







What is Public Policy and What is its Connection to the Budget?

The Governor, the Legislature and the Board of Elementary and Secondary Education have the joint responsibility of setting public policy for the children of Louisiana. Public policy for children includes courses of action, regulatory measures, laws, and funding priorities to address their needs.

Ideally, public policy will be a principled guide to address the needs of children and ensure they mature into productive citizens. It should identify a need and direct resources to meet the need in a way that will assure the desired outcome. Good public policy will provide for investments in evidence-based programs that have been shown, through studies, to provide desired results and deliver a real return on investment.

The executive budget is the primary public policy document for the state. Laws and resolutions that identify needs and responses will not be effective if funding is not provided.

As elected officials, the children of Louisiana are your constituents. The future of Louisiana requires elected officials to make children their top priority to guarantee a vibrant Louisiana in the future.

The term, Evidence-Based Practice (EBP), originated in the medical community in the 1990s. An EBP is the current best practice that has been subjected to strong scientific research and interpreted using a very narrow set of methodological criteria. Since the 1990s, the EBP concept has been adopted in many other fields, including child and family services.



A developmental disability is a severe, chronic intellectual or physical impairment that occurs before a person is 22 years old and is likely to continue indefinitely. The disability results in substantial functional limitations in three or more areas of life activity, reflects the person's need for a combination of individually planned services and is not attributed solely to mental illness.

Children with developmental disabilities require quality supports and services in their homes to be active members within their families and communities. Individually planned services are critical as well as making them available for an extended period of time. Louisiana must support and fully fund an individual and family-centered, comprehensive system, with a coordinated array of culturally competent supports and services designed to promote self-determination, independence, productivity, integration, and inclusion into the community for individuals with developmental disabilities.

Most children with developmental disabilities live with their families where they have enduring relationships with adults and can develop to their fullest potential. Family support services are proven to offer a higher quality of life and a more cost-effective alternative to residential placement. Home and community-based programs are supported with both Medicaid and state funds.

Medicaid Waivers for Persons with Disabilities

With a Medicaid waiver, individuals with disabilities can receive long term care services in home and community-based settings rather than in an institution. Federal rules require people who receive home and community-based services to have full access to the benefits of community living and be offered services in the most integrated settings. Home and Community-Based Services are currently offered to people with developmental disabilities with these waivers:

- New Opportunities Waiver (NOW)
- · Children's Choice Waiver
- Supports Waiver (adults only)
- · Residential Options Waiver

However, Louisiana has about 13,000 individuals who are on the waiting list for waiver services. Many have been on the list for over 10 years and approximately 8,000 of those people receive no other developmental disability services from the state.

Public and Private Institutions

Historically, Louisiana has focused on institutional care for children and adults rather than home and community-based services. In the recent past, eight large state-owned developmental centers have closed, leaving one in operation. Many private, residential facilities remain, with the state providing funding for persons with developmental disabilities to live in these facilities. Louisiana leads the nation in number of people per capita in these facilities. There are people housed in such places who do not need 24 hour support. Not only are they being denied opportunities for independence and selfdetermination, institutionalization is not cost-effective. The average annual cost to serve one person at the stateowned facility (Pinecrest) is \$293,000; at the small private facilities, the cost ranges from \$57,320 - \$72,015. This compares to an average cost of \$55,000 under a NOW waiver.

The waiver provider rate for direct day support has declined from \$16/hr. to \$14.44/hr. since 2009, while the cost of providing services has increased. The low pay and challenging work has resulted in a severe shortage of direct support workers. Even though community-based waiver services have been proven to be more cost effective, the staff shortage will result in more people being placed in costly and less effective residential settings.

Early Steps Program

Early Steps provides services for children from birth to age three years who have developmental delays or a medical condition likely to result in a delay. These services have been proven to change developmental trajectory and minimize delays. Better outcomes are realized for children as well as reduced educational costs by minimizing the need for special education services when the child becomes school-age. In Louisiana, the eligibility criteria for Early Steps was changed in 2012, resulting in 1,100 fewer children receiving services and by August 2015, 4335 children were enrolled in Early Steps. To receive services, children now must have a specified amount of delay in two developmental areas rather than one, or a medical condition likely to lead to a developmental disability.

4,335

Early Steps provides services for 4,335 children,

from birth to age three years, who have developmental delays or a medical condition likely to result in a delay.

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The eligibility criteria for Early Steps changed in 2012, resulting in 1100 fewer at-risk children receiving services.





State Funded Programs for Families and Schools

Two state-funded programs – the Individual and Family Support Program and the Flexible Family Fund – are vitally important to families of children with developmental disabilities. These programs provide limited family support services, but often serve as a lifeline to families while waiting years for more comprehensive waiver services. Funding for the Individual and Family Support Program varies by region and can only meet the most severe needs in some areas of the state. The Flexible Family Fund has a long waiting list due to insufficient funding.

Act 833, of 2014, provides alternative pathways for certain students with disabilities to be promoted and graduate. In order to be effective, this will require a critical review and potential revisions to numerous policies. Educators and policymakers must be diligent with this task to ensure that the Act is implemented with integrity. Training, technical assistance and support is critical for educators and parents of children with disabilities. Onsite monitoring and communication between educators/policymakers and stakeholders will be necessary to ensure effective outcomes.

Act 467, of 2015, requires funding to be based on student needs for all schools, traditional and charter. The state share of funding for schools for the 2015-16 year will be distributed based on student needs, however, local funds for charter schools will continue to be allocated according to each student regardless of the student's level of need.

It is imperative that all funding designated for students with disabilities remain in the school system the children attend or follow them to a charter school. Schools should not lose funding designated to support students with disabilities when students without disabilities go to a different school.



Approximately 6760 children are waiting for home and community based waiver services.

Children represent 52% of the waiting list and could be waiting up to ten years.

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Policy Recommendations – Developmental Disabilities

Public policy to address the needs of children with developmental disabilities should include:

- Appropriate adequate funds for Early Steps to restore eligibility criteria.
- Appropriate adequate funds for new home and community-based waiver slots for people with developmental disabilities.
- Increase the appropriation for home and communitybased waivers for people with developmental disabilities to provide for a \$2.50/hour provider rate increase for direct support.

- Appropriate adequate funds for the state-funded Individual and Family Support and Flexible Family Fund programs.
- Ensure quality and compliance with Act 833 of 2014 providing alternative pathways for certain students with disabilities to graduate from high school.
- Ensure equitable funding to schools that accounts for costs associated with services and supports needed by students with disabilities.
- Build capacity in local communities to deliver quality services appropriate to individual needs.
- Ensure that parenting education programs and statesupported training for child care staff include topics specific to caring for children with developmental disabilities, encouraging acceptance of such children.