Comprehensive Study of AUTISM SPECTRUM DISORDER (ASD) Resources in the Capital Region

2016
In early 2014, the Greater Baton Rouge community celebrated the opening of the Emerge Center, a state-of-the-art facility offering critical new and expanded early intervention services to children with Autism Spectrum Disorder (ASD). With its opening, the leadership of the Emerge Center approached the Baton Rouge Area Foundation with a request. The Emerge Center and others providing intensive early intervention for young children have few options for the children they serve when it is time for them to graduate from their programs. Families are left once again to navigate programs and services for the next phase of their child’s development. The Emerge Center’s leadership asked the Baton Rouge Area Foundation to complete a gap analysis to identify how our community can improve the continuum of care for individuals with autism and their families. We are grateful to the Emerge Center for alerting us to this important community issue.

Though the donors of the Baton Rouge Area Foundation have long supported organizations operating in the Autism Spectrum Disorder space, the Foundation has not been directly engaged on this issue as long as others in the community. The Huey and Angelina Wilson Foundation has supported several organizations in the Capital Area through their competitive grantmaking program, board positions, and community engagement. Likewise, the Irene W. and C.B. Pennington Foundation has supported both service providers, continuum of care initiatives, and research in the autism spectrum disorder space. We thank these organizations for their commitment and leadership to this important cause and are glad to join their ranks.
In July of 2014, the Baton Rouge Area Foundation convened approximately 40 people representing service providers, therapists, educators, advocates, state officials, families of individuals with autism, and other interested parties at the Foundation. We asked these experts to share both their challenges and their vision for a comprehensive continuum of care in Baton Rouge for individuals with autism and their families. At the end of the two-hour session, we asked how many people in the room learned of a new service or support system in Baton Rouge. Nearly every one raised their hand. Minutes from this summit can be found in Appendix A. Following the meeting, we met individually with many of the participants and many others as we continued to learn of more and more organizations operating in this space.

Recognizing that families living with a loved one with an autism spectrum disorder diagnosis know far more than us, we held a meeting with close to 100 families. These families described both the practical, day-to-day challenges like finding a trained baby sitter so they can enjoy a night alone, and the larger, long-term hurdles to accessing care, such as finding and accessing the right educational setting for their child or navigating the transition out of high school and into job training and independent and supported living. The minutes from this meeting can be found in Appendix B.

Over the next 18 months, we educated ourselves through countless meetings and read anything we could get our hands on. Shelley Hendrix, a passionate and tireless advocate formerly with Autism Speaks and the mother of a son with autism, introduced us to people not only in Baton Rouge but also around the country providing best practices in care for individuals with ASD. We visited many of these places around the country to learn first-hand from their experiences. Shelley also provided us with a wealth of knowledge on cutting-edge research being conducted throughout the country on ASD and related disorders and medical conditions. Shelley was our guidepost, and we are grateful for her support in the creation of this report.

Caring for a loved one with ASD is a deeply personal journey for every family. No two families’ experiences are the same. Nonetheless, in all of our meetings, we heard a recurring theme of the ongoing struggles, both emotional and financial, families experience trying to navigate the system of services available. When a young child is diagnosed, every family begins an 18-month roller coaster ride, sifting through the disconnected web of services that are available, identifying which services are right for their child, and searching for support systems. While in many ways Baton Rouge’s resources are ahead of the rest of the country, our families continue to face gaps in services along the life cycle that are in desperate need of solutions.

We welcomed the Huey and Angelina Wilson Foundation as our partner in this endeavor in late 2014. Together, we sought to create a report that would outline existing services in our area and make recommendations for filling the numerous gaps in coverage. We engaged SSA Consultants to help with this work.

In this report, we acknowledge the great successes of our existing providers and offer suggestions to create a more continuous and connected system of supports and services. We know this report outlines a massive undertaking that will take much continued work, cooperation and commitment from everyone in the community to make the appropriate resources available to all families in the region, and we will remain committed to ensuring the recommendations contained in this report are brought to life for the betterment of our community.

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Autism Spectrum Disorder (ASD) is a growing reality both nationally and more locally here in the Capital Region.

With the Center for Disease Control (CDC) ASD prevalence rates at 1 in 68,¹ the challenges presented by this wide-ranging disorder coupled with the high prevalence qualify ASD as a condition that warrants a growing commitment of attention and resources from the scientific, medical, educational, social service, political, and philanthropic communities in the Capital Region.

Baton Rouge has many good resources for families coping with ASD, as detailed in this report. However, there is a lack of coordination, which in turn has created a fragmented infrastructure of resources that is hard for families to navigate, making it difficult to access the right services. These challenges are even more profound for low-income families who struggle to pay for necessary supports, access the ASD resource infrastructure, and navigate the multitude of entities working in this space.

Over the course of completing this report, SSA Consultants, the Baton Rouge Area Foundation (BRAF), and the Huey and Angelina Wilson Foundation met with dozens of parents, providers, educators, health care providers, therapists, and advocates. Several consistent themes emerged in terms of major gaps in our local ASD infrastructure and what resources are most needed to fill those gaps. Although this report outlines 25 specific recommendations for action items that leaders and stakeholders within the Capital Region should undertake to ensure the ASD population has access to the right resources, the recommendations all flow from a few key observations. Unless these observations are acknowledged and addressed, the Capital Region’s ability to meet the needs of families struggling with ASD will remain limited.

¹ See section titled What is Autism Spectrum Disorder? for additional information.
The recommendations contained within this report will have far reaching impacts beyond those with ASD living in the Capital Region. Many of these recommendations will impact communities across Louisiana in positive ways as they are implemented, and many of the systems, programs, and resources proposed in this report can be replicated in other areas throughout South Louisiana and the entire state. Further, although this report focuses on ASD, the recommendations herein will certainly improve the lives of those with other developmental and intellectual disabilities.

First, the single-most common frustration expressed by parents and providers was the lack of coordination within the ASD service provider community. Therapy providers, educators, health care professionals, state agencies, caregivers, and parents all play a critical role in the development of a child with autism, yet there is little communication or coordination among these groups. A single, coordinating organization is needed to offer support above and beyond what existing organizations are currently providing. This entity may need to be a new organization, or it may simply be a reimagined and more robust existing organization or a consortium of existing organizations, all working together. As demonstrated in this report, this nonprofit organization should coordinate between providers to better enable referrals; serve as a family navigator resource by leveraging current resource networks, like Families Helping Families; operate and maintain a robust resource website with guiding information for families; engage in advocacy; coordinate and communicate among state agencies and employers; and fulfill other critical functions. This organization will need a focused executive director and a business plan with reliable funding streams to support its implementation.
Second, although research has demonstrated that ASD can be reliably diagnosed at 18 months, the median age of diagnosis in the United States is four years old. Research has demonstrated that the earlier a child receives a diagnosis and starts intensive therapy, the better the long-term outcomes for the child and his or her family. There are an extremely limited number of physician specialists performing full ASD diagnostic evaluations in Baton Rouge, and children are often not identified as potentially having ASD until they enter the school system. General awareness about ASD “red flags” within the community and specifically among pediatricians, caregivers, day-care centers, parents, and others coming into frequent contact with young children must be improved. Further, the frequent medical and behavioral comorbidities associated with ASD often complicate the diagnosis, treatment, and intervention needed for each child. Our Lady of the Lake Children’s Hospital is exploring the creation of a neurodevelopmental center with a focus on ASD whereby integrated, multi-disciplinary medical services would be provided in one location. The addition of this resource to the community would enable parents to access multiple services in one place and would help ensure more coordinated communication among multiple individuals who are each critical to a child’s development.

Third, Louisiana has invested in Medicaid waiver programs designed to support families where other funding streams cannot. Through these programs, families can access personal care takers and even employment-related training. Funding for the programs flows from the State Department of Health and Hospitals’ (DHH) Office for Citizens with Developmental Disabilities (OCDD) to local human services authorities, like the Capital Area Human Services District. However, almost all of the existing waiver programs have lengthy, often multi-year waiting lists, making the programs nearly irrelevant for families desperate for added supports. According to DHH, the New Opportunities Waiver (NOW) is now serving families who requested services in August of 2004, and the Children’s Choice Waiver is now serving families who requested services in June of 2006. If families can determine which waiting list is appropriate, by the time they are able to access services, their child is no longer a child. DHH and the State Legislature must thoroughly examine these waiver programs and assess whether they are relevant in their current forms. Limited funding is certainly part of the issue: between fiscal year 2010 and 2014, only 150 new NOW slots were appropriated, and although more funding was approved in fiscal year 2015, mid-year deficit reductions froze the waiver slots, which means that even if a new slot becomes available, it cannot be filled. Given the current budget situation in Louisiana, it is unlikely that funding will increase dramatically over the next few years. In the short-term, the Legislature and DHH should immediately analyze how Medicaid expansion might alleviate some of the capacity issues with these waiver programs or provide an opportunity to re-work some of the programs to provide services to more individuals, more quickly. OCDD has undertaken a System Transformation Initiative and has recently conducted numerous stakeholder meetings and work group sessions aimed at improving delivery of community-based services provided by the state Medicaid waiver programs. However, stakeholders continue to express frustration at the slow pace of progress and lack of meaningful change to long waiting lists. OCDD should leverage the work completed to date through this transformation initiative and take meaningful steps to improve the delivery of services provided by the waiver programs, which may include significant restructuring of the programs.

2 http://new.dhh.louisiana.gov/index.cfm/page/136/n/138
3 http://www.laddc.org/Initiatives.cfm?aid=6&lid=31
Fourth, the Capital Region has numerous organizations dedicated to both early intervention and ongoing therapeutic support. Applied Behavior Analysis (ABA) has been demonstrated as an effective intervention, particularly when implemented early and often. However, the Capital Region does not have enough existing capacity for ABA therapy, due in large part to the limited number of licensed Board Certified Behavior Analysts® (BCBAs®) and licensed psychologists who include ABA therapy within their scope of practice. Louisiana has only about 150 certified professionals for the entire state, and educational training programs for ABA cannot produce enough graduates to support the ongoing demand. Providers in the area are desperate for new BCBA hires, and average salaries suggest BCBAs are well-paying jobs. Louisiana State University, Southern University, Our Lady of the Lake College, and the Louisiana Career and Technical College System should invest in programs to train BCBAs, Board Certified Assistant Behavior Analysts®, and Registered Line Technicians™. These campuses can leverage existing programs throughout the state to jump start programs in the Capital Region thereby reducing the time, money, and people necessary to start new programs. Moreover, providers must increase their ABA therapy capacity by hiring more licensed professionals and leveraging available reimbursements through third-party insurance providers and Medicaid. Other programs besides ABA therapy, such as integrated behavioral/developmental programs and various social skills interventions, have also shown efficacy. As no two children with ASD are alike, some children may benefit from alternative evidence-based interventions, and resources must exist to educate parents about these options and link families to available providers.

