtain affordable housing. Public Housing Agencies authorized under state law pay rent vouchers to property owners on behalf of qualifying residents.

For more information, visit the **U.S. Department of Housing and Urban Development** at <https://portal.hud.gov>.

Protection from Abuse

Louisiana law requires the reporting of abuse, neglect, and exploitation of vulnerable adults. The failure to report any incident is a crime. The law grants immunity to any citizen who reports in good faith and protects against retaliation for reporting. Adult Protective Services/Elderly Protective Services (APS/EPS) serves adults who have mental, developmental, or physical disabilities, persona with chronic disease or frail elders. The agency is responsible for investigating reports and arranging for services to protect people who are incapable or protecting or caring for themselves from abuses such as:

- *Physical: hitting, punching, yanking, shoving*
- *Emotional: threats, ridicule, isolation, intimidation, harassment*
- *Sexual: unwanted sexual activity*
- *Exploitation: misuse of money, services, property, power of attorney*
- *Extortion: taking a thing of value from an adult by force, intimidation, abuse or neglect*
- *Neglect: withholding or not assuring basic necessary care such as food, water, medical services, medicine, shelter or utilities*
- *Self-neglect: failing to secure or use basic essential such as food, medical care, medicine, shelter*

If you are concerned about an abusive situation, call **Adult Protective Services** at 1-800-898-4910. You may report anonymously and all investigations are confidential.

For persons living in licensed settings such as a nursing home or group home, call the **Louisiana Department of Health, Health Standards Section** at 1-888-810-1910.

For more assistance investigating abuse, visit **The Advocacy Center of Louisiana** at <http://advocacyla.org>.

For More Information

You may need to speak with a Special Needs Planning Attorney who is familiar with all of the laws and requirements in Louisiana. For assistance in locating an attorney near you, contact the Louisiana State Bar Association – Disabilities Assistance Network at www.lsba.org.



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