Fifth, educational opportunities for children with an ASD diagnosis are limited by the small number of private school classrooms available to special needs children and the limited resources available within public school systems. While funding mechanisms for therapy in educational settings have expanded, few school systems are maximizing the reimbursements available from private and commercial insurance and Medicaid. Until recently, many opted not to offer ABA therapy or other types of therapeutic interventions in the school setting, even though ample funding is available. In particular, no Capital Region school systems are offering ABA therapy during or after the school day. As an initial step, public school systems such as the East Baton Rouge Parish Public School System should hire a designated ASD specialist devoted to overseeing and implementing broad support for students with ASD. Many families will want their child educated in a mainstreamed environment, while others will want an educational setting focused on children with ASD and/or other developmental or learning disabilities. Educational opportunities must be increased to include options for whatever environment a family deems appropriate. Schools around the country have demonstrated effective programs, with both inclusive and exclusive classrooms, that can be used as models in the Capital Region. Many organizations in the Capital Region are already working to incorporate therapeutic interventions into the classroom. For example, the Central Community School System, in partnership with Central City Autism Awareness, is working to bring therapeutic gyms for daily therapies to local schools, as well as working with students to teach everyday life skills. Launch Therapy Center in Livingston Parish was recently founded to increase alternative therapeutic opportunities, including a therapeutic preschool, and the Behavioral Intervention Group (BIG) has implemented an intensive kindergarten classroom at its campus in Baton Rouge. The financial systems in place in Louisiana can also support specialty charter schools by leveraging reimbursements from insurance providers and state and local funding sources for special education students. The Emerge Center has recognized this need in the community and is currently evaluating its capacity to expand programming to include an ASD charter school for kindergarten through 5th grade.
Finally, when a child ages out of high school and reaches the age of adulthood, Baton Rouge offers limited resources for the young adult and his or her family. Many families we interviewed described this moment in time as the services “cliff,” where support essentially disappears. While there are some existing resources, our discussions with families indicated that many do not know about all of the existing opportunities or how to access them. The Capital Region must develop a comprehensive infrastructure to support these young adults. This infrastructure must include post-secondary educational opportunities, independent and supported housing opportunities, programs to develop independent living skills, a functioning transportation system, and job training and placement programs. Existing early intervention and ongoing service providers should work to develop transition plans for connecting clients with adult services and should consider expanding their own services. This work will require commitment and collaboration from universities, the community college and technical system, employers, and other organizations working collaboratively to create a web of opportunities. Programs around the country can be imported to Baton Rouge and serve as a model for what will ultimately be required here.

This report seeks to identify the significant gaps in our community apparent to a family struggling with an ASD diagnosis. Through this analysis, we will outline recommendations necessary to improve the overall infrastructure related to the continuum of care for ASD. We acknowledge that the recommendations herein will be relevant and important to families beyond those with an ASD diagnosis. As such, their implementation becomes evermore important. Some of the included recommendations are short-term in nature and can be implemented quickly; however, some of these recommendations are long-term and will require significant cooperation from many stakeholders in the Capital Region. We envision the coordinating entity outlined in this report will take on the role of rallying behind this report and its recommendations.
COMMUNITY

1. The Capital Region needs a comprehensive ASD support entity to provide orientation and ongoing navigation services to parents or guardians and serve as the interface and convening entity focused on strengthening the ASD infrastructure and facilitating easier citizen/family navigation of the system. This entity could be a reimagined, existing organization with more robust resources, an entirely new creation partnering with existing navigation resources, or a coalition of existing providers and resources, all working together. Dimensions of this entity, when fully developed, should include the following:

   a. A comprehensive, interactive website resource for families/caregivers and the full range of ASD stakeholder organizations that is a source of good information and facilitates connections to available resources. The Baton Rouge Area Foundation is committed to funding the initial website build-out and will partner with the proposed new organization or an existing local organization to ensure its long-term sustainability, as ongoing maintenance and updating of the website will be critical to its success. The Baton Rouge Area Foundation’s work to date with Exceptional Lives⁴ to develop online guides and a resource database for families in the Capital Region should continue and be integrated into the work of the comprehensive ASD support entity recommended herein.

   b. A navigator for families with newly-diagnosed children that provides expert one-on-one case management services, ideally located in more than one location or geographic area, to provide comfort, to serve as a connection to widely recognized information sources, to facilitate family decision making, and to connect families to available resources and the ASD community.

   c. A high-quality respite program/service that provides families/caregivers needed support to rest and rejuvenate while their loved one is in an appropriate and safe setting. This could also include training for babysitters and other direct care providers.

   d. An interface and convening entity of ASD stakeholder organizations to facilitate ongoing collaborative needs assessment, planning, innovating, problem solving, and advocacy that connects policymakers, public agencies (state and local), community leaders, health care providers, early childhood providers and advocates, Pre-K-12 school systems, and employers. The interface should provide a collaborative environment for individual stakeholders to communicate on a regular basis, organize opportunities to create real policy change, establish an ongoing gap analysis for the Capital Region, and build an employer network.

⁴ Find more information on Exceptional Lives on page 81 of this report.
2. A comprehensive, robust ASD stakeholder organization\textsuperscript{5} based in the Capital Region should design and execute a community education campaign focused on \textit{Learn the Signs of Autism},\textsuperscript{6} a practical guideline that can aid families and other caregivers in identifying early red flags that could warrant a formal evaluation. This campaign should include training sessions, awareness campaigns, and provide informational materials to the following targeted groups:

   a. Parents/family caregivers
   b. Childcare providers
   c. Educators
   d. Social service and recreation organizations serving young children
   e. Churches
   f. Civic groups
   g. Other health care professionals (e.g., nurses, physician extenders, technicians)

3. A working group that includes community leaders, business organizations, local and state education, health care and workforce officials, among others, should be established to govern a project dedicated to the establishment of a sustainable enterprise in the Capital Region that offers comprehensive transition support services to young adults with ASD and related disorders. Dimensions of this service hub model should include the following:

   a. Interface with Pre-K-12 school systems, post-secondary institutions, employers, and ASD stakeholder organizations
   b. Access to health care resources (OCDD and CAHSD programs and benefits)
   c. Support for developing independent living skills
   d. Post-secondary education support, including interfacing with post-secondary disability services offices and facilitating partnerships between private-sector support providers and post-secondary institutions
   e. Programs for development of job-readiness skills
   f. Job training and placement programs, including interface with Louisiana Rehabilitation Services and engagement with area employers and business organizations
   g. Wide array of housing options
   h. Transportation options
   i. Social skills and activities
   j. Legal assistance

\footnotesize{\textsuperscript{5} See Community Recommendation 1 on page 16.\\
\textsuperscript{6} Autism Speaks, “Learn the Signs of Autism,” available online at autismspeaks.org/what-autism/learn-signs.}
1. The Louisiana Chapter of the American Academy of Pediatrics (AAP) should lead an ongoing, focused campaign to endorse and encourage best practices in ASD treatments, particularly related to ASD screening and surveillance best practices and ongoing medical training.
   
   a. Promotion and distribution of AAP-developed guidelines, tools, and other collateral resources developed for pediatric health care professionals and new parents.
   
   b. Engagement with Louisiana medical schools/pediatric programs to identify and promote any new opportunities to better prepare pediatric residents for early diagnosis of ASD.
   
   c. Engagement with Louisiana medical schools/pediatric programs and physician clinics to identify and promote any new opportunities for ongoing training in comorbid conditions and best practices associated with the treatment of ASD.

2. Area providers, including the Baton Rouge Clinic, the Baton Rouge General, Lane Regional Medical Center, Ochsner Health System, Our Lady of the Lake Children’s Hospital, and Women’s Hospital should lead an effort to build the cadre of pediatric physician specialists and psychologists needed in the Capital Region to offer all young children with ASD timely, local access to comprehensive diagnostic evaluations and treatment prescriptions. These hospitals should undertake a targeted campaign to recruit these specialists to the Capital Region and expand hospital resources to support and retain them.

3. All children with ASD who present with symptoms of potential co-morbid medical conditions should be referred to a physician specialist who can best determine the treatment regimen necessary.

   The Baton Rouge community should support the creation of a designated neurodevelopmental center, like Our Lady of the Lake’s Pediatric Development and Therapy Center, that focuses on the treatment of medical comorbidities within an integrated developmental and behavioral care facility.

4. Our Lady of the Lake Children’s Hospital and the Pennington Biomedical Research Center should lead a sustained effort to establish the Capital Region as a nationally recognized ASD research and care network hub with a specific emphasis on biomedical treatments and therapies for those with ASD.

   Through this effort, the Capital Region could create an Autism Treatment Network facility, as well as an Autism Center of Excellence that is eligible for federal funding. Achieving this status helps in the pursuit of additional federal dollars for research related to autism. Further, Baton Rouge should work to develop the necessary capacity and resources to become an Autism and Developmental Disabilities Monitoring Network site.

   The Our Lady of the Lake Pediatric Development and Therapy Center, a neurodevelopmental therapy and autism treatment center, wants to become an Autism Treatment Network facility when fully implemented and should be a natural site for implementation.
THERAPEUTIC SERVICE PROVIDERS

1. Expand current early childhood intervention services capacity at both existing and potential new providers across the Capital Region to meet the population demand estimates, leveraging the sustainable and proven models (financial and service delivery) developed by the Capital Region’s existing early intervention service providers, including the Emerge Center and Behavioral Intervention Group (BIG).

2. All early childhood intervention providers should offer school transition services to facilitate an informed, practical transition for all families “graduating” from the early childhood intervention environment to a Pre-K-12 school environment. In particular, families need support navigating the following decisions:
   
   a. School environment and school fit options,
   b. Transportation services,
   c. Availability of therapeutic services,
   d. Coordination with health care providers, and
   e. Understanding the education diagnosis/Individualized Education Plan (IEP) process.
PRE-K THROUGH 12 EDUCATORS

1. Public school systems in the Capital Region should conduct an independent assessment of their special education system as it relates to serving students with an ASD diagnosis for the purpose of organizational and operational redesigns to improve quality of system performance. Following the findings of this assessment, the recommendations should be implemented. The ideal system attributes include:

   a. Student/parent-centered design
   b. Collaborative culture
   c. ASD expertise (including ABA therapy experts and a dedicated ASD expert to support staff development and coordinate service delivery)
   d. Comprehensive transition planning and support services
   e. Determination to leverage available resources

2. Public education systems and private schools should develop the organizational and operational infrastructure needed to leverage third party reimbursement, including private/commercial insurance and Medicaid reimbursement, of ABA and other relevant therapies and health care services.

3. In addition to the Emerge Center, relevant ASD community stakeholders should conduct a feasibility study for the establishment of an East Baton Rouge-based charter school serving Pre-K-6 or Pre-K-12 students with ASD and related disorders. This study should analyze the breadth of disabilities and disorders the school could service and does not need to be exclusive in nature, but could provide inclusive education to both typical and non-typical children. The feasibility study should include:

   a. Required demand for viability
   b. Transportation to potentially extend reach beyond East Baton Rouge
   c. Funding
   d. Accountability standards
POST-SECONDARY EDUCATIONAL INSTITUTIONS

1. Capital Region post-secondary educational institutions should establish ABA post-secondary education programs for Board Certified Behavior Analysts (BCBA), Board Certified Assistant Behavior Analysts (BCaBA), and Registered Behavioral Technicians (RBT) in the Capital Region. Nicholls State University has an established BCBA program and leadership from that program could collaborate to help establish similar post-secondary education programs in the Capital Region.

The BCBA program is an advanced degree program. Louisiana State University (LSU), Southern, and/or Our Lady of the Lake (OLOL) College should consider implementing this program on their respective campuses. The BCaBA program is an undergraduate-level program. LSU, Southern, and/or OLOL College should consider implementing this program on their respective campuses. The RBT training is a 40-hour program. Baton Rouge Community College and River Parishes Community College should consider implementing this program on their respective campuses.

2. Post-secondary institutions in the Capital Region should invest resources in designing and implementing a comprehensive, inclusive program to support students with diverse learning needs and intellectual disabilities. The program should include not only academic components to help students achieve a certificate or degree, but also employment, independent living, and community involvement support to assist students learn how to live independently and gain employment. The Disability Services offices should work closely with Financial Aid offices within these institutions to have the program approved as a Comprehensive Transition and Post-Secondary (CTP) program so students eligible for federal assistance such as Pell Grants and Work-Study programs can deploy these funding options.
STATE AGENCIES AND LEGISLATURE

1. The Louisiana Department of Health and Hospitals (DHH) should establish developmental screening performance metrics for its Healthy Louisiana (Medicaid managed care, formerly named Bayou Health) contracts that are consistent with Centers for Disease Control and Prevention (CDC) guidance.7

   a. Screening for developmental delays and disabilities during regular well-child doctor visits at:
      
      i. 9 months
      ii. 18 months
      iii. 24 or 30 months
      iv. Additional screening as needed if a child is at high risk for developmental problems due to pre-term birth, low birth weight, or other reasons

   b. Screening for ASD during regular well-child doctor visits at:
      
      i. 18 months
      ii. 24 months
      iii. Additional screening as needed if a child is at high risk for ASD (e.g., having a sister, brother, or other family member with ASD) or if behaviors sometimes associated with ASD are present

2. The Office for Citizens with Developmental Disabilities (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 districts/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.

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.
1. The Louisiana Department of Education (DOE) should establish a requirement, as a condition of state licensure, that all staff of licensed early learning centers be trained as part of the new employee orientation requirements (LA Title 28 Chapter 17.1719) to recognize the “red flags” that may indicate risk for an ASD diagnosis.

The Louisiana Autism Spectrum and Related Disabilities Project (LASARD), a collaborative effort between the Louisiana State University Health Sciences Center (LSUHSC) Human Development Center and DOE, offers a one-hour training that illustrates “red flags” that may indicate a child has ASD. They also offer 12 hours of DOE approved training for caregivers regarding ASD detection and intervention. DOE may wish to leverage this existing resource to implement this new licensure requirement by allowing early learning center employees to be trained through this program.

2. The DOE should continue to work with policymakers on the state and federal levels to maximize the opportunities for students with exceptionalities to be included in the state accountability system.

3. The DOE should establish a state-level ASD champion/expert to consult with local school systems, advocate for best practices, assist with troubleshooting and problem solving, and understand available resources, connect school systems to those resources, and serve as a liaison with other appropriate state agencies (i.e., DHH, Louisiana Workforce Commission, Department of Child and Family Services).

Louisiana Rehabilitation Services

1. Local school systems, post-secondary institutions, and the state should access the full amount of federal funding for transition, vocational rehabilitation, and employment services by providing the required local or state match. In light of the current state budget constraints, the Louisiana Workforce Commission, Louisiana Rehabilitation Services (LRS), local school systems, the Louisiana Community and Technical College System, and other Capital Region post-secondary institutions should form a working group to explore and pursue alternative sources of matching funds to support LRS programs and make recommendations to the Governor and State Legislature.
Louisiana State Legislature

1. The Louisiana Legislature should support the following changes to education funding:
   
   a. Increase the Minimum Foundation Program (MFP) base per pupil funding by 2.75% as recommended by the MFP Task Force,
   
   b. Implement a differentiated or tiered MFP for special education students based upon disability diagnosis and levels of intervention, similar to the differentiated funding model currently utilized by the Recovery School District in New Orleans, and
   
   c. Increase the funds set aside for High Cost Services by at least $7 million in addition to the $5.4 million allocated for the 2015-2016 school year, totaling approximately $21 million, as recommended by the MFP Task Force.

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.

Other

1. The Louisiana Department of Health and Hospitals, the Louisiana Department of Public Safety, and the Louisiana State Police, in collaboration with local law enforcement, should design and implement an ASD identification card program.

2. The Louisiana Bureau of EMS and the Capital Area law enforcement agencies should design and promote public policy standards that require law enforcement and emergency first responders to complete training on how to recognize ASD citizens and appropriately communicate with and engage them. There are several tools and programs that have been developed that can be leveraged for this purpose.
Assessment Methodology
This community assessment was conducted with the dual purpose of:

1. providing a general description of the ASD resources and services infrastructure currently available in the Capital Region, and

2. recommending strategic priorities focused on building an ASD resources and services infrastructure more ideally suited to serving the Region’s current and projected future needs with an eye toward what our community can reasonably develop and sustain.

Some of the observations and recommendations offered in this report touch upon issues related to health care service delivery and health care providers. These observations and recommendations were developed through review of relevant, current ASD literature and interviews with health care professionals in the Capital Region.

We recognize an ASD diagnosis is commonly accompanied by other medical, physical, and/or mental conditions, for example: Attention Deficit Disorder (ADD), Attention Deficit/Hyperactivity Disorder (ADHD), gastrointestinal issues, sleep disorders, seizures, intellectual disability, and many others. Fully addressing the complexity of this ever varying mix of disorders and conditions is well beyond the scope of this community assessment project.

However, we believe the focused attention of this report on ASD provides insights that may also prove useful to addressing this larger mix of co-occurring conditions. A discussion on these comorbidities and the existing literature is included in this report.
The methodology utilized to conduct this assessment included the following work components.

1. **Materials Review** - The project team, in collaboration with ASD stakeholders and experts, gathered and reviewed a large cache of relevant documents and materials that provided the team with a solid understanding of relevant history, the present state, and dynamics of the anticipated future environment. Some of these materials and documents are specifically mentioned in this report with copies or excerpts provided as figures in the body or included as appendices to the report.

2. **Interviews and Follow-Up Work Sessions** - The project team conducted interviews with key leaders and ASD stakeholders to gain a broad understanding of the Capital Region’s ASD resources and services infrastructure, including current capacities, issues of concern, and perceived strategic priorities for strengthening the ASD infrastructure. Most interviews were conducted in person with telephone and email follow-up as necessary.

3. **Comparative Research of Organizational and Operational Models** - The project team reviewed and analyzed a selected group of relevant organizations/business models for the purpose of identifying organizational structures and operational practices that could prove useful in crafting strategic priorities.

4. **Assessment Results Summary** - Utilizing all information and stakeholder input gathered through the assessment activities, the project team developed a community assessment report (this document) featuring general observations and recommendations organized into distinct subtopics.
Comprehensive Study of Autism Spectrum Disorder Resources in the Capital Region | 2016
What is Autism Spectrum Disorder?

ASD DIAGNOSIS OCCURANCE RATE
BATON ROUGE ASD DIAGNOSIS OCCURANCE RATE
Autism Spectrum Disorder (ASD), often referred to as autism, is a general term for an array of complex brain development disorders that are characterized by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.\(^8\)

ASD is frequently associated with intellectual disability, motor coordination difficulty, and physical health problems such as sleep disorders, seizures, and gastrointestinal issues.\(^9\)

Health care professionals in the United States utilize the ASD diagnostic criteria found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). This current version of the DSM was published in May of 2013. Prior to the publication of DSM-5, the array of autism disorders was organized into basic subtypes, including:

1. Autistic disorder (sometimes called autism or classical ASD),
2. Childhood disintegrative disorder,
3. Pervasive developmental disorder – not otherwise specified (PDD-NOS), and
4. Asperger syndrome.

The full text of the DSM-5 diagnostic criteria for ASD and the related diagnostic criteria for Social Communication Disorder (SCD) is provided by Autism Speaks on its website.\(^10\)

The character and severity of ASD can vary significantly from individual to individual. Autistic Disorder (classical ASD) is the most severe form of ASD. ASD is found in all ethnic and socioeconomic groups and affects people of all ages. However, males are four times more likely than females to have an ASD.\(^11\)

\(^9\) ibid
WHAT CAUSES AUTISM?

Scientists are not certain about what causes ASD, but it is likely that both genetics and environment play a role. Researchers have identified a number of genes associated with the disorder. Studies of people with ASD have found irregularities in several regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. While these findings are intriguing, they are preliminary and require further study. The theory that parental practices are responsible for ASD has long been disproved.

Autism Fact Sheet, National Institute on Neurological Disorders and Stroke
ASD is generally regarded as a lifelong disorder by mainstream medicine despite the assortment of supposed autism cures promoted on the internet. Many different types of treatments are utilized today to address ASD. The federal Centers for Disease Control and Prevention (CDC) state that these different treatments can be organized into the following four general categories.

**Behavior and Communication Approaches**
According to reports by the American Academy of Pediatrics and the National Research Council, behavior and communication approaches that help children with ASD are those that provide structure, direction, and organization for the child in addition to family participation.

**Dietary Approaches**
Some dietary treatments have been developed by reliable therapists. But many of these treatments do not have the scientific support needed for widespread recommendation. An unproven treatment might help one child, but may not help another.

Many biomedical interventions call for changes in diet. Such changes include removing certain types of foods from a child’s diet and using vitamin or mineral supplements. Dietary treatments are based on the idea that food allergies or lack of vitamins and minerals cause symptoms of ASD. Some parents feel that dietary changes make a difference in how their child acts or feels.

**Medication**
There are no medications that can cure ASD or even treat the main symptoms. But there are medications that can help some people with related symptoms. For example, medication might help manage high energy levels, inability to focus, depression, or seizures.

**Complementary and Alternative Treatments**
To relieve the symptoms of ASD, some parents and health care professionals use treatments that are outside of what is typically recommended by the pediatrician. These types of treatments are known as complementary and alternative treatments (CAM). They might include special diets, chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g., secretin), or body-based systems (like deep pressure).

These types of treatments are very controversial. Current research shows that as many as one third of parents of children with ASD may have tried complementary or alternative medicine treatments, and up to 10% may be using a potentially dangerous treatment.

There are a few very recent and very small reputable studies that indicate some children diagnosed with ASD can achieve an “optimal outcome” that includes reaching normal cognitive function and no longer meeting the diagnostic criteria for any ASD.12 13

ASD DIAGNOSIS OCCURRENCE RATE

The frequency of ASD diagnosis occurrence has increased dramatically in recent decades, from an estimate of 1 in 200 in 1990s to approximately 1 in 68 today – as reported by the CDC surveys.\textsuperscript{14} There is considerable question and debate in the scientific/medical community about the current 1 in 68 diagnosis occurrence rate. Specifically, how much of this increase is due to actual ASD occurrence increase and how much is due to other factors such as diagnostic definitional changes, new diagnostic tools and practices, and greater ASD awareness?

There is a data collection effort underway through the Autism and Development Disabilities Monitoring Network (ADDM Network) to better understand the ASD prevalence rate. The ADDM Network, for example, found in Alabama a prevalence rate of 1 in 175, while New Jersey found a prevalence rate of 1 in 45.\textsuperscript{15} Louisiana is not currently an ADDM Network participant.

An additional data collection effort reported by the CDC is the National Health Interview Survey (NHIS) which is a nationally representative household survey restricted to children ages three to 17 years old. The most recent NHIS report was published November 13, 2015. The methods, results, and conclusions of the NHIS survey are provided in the report abstract.


Methods

In NHIS, one child is randomly selected from each family to be the subject of detailed questions on health conditions, functional limitations, and health care utilization. Parents are asked if a doctor or health professional had ever told them that their child had each of a series of developmental disabilities. Prevalence estimates of ASD, ID [intellectual disabilities], and other DD [developmental disabilities] for children aged 3-17 years were calculated using data collected in 2011-2014.

Results

The estimated prevalence of ASD based on 2014 data was 2.24%, a significant increase from the estimated annualized prevalence of 1.25% based on 2011-2013 data. In contrast, the prevalence of other DD declined significantly from 4.84% based on 2011-2013 data to 3.57% based on 2014 data. The prevalence of ID did not significantly change from 2011-2013 (1.27%) to 2014 (1.10%). The prevalence of having any of the three conditions was constant across survey years.

Conclusions

The revised question ordering and new approach [change in the order and wording of questions to parents] to asking about developmental disabilities in the 2014 NHIS likely affected the prevalence estimates of these conditions. In previous years, it is likely that some parents of children diagnosed with ASD reported this [developmental disability] as other DD instead of, or in addition to, ASD. Following these changes, the 2014 ASD estimate was more similar to ASD prevalence estimates from other sources.16

This new NHIS information would translate into an ASD diagnosis occurrence rate of approximately 1 in 45. Research focused on the many unknowns regarding ASD diagnosis occurrence continues.

Utilizing both the 1 in 68 and 1 in 45 ASD diagnosis occurrence rates and the U.S. census data for the Baton Rouge MSA, we can estimate that in 2010 the Greater Baton Rouge population of 802,484 included approximately 11,800 (1 in 68) or 17,835 (1 in 45) people with an ASD diagnosis. Figure 1 subdivides the estimated Baton Rouge MSA population with an ASD diagnosis into 14 distinct age groups.

### 01 Baton Rouge MSA Population with an ASD Diagnosis, 2010

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Baton Rouge MSA % of Population</th>
<th>Baton Rouge MSA Population</th>
<th>ASD Rate 1 in 68</th>
<th>ASD Rate 1 in 45</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0 to 4</td>
<td>6.84%</td>
<td>54,890</td>
<td>807</td>
<td>1,220</td>
</tr>
<tr>
<td>Age 5 to 9</td>
<td>6.79%</td>
<td>54,489</td>
<td>801</td>
<td>1,211</td>
</tr>
<tr>
<td>Age 10 to 14</td>
<td>6.81%</td>
<td>54,649</td>
<td>804</td>
<td>1,214</td>
</tr>
<tr>
<td>Age 15 to 17</td>
<td>4.16%</td>
<td>33,383</td>
<td>491</td>
<td>742</td>
</tr>
<tr>
<td>Age 18 to 20</td>
<td>5.20%</td>
<td>41,729</td>
<td>614</td>
<td>927</td>
</tr>
<tr>
<td>Age 21 to 24</td>
<td>6.68%</td>
<td>53,606</td>
<td>788</td>
<td>1,191</td>
</tr>
<tr>
<td>Age 25 to 34</td>
<td>14.41%</td>
<td>115,638</td>
<td>1,701</td>
<td>2,570</td>
</tr>
<tr>
<td>Age 35 to 44</td>
<td>12.93%</td>
<td>103,761</td>
<td>1,526</td>
<td>2,306</td>
</tr>
<tr>
<td>Age 45 to 54</td>
<td>13.84%</td>
<td>111,064</td>
<td>1,633</td>
<td>2,468</td>
</tr>
<tr>
<td>Age 55 to 59</td>
<td>6.15%</td>
<td>49,353</td>
<td>726</td>
<td>1,097</td>
</tr>
<tr>
<td>Age 60 to 64</td>
<td>5.28%</td>
<td>42,371</td>
<td>623</td>
<td>942</td>
</tr>
<tr>
<td>Age 65 to 74</td>
<td>6.31%</td>
<td>50,637</td>
<td>745</td>
<td>1,125</td>
</tr>
<tr>
<td>Age 75 to 84</td>
<td>3.26%</td>
<td>26,161</td>
<td>385</td>
<td>581</td>
</tr>
<tr>
<td>Age 85 and over</td>
<td>1.35%</td>
<td>10,834</td>
<td>159</td>
<td>241</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>100%</strong></td>
<td><strong>802,564</strong></td>
<td><strong>11,802</strong></td>
<td><strong>17,835</strong></td>
</tr>
</tbody>
</table>

Utilizing both the 1 in 68 and 1 in 45 ASD diagnosis occurrence rates and U.S. census projections data through 2030 for the Baton Rouge MSA, we estimate that in 2030 the Greater Baton Rouge population of approximately 1 million will include approximately 3,500 (1 in 68) or 5,300 (1 in 45) citizens ages 0-21 with an ASD diagnosis and within that group, approximately 930 (1 in 68) or 1,400 (1 in 45) children ages 0-4.

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17 MSA - Metropolitan Statistical Area; Baton Rouge MSA includes the following parishes: Ascension, East Baton Rouge, East Feliciana, Iberville, Livingston, Pointe Coupee, St. Helena, West Baton Rouge, and West Feliciana.
Figure 2 shows the annual projected totals for age 0-21 and 0-4 through 2030 for the Greater Baton Rouge area with an ASD occurrence rate of 1 in 68. Figure 3 shows the annual projected population totals for age 0-21 and 0-4 through 2030 for the Greater Baton Rouge area with an ASD occurrence rate of 1 in 45.

**02 Annual Baton Rouge MSA Population with ASD Occurrence Rate of 1 in 68**

<table>
<thead>
<tr>
<th>Year</th>
<th>Baton Rouge MSA Population</th>
<th>Births</th>
<th>ASD Births 1 in 68</th>
<th>ASD, Age 0-21 Years</th>
<th>ASD, Age 0-4 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>804,406</td>
<td>10,988</td>
<td>162</td>
<td>2,899</td>
<td>786</td>
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<tr>
<td>2011</td>
<td>809,017</td>
<td>11,146</td>
<td>164</td>
<td>2,931</td>
<td>797</td>
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<tr>
<td>2012</td>
<td>813,628</td>
<td>11,304</td>
<td>166</td>
<td>2,965</td>
<td>808</td>
</tr>
<tr>
<td>2013</td>
<td>818,238</td>
<td>11,462</td>
<td>169</td>
<td>2,997</td>
<td>820</td>
</tr>
<tr>
<td>2014</td>
<td>822,849</td>
<td>11,620</td>
<td>171</td>
<td>3,031</td>
<td>831</td>
</tr>
<tr>
<td>2015</td>
<td>827,460</td>
<td>11,778</td>
<td>173</td>
<td>3,065</td>
<td>843</td>
</tr>
<tr>
<td>2016</td>
<td>835,610</td>
<td>11,810</td>
<td>174</td>
<td>3,100</td>
<td>853</td>
</tr>
<tr>
<td>2017</td>
<td>843,760</td>
<td>11,841</td>
<td>174</td>
<td>3,134</td>
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<tr>
<td>2018</td>
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<tr>
<td>2020</td>
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<td>11,936</td>
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<tr>
<td>2021</td>
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<td>3,252</td>
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<tr>
<td>2022</td>
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<td>3,276</td>
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<tr>
<td>2023</td>
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<tr>
<td>2024</td>
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<tr>
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<tr>
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<tr>
<td>2030</td>
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<td>3,514</td>
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<tr>
<td>Year</td>
<td>Metro Population</td>
<td>Births</td>
<td>ASD Births 1 in 45</td>
<td>ASD, Age 0-21 Years</td>
<td>ASD, Age 0-4 Years</td>
</tr>
<tr>
<td>------</td>
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<tr>
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<td>10,988</td>
<td>244</td>
<td>4,380</td>
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<td>1,205</td>
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<td>251</td>
<td>4,480</td>
<td>1,222</td>
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<tr>
<td>2013</td>
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</tr>
<tr>
<td>2014</td>
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<td>11,620</td>
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<td>2017</td>
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<td>1,300</td>
</tr>
<tr>
<td>2018</td>
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<tr>
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<tr>
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<td>2025</td>
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<td>2027</td>
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<tr>
<td>2030</td>
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<td>12,966</td>
<td>288</td>
<td>5,311</td>
<td>1,411</td>
</tr>
</tbody>
</table>

The 2010 estimates and the projections (through 2030) presented here make clear that ASD is a significant and growing reality in the Capital Region. The challenges presented by this wide-ranging disorder, coupled with the prevalence of occurrence, qualifies ASD as a condition that warrants a growing commitment of attention and resources from the scientific, medical, educational, social service, political, and philanthropic communities in the Capital Region.
Key Providers & Organizations in the Capital Region
The following is an alphabetical sampling of key service providers and advocacy organizations located in the Capital Region that are actively serving individuals with an ASD diagnosis and their families. The list is not an attempt to create a comprehensive inventory of all service providers and advocacy organizations in the Capital Region. Rather, it is a listing of significant organizations identified through this assessment project.

**Early Intervention**
Abilities is a 30 year old company that offers comprehensive pediatric therapy services. Abilities provides specialized speech and occupational therapy to rehabilitate, remEDIATE, or facilitate motor, play, social, emotional, sensory processing, feeding, and language skills throughout childhood and into young adulthood. Academic instruction is also available in both individual and small group sessions to facilitate academic success.

Abilities employs a client-centered approach in all aspects of therapy and works closely with every family to understand each child’s strengths and weaknesses. Abilities understands the importance of this individualized and client-centered approach, especially for children with ASD, and tailors a therapy program that is best fit for each child. Abilities accepts private pay and private and commercial insurance.

For more information, visit www.abilitiesinfo.com.

**Early Intervention, Ongoing Therapeutic Support**
Access to Better Communication (ABC) opened nearly 20 years ago as a general pediatric speech language pathology group. They work with children and adults ages two - 20 and involve parents in the program through parent training. ABC focuses on speech and language development, functional communication, and social communication/cognition.

ABC offers individual and group (Social Compass groups) sessions for children on the spectrum to improve in this area. In the past, they have offered ABA therapy and are actively looking for a BCBA therapist to offer this service. ABC accepts private pay and private and commercial insurance.

For more information, visit www.abclouisiana.com.
Early Intervention, Pre-K-12 Education, Adult Transition, and Social Interaction

Established in the 1950s by a group of parents, the Arc Baton Rouge is one of the largest nonprofit providers in South Louisiana of programs, services, and supports for children and adults with intellectual and developmental disabilities, such as ASD, Asperger’s syndrome, Down syndrome, cerebral palsy, fetal alcohol syndrome (FASD), and similar conditions and the families of individuals with one of these conditions. The mission is to improve the lives of these individuals through advocacy, services, and support. The Arc Baton Rouge service area includes eight parishes: East and West Baton Rouge, Ascension, Livingston, Iberville, Pointe Coupee, East and West Feliciana.

The Arc Baton Rouge provides early intervention for infants and toddlers, transition support for students exiting high school, skills training, vocational and employment support for adults, respite services for caregivers, supported living/socialization, and inclusive sports and recreation.

Early Intervention services are offered to children from birth to three years of age who are eligible for the EarlySteps Program (EarlySteps is described in greater detail later in the State Support Services section of this report). The team consists of parents, support providers, and primary providers, such as physical therapists, occupational therapists, speech therapists, special instructors, and social workers. They travel to the home or child care facility and work with the child in his or her natural environment. The Children’s Services program also includes training and technical assistance, family support projects, and school-age support.

Eligibility and funding differ depending on the program accessed and age of the client and can include state funded programs like EarlySteps and DHH state waivers, and private pay.

For more information, visit the Arc online at www.arcbatonrouge.org or contact them by email at info@arcbatonrouge.org.
**Navigator, Advocacy**

The Autism Society – Louisiana, an affiliate of the Autism Society of America, is a coalition of regional chapters with the mission to provide advocacy, information, and support to individuals with autism and their families and to promote lifelong opportunities in order that they may be fully included in their communities. Autism Society – Louisiana’s services include advocating for appropriate services and opportunities for people with ASD and providing educational conferences and workshops to educate families and professionals on current trends related to the diagnosis. Additionally, Autism Society – Louisiana provides families access to a toll-free 1-800 number that provides support and assistance to address individual needs and refers callers to the Autism Society chapter in their area (1-800-955-3760). They also provide a Resource Guide that families can use as a reference when locating services near them.

For more information, visit [www.lastateautism.org](http://www.lastateautism.org).

**Navigator, Advocacy**

Autism Speaks is the world’s leading science and advocacy organization, dedicated to funding research into the causes, prevention, treatments, and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks provides funding support for research along the entire research continuum – from discovery to dissemination – for innovative projects that could significantly improve the lives of individuals with autism. Through their Autism Treatment Network (ATN), Autism Speaks collaborates with hospitals and academic institutions to develop evidence-based protocols and standards of care for the most challenging autism-related conditions. Additionally, Autism Speaks educates individuals with autism, their families, and professionals by providing “Tool Kits” that cover topics including diagnosis, locating providers, housing and independent living, transition planning, and employment. Through Autism Votes, the organization’s advocacy arm, Autism Speaks works to maximize support and funding for autism research, surveillance, awareness, services, and advocates at the federal, state, and local levels for insurance reform that maximizes coverage of evidence-based treatments.

For more information, visit [www.autismspeaks.org](http://www.autismspeaks.org).
**Early Intervention, Ongoing Therapeutic Support**

Autism Spectrum Therapies (AST) is a private provider network with service locations throughout the United States. AST’s services are designed to serve three basic principles. These principles include individualization, therapy is customized to meet the needs and goals of each client; family focus, such that the entire family is supported and included in therapy; and the natural environment, where services are provided in a natural setting. AST integrates social skills into their ABA programs. Their programs are available for children and adults. AST accepts private pay, Medicaid, and private and commercial insurance.

For more information, visit [http://www.autismtherapies.com/](http://www.autismtherapies.com/).

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**Early Diagnosis**

The pediatric neurologists at the Baton Rouge Clinic use advanced evaluation and imaging technologies to analyze a child’s brain anatomy and its electrical activity. By utilizing an array of sophisticated diagnostic tools and genetic testing, the physicians at the clinic are able to diagnose and define many childhood disorders, including ASD, which leads toward more effective methods of treatment. The clinic currently staffs two pediatric neurologists who complete full evaluations on ASD.

For more information, visit [https://batonrougeclinic.worldsecsystems.com/pediatric-neurology](https://batonrougeclinic.worldsecsystems.com/pediatric-neurology).

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**Early Intervention, Ongoing Therapeutic Support**

The Baton Rouge General Pediatric Rehab Center, currently located on the Mid City campus, offers physical, occupational, and speech therapy services to children from birth – 18 years of age. With years of experience and advanced certifications in pediatrics, the therapists work with children of all ages and abilities. Their programs help children and parents learn basic developmental skills such as eating, dressing, walking, writing, and communicating. The Center offers a unique, team approach to sensory integration and processing and assisting children in developing language and social skills. They also offer specialized skills that may require adaptive equipment, orthotics, or assistive technology. They personalize the child’s program to fit his or her individual needs and personality. Together, their team of therapists work to maximize each child’s potential. The Baton Rouge General is committed to creating exceptional experiences and value for the people they serve through health and healing. Baton Rouge General accepts commercial and private insurances, private pay, and Medicaid.

For more information, please visit [www.brgeneral.org/services/pediatrics](http://www.brgeneral.org/services/pediatrics).
Early Intervention, Ongoing Therapeutic Support

Behavioral Intervention Group (BIG) is a private organization established in 2007 that consists of a group of dedicated therapists aimed at providing the skills, teaching environments, and learning opportunities necessary to improve the quality of life for children with ASD and other developmental disorders. Students from the Nicholls State University Applied Behavior Analysis program also participate in BIG programs as a practicum site.

BIG offers a therapeutic approach based on the principles of Applied Behavior Analysis (ABA)18 therapy using the Comprehensive Application of Behavior Analysis to Schooling (CABAS®) methodology. Utilizing ABA therapy, BIG offers intensive behavior management programs and directs treatment at reducing significant maladaptive behaviors while helping children acquire necessary replacements and adaptive behaviors. Throughout the process – under the direction of an assigned behavior analyst who closely supervises and coordinates a child’s program – BIG provides a highly individualized curriculum of behavioral instruction and training, continually optimized to meet each child’s changing needs as they progress.

Following CABAS® methodology, BIG takes a highly research-driven and individualized approach to early intervention as each therapist closely tracks the progress of each child’s plan using a range of metrics.

The organization also conducts Teacher Performance Rate and Accuracy Scales (TPRAs) through frequent observations of teaching sessions by supervising staff to ensure that therapists are teaching correctly and efficiently and that children are learning the skill that is being taught. BIG is currently seeking accreditation as a CABAS® model program and seeks to become the first CABAS® approved site in Louisiana.

BIG also has Pre-K and kindergarten classrooms (Accelerated Independent Learner classrooms) and works with schools to transition kids into an education setting. BIG currently accepts children up to approximately eight years old. Enrolled children attend full-time, Monday through Friday.

BIG accepts private and commercial health insurance and private pay. It currently serves approximately 50 children, but is capable of accepting up to 100 children at its current location.

For more information, visit www.big-br.com.

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Please see page 116 for a detailed explanation of ABA therapy.
Social Interaction, Recreation

BREC is an East Baton Rouge Parish government agency that operates public park and recreation facilities and programs throughout East Baton Rouge Parish. BREC’s mission is to contribute to a healthier, more vibrant community by providing exceptional parks, open spaces, and recreational experiences for all of East Baton Rouge Parish. BREC offers programming developed specifically to benefit non-traditional park users and under-served communities such as teenagers, children, and residents with disabilities, residents without transportation and those who live in play deserts, and low-income residents.

In the summer, BREC offers eight weeks of daily, non-residential, inclusive camps with a low staff to child ratio. Additionally, BREC offers Camp Sunshine which is an exclusive camp serving approximately 75 children per week with disabilities. Each weekly session of Camp Sunshine is broken down by age with a very low staff to child ratio. BREC performs leisure/ability assessments on each child that participates in their programs to gauge functionality and determine what supports they will need to succeed in the program. BREC partners with the Arc Baton Rouge who provide aides for children on waiver programs requiring this assistance by covering camp-related costs of having an aide accompany the child (i.e., admissions fees) for those children participating in inclusive camps. The camp costs $90 per week regardless of a child’s ability level.

Year round programing includes:

- Themed Sunshine Socials that attract a range of 150 - 200 attendees each month; a $5 donation benefitting Families Helping Families of Greater Baton Rouge is required for admission,

- Seasonal inclusive sports partnering with the Arc Baton Rouge, $10 per player, to include soccer, basketball, pickleball, kickball, and volleyball that can accommodate up to 60 participants each, and

- Adult Interactive days offering field trips, self-defense classes, karaoke, and electronic fitness games, among other activities. Each day can accommodate up to 8 - 10 participants and range in costs from no cost to $22.

For more information about BREC programs, contact John Lopez or Kendall Aguillard at 225-272-9200 or visit http://www.brec.org/.
**Ongoing Therapeutic Support**

Bridges Learning Solutions, Inc. is a for-profit organization that provides intensive Applied Behavior Analysis (ABA) services for a population of students that is grossly underserved in our community. Located on the campus of Greater Baton Rouge Hope Academy, Bridges currently serves students through age 13 who emit behaviors that hinder their participation in more typical classroom settings. As part of the program, students receive highly individualized 1:1 and 2:1 ABA therapy in a clinic-based setting with direct access to school-based therapy provided on site. Students have opportunities to socialize with peers on campus throughout the day as the program implements personalized strategies to increase socially significant behaviors.

Bridges uses a streamlined process to continually monitor and measure students’ progress toward transition to a less restrictive setting based on acquisition of the prerequisite skills necessary for success. Since the doors opened in August 2015, Bridges students have met twice as many short- and long-term objectives as were achieved in previous years in a more typical classroom setting. Bridges provides a comprehensive approach to learning, utilizing evidence-based treatments and curricula that include academics, communication, self-management, school, and self-sufficiency skills, as well as gross and fine motor skills instruction.

As students acquire new skills and interests, their parents receive group and individualized training to implement and measure the success of programming at home. The clinic recognizes the important role of parents as students’ first teachers and strives to develop a home to school relationship that fully supports students’ overall success. As Bridges grows as a clinic, it looks forward to creating and maintaining lifelong relationships with the families in the community.

Bridges currently accepts Medicaid, private and commercial insurance, and private pay. While the majority of Bridges clients are Hope Academy students, the clinic accepts clients who are not Hope Academy students.

For more information, visit [www.bridgeslearningsolutions.com](http://www.bridgeslearningsolutions.com) or contact Jenny Cronier, M.Ed., LBA, BCBA, CABAS® Teacher 1 at [jcronier@bridgeslearningsolutions.com](mailto:jcronier@bridgeslearningsolutions.com).
Early Intervention to Adulthood
Butterfly Effects is a private provider network with service locations throughout the United States, including in East and West Baton Rouge Parishes. Butterfly Effects’ service model uses Applied Behavior Analysis (ABA) to affect a desired change in a child’s behavior. Board Certified Behavior Analysts at Butterfly Effects work with children, their families, caregivers, and teachers to develop treatment goals; engage and teach children utilizing ABA; record behaviors, antecedents, and consequences so that teachers and support staff can learn how to prevent and understand what reinforces are most effective; work with families, caregivers, and teachers so they can apply ABA therapy in a consistent and ongoing basis; and continue to evaluate and adapt therapy approaches as necessary. Butterfly Effects’ support staff will coordinate with psychologists, pediatricians, and other direct care providers as requested by the family and frequently participate in school-held IEP reviews and behavioral plan meetings. Team members have 24/7 access to progress notes. Butterfly Effects accepts private pay, Medicaid, and private and commercial insurance.

For more information, visit www.butterflyeffects.com.

Early Diagnosis, Early Intervention, Ongoing Therapeutic Support, Navigator, Financial Support, Adult Services
Capital Area Human Services District is a multi-parish State agency established to direct the operation and management of public, community-based programs and services relative to mental health, developmental disabilities, and addictive disorders services for Ascension, East Baton Rouge, East Feliciana, Iberville, Pointe Coupee, West Baton Rouge, and West Feliciana parishes. CAHSD serves as the single point of entry for the Office for Citizens with Developmental Disabilities (OCDD). CAHSD provides services in the areas of Adult Behavioral Health, Child/Adolescent Behavioral Health, Developmental Disabilities, and Support Services for Adult Behavioral Health. Services specific to Developmental Disabilities include diagnosis and evaluation, crisis assessment, financial support through the Flexible Family Fund, family support, residential placement services, respite services, services coordination, waiver certification, and habilitation/vocational contract services. CAHSD provides early intervention services such as Applied Behavior Analysis (ABA) therapy through the Accelerated Supports for a Child’s Evolving Neurodevelopment (ASCEND) program and other therapy services for clients ages 2 to 5 years. CAHSD is currently serving six clients daily from 7:30 a.m. - 3:30 p.m. CAHSD’s model utilizes private/commercial health insurance, Healthy Louisiana (Medicaid managed care, formerly called Bayou Health), and private pay.

For more information, visit www.cahsd.org.
**Early Intervention to Adulthood**
CARD is among the world’s oldest and largest providers of evidence-based autism treatment using the principles and procedures of Applied Behavior Analysis (ABA). CARD provides ABA-based therapy at over 40 locations throughout the United States, including a location in Baton Rouge, Louisiana. CARD Baton Rouge currently serves children, adolescents, and adults diagnosed with ASD. CARD offers a flexible service delivery model that includes school, community, home, and clinic-based intervention services, seven days a week from 8:00 a.m. to 7:00 p.m. Plans for expansion are being developed. CARD accepts private and commercial health insurance, Healthy Louisiana (Medicaid managed care, formerly called Bayou Health), and private pay.

For more information, visit [www.batonrouge.centerforautism.com](http://www.batonrouge.centerforautism.com).

**Early Diagnosis, Early Intervention, and Social Interaction**
Chesney Center Therapies (CCT) is a private therapy clinic offering individualized physical therapy and occupational therapy for children as well as speech therapy for children and adults. They focus on providing excellent therapeutic services to their patients and families by empowering them with skills and strategies that will provide the greatest potential for a full, productive life. Family members are active participants in the therapy sessions in an effort to facilitate carryover of treatment goals into daily routines.

In addition to individualized therapy sessions, CCT offers screenings and evaluations for ASD as well as social groups where social skills are mediated by a speech-language pathologist through games and interactive activities. Chesney Center Therapies was founded by Shelley Chesney, M.S., CCC-SLP, LSLS Cert AVT, whose specialty is working with individuals with hearing loss. She is currently the only LSLS Certified Auditory-Verbal Therapist in the state of Louisiana. Chesney Center Therapies accepts private pay and is in-network with all major private health insurance companies.

For more information, visit [www.ChesneyCenterTherapies.com](http://www.ChesneyCenterTherapies.com).
Education
The Diocesan Department of Special Education was established in 1962 as a way to provide academic services to K-12 students who were otherwise unable to attend regular education classes. In recognition of a need to provide greater accessibility to families of special-needs students, planning to incorporate services at already established Catholic Schools in the Baton Rouge Diocese began in the 2012-2013 school year.

Expansion of services from the traditionally one-site model officially began with the 2015-2016 school year. Catholic Schools in the Baton Rouge Diocese consists of 30 primary and secondary schools spread across eight south Louisiana civil parishes. The first year of expansion brought services to six school sites with eight classrooms/labs. The mission of the department is to utilize the Rigor Relevance Framework© in a unique way to address the specific learning goals of the students it serves. In an atmosphere of Catholic Faith Formation, the program seeks to prepare students for their roles as Disciples of Christ and contributing members of a diverse society. Current programming includes classes specific to Autism; classes for Intellectual and Other Exceptionalities; and lab services (for regular education students) to address Dyslexia.

Classes for students with exceptionalities are considered part of the non-public, accredited, special education “school” established in the summer of 2015 by the Board of Elementary and Secondary Education (BESE). As such, students are considered enrolled in the special education “school” and not at the host (Catholic School) site.

Lab services, such as Dyslexia labs, for regular education students are provided in conjunction with a student’s regular education programming. Lab students are enrolled in the host (Catholic School) site and simply pay an additional fee to the Special Education Department for any lab services.

Services specific to Autism include classrooms with class sizes of four to six students, depending on the students’ overall functioning. Student-specific programming drives instructional practices.

For more information, please visit: www.csobr.org.
Adult Transition

COEA, located in Gonzales, Louisiana, was founded in 1964 by a group of parents of children with developmental disabilities. The concerned parents came together in an effort to find an alternate route for educating their children and to develop meaningful activities for them to be a part of. The group quickly grew into a thriving agency, well known as the primary resource for families in need of support for their child or family member with developmental disabilities. As the oldest and largest nonprofit agency based in Ascension Parish, COEA is continually striving to meet the needs of persons with disabilities by expanding and improving services.

The Arc of East Ascension’s mission is to enhance the quality of life for persons with disabilities and their families through services and advocacy that support choice, independence, and dignity. The vision of the Arc of East Ascension is to see a future for people with disabilities that is all-inclusive and ensures a quality of life through education, employment, family/community involvement, housing, recreation, and access to services.

COEA is dedicated to providing the highest standards of excellence in service provision for individuals with developmental disabilities and the elderly throughout the community. The organization is committed to developing and expanding both progressive and enabling opportunities, educating, advising, and counseling individuals and/or families in the identification of issues pertaining to developmental disabilities and, when appropriate, resolving such issues and problems, educating the public through an information and referral process, identifying, utilizing, and cooperating with community resources to facilitate and maximize a common purpose and directive, and encouraging and developing diverse citizen relationships.

COEA’s Diversified Employment Services prepare workers in basic work skills and attitudes, including job responsibilities, safety, attendance, punctuality, and work ethics. COEA provides assistance in training workers until they fully meet performance standards for typical full or part-time positions. COEA provides employees who perform consistently and with the highest quality of work possible.

Programs offered by COEA include adult day training programs, supported independent living, respite, supported employment services, and advocacy services.

For more information, visit http://www.coeathearc.com/.
**Pre-K-12 Education**

The Dunham School is a private, Pre-K through grade 12 Christian school located in Baton Rouge with the goal of “Educating the Mind and Heart for Christ.” The Dunham School provides students with a college-preparatory education accompanied by a Christian framework. To meet the needs of students with learning differences, the McKay Academic Center for Excellence provides a place where students who learn differently can receive the support they need to progress academically. The McKay Center offers services including advanced learning and college placement, tutoring, academic support services (including shadow-support, classroom accommodations, and testing accommodations), academic coaching, reading remediation, individualized and small group courses, and compensation classes.

Compensation classes are designed to meet the needs of students who require a more comprehensive, specialized learning environment. These classes provide appropriate, individualized academic services in a prescribed manner so as to move students to more participation in the traditional classroom, as their individual progress allows. These classes are staffed by a lead teacher and an assistant teacher. They have limited enrollment and are appropriate for students with a variety of learning challenges (such as language-based learning differences, high functioning Autism, Sensory Integration Disorder, Pervasive Developmental Delays, and other similar diagnoses).

McKay Center services are billed to insurance providers in addition to normal tuition and are available to students who have received a psycho-educational evaluation and/or approval by the administration.

For more information, visit [www.dunhamschool.org](http://www.dunhamschool.org) or call (225) 767-7097, extension 307.

**Early Intervention**

Head Start is a federally funded program focused on providing educational and other services for children from birth to age five who live in poverty. The focus of Head Start services is to assess and promote early childhood development. Program service areas include education, nutrition, physical health, family services, parental empowerment, disability services, fatherhood initiative, grandparents raising grandchildren, and transportation.

In East Baton Rouge Parish, the Head Start program is administered by the City of Baton Rouge/Parish of East Baton Rouge. The program serves approximately 1,500 children each year through 14 Head Start Centers. Head Start reserves 10% of funded slots for children with disabilities and works closely with community agencies to provide services that meet the needs of these children. Ninety teachers are currently part of the Head Start Program, 15 of whom hold Associate's degrees, 50 hold Bachelor's degrees, and 25 hold Master's degrees.

To enroll in the program, a child must live in East Baton Rouge Parish, must be six months to three years old for Early Head Start or three or four years old for Head Start, and the family must meet the federal income eligibility requirements. Services are available to eligible families without charge.

For more information, visit [www.brgov.com/dept/headstart/](http://www.brgov.com/dept/headstart/).
**Early Intervention**

The Emerge Center for Communication, Behavior, and Development opened in 2014. The Emerge Center, formerly the Baton Rouge Speech and Hearing Foundation founded in 1960, is a nonprofit therapeutic center that provides comprehensive services for children with autism and other communication challenges ages 18 months to seven years old. The Emerge Center uses a team-focused therapeutic model to provide many of the services children with autism need under one roof. The focus on the family starts at the intake process which is coordinated by a social worker and families are a part of the team throughout the treatment process.

The Emerge Center offers multiple unique therapy and education programs for children with autism, including full time and part time therapy programs. The Emerge multidisciplinary treatment model includes Applied Behavior Analysis (ABA), speech language therapy, and occupational therapy. In 2014, Emerge added a Therapeutic Educational program which now includes two unique classrooms led by highly trained special educators. Students in the Emerge Kindergarten have the opportunity to receive on-site therapy services including speech therapy, occupational therapy, and ABA. The Emerge Center’s psychology department, audiology department, and social work department provide a well-rounded treatment team able to address behavior, social, and emotional challenges for children with ASD and their families.

Emerge’s state-of-the-art building was designed with the needs of the clients in mind. Nine group speech therapy rooms, a cafeteria, small and large group and individual ABA spaces, and a full indoor/ outdoor Occupational Therapy gym are part of the Emerge Center’s specially designed facility. Parents can also benefit from parent support groups or find resources in the Emerge Lending Library and Resource Room. A large-scale conference and training center is also available for in-house and external trainings, conferences, and meetings. The Emerge Center accepts Medicaid, private and commercial insurance, and private pay for services.

For more information visit [www.emergela.org](http://www.emergela.org).
Advocacy, Navigator, Social Interaction, Recreation, Professional Development

Families Helping Families (FHF) of Greater Baton Rouge is a nonprofit organization with the mission to provide the individualized services, information, and support needed to positively enhance the independence, productivity, and integration of persons with disabilities into the community. Accepting all ages and all disabilities, FHF provides all its services free of charge to families. As a family-driven resource center for individuals with disabilities and their families, FHF provides information and referral services, education and training, and parent-to-parent support. FHF provides unbiased and factual support, information, and referral by sharing resources to individuals with disabilities to guide them to services that they otherwise would not have known were available to them.

Through its Resource Center for Autism Spectrum Disorders program (RCASD), FHF offers one-to-one support, family-oriented education, referrals, and various communication software assisting children with social and verbal communication. The RCASD works to raise awareness, acceptance, and inclusion of those having ASD in the community through the annual Active for Autism 5k Run/Walk and Fun Fest and various presentations at schools and in the community. FHF supports inclusive education by supplying resources, workshops, and presentations to empower parents to become advocates for their children receiving education services.

Transitional services for school to higher education or school to work are also offered through FHF programs. Guiding parents through individual education plans, behavioral issues, and other learning disabilities, FHF staff advocates can work with parent/teacher relationships and help ensure a positive learning environment. FHF also offers a parent-2-parent program that links “experienced” families to new families to share information about disabilities and provide emotional support.

To connect with to FHF, call the office at 225-216-7474, email info@fhfgbr.org, or visit www.fhfgbr.org. Interested individuals can also text “FHFGBR” to the number 22828 to sign up for weekly e-blast with upcoming events.
**Adult Transition**

The Frances Center (FCCE) is a private, nonprofit vocational and academic center in Baton Rouge with a mission to serve the community as a catalyst in the employment and continued education of persons with intellectual and developmental disabilities (IDD). FCCE provides supported self-employment to help adults choose a career path in a flexible environment. The Center offers tutoring and educational opportunities for those continuing academic pursuits.

The Frances Center opened in 2012 as the pilot program for the ABiliMall Model of Supported Self-Employment, which is an integrated self-employment support system for adults with disabilities. FCCE is a multi-vendor mall with booth stores and continuing education/personal development classes for our vendors. This combination provides an integrated approach to exploring careers, building workplace skills, and creating life-literacy with emphasis on functional reading and applied mathematical skills. FCCE’s goal is to provide a work environment rich in self-determination opportunities. They encourage self-directed choices and dignity of risk with a belief in natural consequences to further participants’ personal and vocational growth more effectively than the traditional process of “teach, model, do”.

Through this innovative program design, FCCE will meet their goals by implementing these features:

- A focus on self-determination as the foundation of the path to self-sufficiency,
- A work environment that accentuates individual preferences and accommodates personal needs linked to ones’ life circumstances,
- A model of self-employment that focuses on the need for supports, such as financing, skills training in specific tasks, and assistive technology,
- The placement of the person, not the market, first to ensure commitment to the employment process,
- The empowerment of individuals through self-employment to establish partnerships with businesses and private individuals to benefit their interests,
- The creation of an avenue for increasing individual wealth for individuals recognizing self-employment as the only substantial option available under the Social Security and Medicaid/Medicare systems to accumulate personal wealth, and
- The provision of continuing educational opportunities utilizing systematic instructional techniques to master the most common skills required for success in the workplace and assist those clients that desire so in the pursuit of completion of secondary educational goals through the completion of the HiSET equivalency program.

Currently, client capacity is restricted only by the ability to fund and staff personnel that are qualified to teach our population. With current staff, the Frances Center can comfortably accommodate 20-25 clients.

For further information, please visit [www.francescenter.com](http://www.francescenter.com) or contact Dr. M. Jo Monroe at 225-755-0990 or in person at 2575 O’Neal Lane in Baton Rouge, Louisiana.
**Adult Transition**

Gateway Transition Center, Inc. (GTC) is a nonprofit organization in the Greater Baton Rouge area, founded by Steve and Sharon Whitlow in 2014, focused on helping young adults with ASD and their families transition out of high school and into the "adult world". Careful planning with an Advisory Board of local therapists, educators, and parents, along with consultations with and visits to model programs in other states, and a review of research-supported practices in the field of transition, led to the creation of GTC’s model of programs, which were launched in Fall 2015. GTC believes its model could be replicated across the Capital Region and beyond to meet community needs.

GTC offers a comprehensive and individualized three-tiered program to prepare young adults with ASD ages 18 to 26 to meet their fullest potential:

1. **Day Program** at GTC helps young adults with ASD develop fundamental social, pre-vocational, and life skills needed to live, work, and thrive through community-based one-on-one and small group training. GTC is currently accepting applicants for the Day Program. The current capacity for the Day Program is ten participants.

2. **Gateway Ink** is a social enterprise screen printing business that serves as a job training program for young adults with ASD. Participants earn a real paycheck and learn social skills that are transferrable to jobs in the community. Gateway Ink also includes small-group training focused on money management and job-related social skills. GTC is currently accepting applicants for Gateway Ink. The current capacity for Gateway Ink is ten participants.

3. GTC is currently developing its **Vocational Track** program, which will help young adults with ASD to gain meaningful employment in the community, which includes support for post-secondary education and training, engagement of employers to create job opportunities, job placement, and ongoing job coach services in supported employment.

GTC also offers a program for high school students and their families, called **Transitioning Together**. Parents learn about services in the community for adults with ASD, and the students have an opportunity for social interaction and thinking about their futures in a safe environment. Transitioning Together consists of two 1-hour family sessions and eight 1.5 hour-group sessions over the course of eight weeks.

GTC is committed to making its services accessible to all eligible participants, regardless of their ability to pay. Through the generosity of donors and grants from local foundations, GTC is able to keep fees as low as possible and to offer scholarships to those in financial need. GTC is also exploring opportunities to partner with Louisiana Rehabilitative Services and Medicaid waiver programs for funding in the future.

For more information about GTC programs or to schedule a tour of the facilities, visit the GTC website at [www.gtcbcr.org](http://www.gtcbcr.org) or contact Cassie Dinecola, LMSW, Executive Director, at 225-384-6338 or cassie.dinecola@gtcbcr.org.
Pre-K-12 Education
Greater Baton Rouge Hope Academy is a nonprofit 501(c)3 non-public school established in 2007 that accepts students who learn differently. These include mild/moderate learning challenges, ASD, ADHD, learning disabilities, dyslexia, Down Syndrome, and more typical learners on grade level who benefit from a low pupil/teacher ratio.

Hope Academy includes Kindergarten through 12th grade classes working toward a state-approved high school diploma and older special needs students not pursuing high school diplomas, through age 21. Hope Academy’s climate is one of inclusion, encouragement, positive relationships, and recognition of accomplishments.

Hope Academy’s instructional curriculum is as unique as its learners. A sound, flexible diagnostic-prescriptive approach is utilized, with proven research-based methods and materials adapted to meet individual needs, allowing the program to be designed to fit the child, rather than forcing the child to fit a program. Every child has a learning plan which allows progression on their unique level and pace. Academic, social, and behavioral objectives, benchmarks, and anticipated timelines are set for each student.

Low staff/student ratios are coupled with small group and one-on-one instruction. Many students with learning and developmental challenges have trouble with relationships, reading social cues and distinguishing between appropriate and inappropriate behavior, reading facial expressions, and understanding language nuance. Social skills programs embedded daily in the classroom provide students with greater confidence in social situations.

An intramural sports program, clubs, dances, and other activities enhance the social skills and self-worth of Hope Academy students. Many students coming to Hope Academy have been marginalized in previous experiences and excluded from many activities. Hope Academy strives for student participation in all activities. The combination of specialized academics, social skills training, and participation in extracurricular activities results in feelings of acceptance, happy demeanors, friendships, and most importantly, success. Hope Academy pairs with several local universities in a coordinated effort to serve all of its students.

The Hope Academy financial model relies upon tuition, but Hope Academy also participates in the Louisiana Student Scholarship for Education Excellence Program and the School Choice Scholarship for Students with Certain Exceptionalities.

Hope Academy currently serves approximately 155 students residing in up to ten parishes within the state.

For more information, visit http://hopeacademybr.org/.
**Navigator, Professional Development**
Greater Baton Rouge Learning Disabilities Coalition (GBRLDC) is a nonprofit group of parents and professionals who work together to help children with learning disabilities in the Greater Baton Rouge Area. GBRLDC has the mission to improve the lives and education of individuals with learning disabilities, provide professional development for helping professionals working with people and families coping with learning disabilities, provide resource information for parents of children with learning disabilities, provide networking opportunities for parents and professionals interested in helping people with learning disabilities, promote learning disability awareness within the community, provide and maintain online resources for the community, and educate volunteers working with children and adults with learning disabilities. GBRLDC hosts an annual conference that serves as a community resource to increase academic success for children with learning disabilities. The annual conference is free of charge to parents and teachers but offers low-cost continuing education credits to professionals.

More information about GBRLDC can be found online at [www.gbrldc.org](http://www.gbrldc.org).

**Advocacy, Navigator**
The Louisiana Developmental Disabilities Council (LADDC) is an organization of persons with developmental disabilities, parents, advocates, professionals, and representatives from public and private agencies who are appointed by the Governor to develop and implement a five-year plan to address the needs of persons with disabilities. LADDC has the mission to lead and promote advocacy, capacity building, and systemic change to improve the quality of life for individuals with developmental disabilities and their families. The current Five Year Plan, effective from Federal Fiscal Year 2012 through Federal Fiscal Year 2016, contains goals that focus on the following areas: quality assurance, community supports, health, education, employment, recreation, and child care.

For more information about LADDC and its work, visit [www.laddc.org](http://www.laddc.org).
Early Intervention

The McMains Children’s Developmental Center is a nonprofit, multi-disciplinary, pediatric outpatient clinic providing a comprehensive range of diagnostic, treatment, and rehabilitation services to children ages 0 to 18. Opened in 1954, the Center works with children with cerebral palsy and other motor delays, mild to severe speech and language problems, sensory processing disorders, fine motor delays, autism, ADHD and learning disabilities, and children with Down, Rett, Jaubert, and Charge syndromes. McMains staff include licensed professional physical therapists, occupational therapists, speech/language pathologists, educational therapists, and social workers as well as a medical psychologist and volunteer pediatricians and orthopedists. The McMains Center incorporates a comprehensive, integrated, holistic approach to service delivery by wrapping its core therapies with ancillary services such as augmentative and alternative communication (AAC), assistive technology assessment, and daily living skills and training. Beyond clinical offerings, the McMains Center also offers an adapted bike program, an adapted gardening program, an annual summer arts camp for children with disabilities and their siblings, and an annual family-centered adapted canoe trip. McMains accepts private pay, private and commercial insurance, and Medicaid.

For more information, visit www.mcmainscdc.org.

Early Intervention to Adulthood

NeuroTherapy Specialists, Inc. is an outpatient rehabilitation facility that has been providing physical, occupational, and speech therapy to Baton Rouge and surrounding communities since 1988. NeuroTherapy uses a team-based approach where therapists and families work together to design a treatment plan that best meets a child’s needs. Summer programs and social groups are offered which are supervised by a therapist to encourage appropriate social interaction. The facility accepts private pay and commercial and private insurance.

For more information, visit www.neurotherapyspecialists.net.
Early Intervention to Adulthood

One Step At A Time opened in 2010 and offers behavioral interventions, including ABA therapy, to all age groups in individual and group settings. One Step At A Time also provides contracted services to schools, districts, and educational programs including evaluations, group and individual therapy, as well as the development and implementation of Behavior Intervention Plans.

Daniel L. NoackLeSage, M.A., is a Board Certified Behavior Analyst and Licensed Behavior Analyst working in the Greater Baton Rouge and surrounding areas. He primarily offers behavior analytic based intervention, therapy, consultation, and personnel development training via his practice, One Step At A Time Behavioral Services, LLC. Currently, Mr. NoackLeSage is working with several education programs in Baton Rouge and the South Louisiana region. Aside from his work in these areas, he also extends his practice towards various realms such as employee performance, community programs, and health and fitness benefits.

The mission of One Step At A Time Behavioral Services, LLC revolves around effective, efficient, and rewarding services for all members of the community, regardless of age and ability. By constantly evolving and progressing forward in an attempt to achieve meaningful results, the organization can better serve the individuals, families, and groups seeking behavioral services in their lives. By providing services that are flexible to the needs to both the individual and group, the possibilities of progress are endless when creating lasting change that is appropriate, purposeful, and beneficial for everyone involved. One Step At A Time Behavioral Services, LLC currently only accepts private pay.

For more information, visit www.onestepatatimebehavioral.com or contact Daniel L. NoackLeSage, M.A., BCBA, LBA via telephone (225-975-2924) or via email at onestepbehavior@gmail.com.
Early Diagnosis, Early Intervention

Our Lady of the Lake Pediatric Development and Therapy Center has grown significantly over the past five years and utilizes a multi-disciplinary approach in the assessment and management of pediatric developmental disabilities, including ASD. Led by a developmental pediatrician, the team consists of twenty health professionals including physical therapy, speech therapy, occupational therapy, social work, psychology, and nursing. The team coordinates the care of children with developmental disabilities, including ASD and thoroughly evaluates and supports patients medically, physically, emotionally, and socially. Currently, the center serves as the only neurodevelopmental center of its type in Louisiana and sees patients from throughout Louisiana as well as Mississippi and Alabama. Additionally, through its therapy and medical services, it continues to provide long-term care to numerous children in the Baton Rouge Area.

Recent innovations in services include the Infant/Toddler Clinic where occupational and speech therapy work with the developmental pediatrician to assess children zero to three years of age. Through this team, more infants and toddlers with complex medical needs and developmental delays can be diagnosed and treated sooner. This includes an increased number of children with concerns for Autism - facilitating early diagnosis and intervention which is essential for this population. Other innovations including feeding assessments both for sensory and motor issues including fiber optic endoscopy to evaluate for swallowing disorders. Thus, the Center continues to expand its role as a major regional destination site for children of varied ages and conditions.

The Center is currently developing plans for a significant presence on the new Our Lady of the Lake Children’s Hospital campus with the hope of attracting additional pediatric specialists to the Baton Rouge area including pediatric neurology. This neurodevelopmental center will further integrate medical specialists from the children’s hospital with the current team to better address the multiple medical issues that affect children with ASD and developmental disorders. Through this unique approach, additional therapies and interventions are made more effective through the management of medical disorders that exacerbate behavioral and developmental problems.

Towards the end of increasing the number of pediatric specialists available, the Center will add a second developmental pediatrician in the summer of 2016. This will increase the number of patients with ASD who can be seen. Currently, the capacity per developmental pediatrician is 100 new patient evaluations per year with 200 patients per physician seen annually in follow-up visits. 100 patients with ASD are also seen weekly for therapy by the staff.

For more information, visit www.ololphysianguip.com/pediatricdevelopmentandtherapy or call at (225) 765-6346.
**PORT CITY ENTERPRISES**

**Adult Transition**
Port City Enterprises is a nonprofit organization that provides vocational training opportunities, supported community living options, and habilitation services to persons with developmental disabilities. The organization’s philosophy is to enable persons with disabilities to live and work as independently as possible by providing necessary support for an individual to maintain his or her placement of residence and/or employment. Services are designed to assist individuals in acquiring, retaining, and/or improving skills in a safe environment. In order to be admitted to Port City Enterprises an individual must be 22 or older, live in the geographical services area, and have a primary diagnosis of mental retardation or developmental disability as defined by the Office for Citizens with Developmental Disabilities. Port City Enterprises receives funding from several agencies including: Capital Area Human Services District, Capital Area United Way, Title XIX Group Homes, Medicaid and other private funding sources. An individual approach to community based services is utilized in both the Supported Employment and Supported Community Living programs. Initial assessments are carefully conducted to ensure the individual’s desires, wants, and preferences as well as, the individual’s skills and abilities and needs for supports necessary to reach and to maintain the highest level of independent functioning. Port City Enterprises primarily serves individuals in East and West Baton Rouge Parishes, Iberville, and Pointe Coupee parishes.

For more information, visit [www.portcityenterprises.org](http://www.portcityenterprises.org).

**Early Intervention, Pre-K-12 Education**
St. Lillian Academy (SLA) is a nonprofit, non-denominational Christian school in Baton Rouge that serves children who have communication and learning challenges. SLA accepts students who are struggling in their current education setting as well as students with diagnoses such as ASD, Down syndrome, apraxia, communication disorders, and attention and focus issues. Student ages are three and older.

This school offers a unique team-based method of classroom teaching and therapeutic support. SLA serves as a “wellness” program for the child and family by using a whole child approach to education. Through collaborative efforts with supporting partners and agencies, SLA aims to provide a comprehensive, consistent program that provides a predictable environment for the students to take risks and learn new skills.

Excellence in Speech Pathology, LLC (ESP) is the outpatient provider for speech, occupational and physical therapy services. ESP is an outpatient clinic housed on the campus of the school. 90% of SLA students receive all of their therapy at the school. SLA also provides behavioral support through consultation with Daniel NoackLeSage, M.A., LBA, of One Step At a Time Behavior.

The SLA financial model utilizes tuition, which covers academic programming and in-school behavioral supports. ESP therapy services (speech, occupational and physical therapy) are billable therapy services through out-of-pocket pay or medical insurance billing.

SLA currently serves 30 children and is in the process of expanding capacity to 50 children.

For more information, visit [www.stlillian.org/home](http://www.stlillian.org/home).
**Advocacy**

Unlocking Autism (UA) was formed in February 1999 in Baton Rouge to raise awareness about Autism Spectrum Disorder and bring the ASD community’s issues from individual homes to the forefront of national dialogue. Since establishment, UA’s founding principle has been to focus on unity within the autism community. To this day, UA strives to bridge gaps collaboratively with every organization within the autism and broader disability community for the purposes of improving the lives of individuals on the spectrum across the lifespan. They have always welcomed all of those living with or touched by autism regardless of their opinions on causes, therapies, and treatments because they recognize that everyone’s experience is different. They connect and assemble groups for the greater good.

UA’s mission is to form strong bonds in the autism community through a spirit of service while equipping individuals living with autism, and those in their circle of care, with necessary tools to build a brighter future for the community as a whole. UA believes God’s promise that everyone living with autism has a hope and a future and that strong faith combined with action will ignite the power of our whole community for effective change.

UA seeks to:

- Educate individuals about pending legislation and existing laws.
- Teach whole person care methods, including biomedical treatments and behavioral therapies.
- Assist parents of newly diagnosed children, or newly diagnosed adults, by providing support through a 24-hour hotline.
- Raise funds for research projects that integrate gene-environment interaction with a focus on biomedical treatment protocols.
- Work to increase society’s ability to work with and understand people with autism.
- Help those on the autism spectrum reach their greatest potential in leading fulfilling and productive lives in relationships, society, and employment.
- Educate parents, and prospective parents, on the importance of environmental factors to the developing brains of children both born and unborn.
- Works to preserve personal health choice with regard to treatment and medical procedures.
- Integrate the community in cross-collaborative efforts to bring about change more rapidly.

UA has hosted the nation’s only 24/7 Autism Hotline since inception which can be accessed by calling 1-866-366-3361. UA has held local, state, and national grassroots policy development conferences, as well as hosting national rallies and marches in Washington, DC for autism since 2000. Since 1999, UA has served hundreds of thousands of families and individuals living with autism across the spectrum, across the lifespan, and across socioeconomic lines. They are not bound by geographic borders.

For more information please visit www.unlockingautism.org and www.thepowerofonemarch.org.
Adult Transition

VOAGBR is a locally-managed affiliate of Volunteers of America, one of the nation’s oldest, largest, and most comprehensive human services organizations. Established in Baton Rouge in 1921, VOAGBR currently provides services to a 19-parish area in South Louisiana, including the Greater Baton Rouge, Lafayette, and Lake Charles areas. The organization takes a person-centered approach and works to address both urgent and ongoing needs, with the goal of helping each individual and family become as healthy and self-reliant as possible. VOAGBR’s vision is to engage the energy and spirit of the people of South Louisiana, to care for our neighbors who need help today, and to build healthier, more compassionate communities for tomorrow.

Areas of focus in the Capital Area include promoting self-sufficiency for the homeless, strengthening families, serving veterans, caring for the elderly, fostering independence in individuals with disabilities, empowering individuals with HIV/AIDS, and supporting positive development for children and youth.

Residential Services provide 24-hour support and supervision to residents in a family-like atmosphere. Supported Living Services assist people with daily living skills within the family home or by helping them develop the necessary life skills to live successfully in their own home. A Pre-Vocational Day Program provides education and training so program participants can gain a skill set, earn supplemental income, achieve a level of self-sufficiency, and build relationships in their community.

Behavioral health services for children and families include a therapeutic group home, intensive case-management services, and outpatient counseling. VOAGBR offers several affordable housing options across south Louisiana for adults living with severe and persistent behavioral health issues.

VOAGBR is the designated Child Care Resource and Referral agency for 17 parishes in South Louisiana and provides support for child care providers through training and on-site technical assistance and serves as a referral source for parents looking for local child care services, including services for children with disabilities.

VOAGBR’s housing programs assist homeless individuals and families with obtaining permanent affordable housing, with a special focus on individuals with behavioral health issues or other disabilities. The Drop-in Center also provides case management as well as a place for homeless individuals to do their laundry, shower, receive mail, and use the telephone.

For more information, go to www.voagbr.org or email info@voagbr.org.
Early Intervention
Woman’s Center for Wellness has several programs in which they integrate clients who have an ASD diagnosis. These programs include: Swimstrong, summer school readiness (handwriting, letter recognition, etc.), one-on-one occupational therapy, physical therapy and speech therapy for infants to adults, audiologists, and nutritionists onsite. If appropriate, patients are also treated in a full size warm water therapy pool. Each of their potential clients participates in an intake evaluation, though they refer out for a formal DSM diagnosis. The Center currently serves 150 pediatric clients with seven therapists and primarily receives referrals from neurologists and pediatricians.

For more information, visit www.womans.org/locations/maps/womans-center-for-wellness.

The resources outlined demonstrate the wealth of available services to families in our community. Baton Rouge has benefited from the numerous organizations who have successfully implemented programs to address many of the needs in our community. However, the overwhelming sentiment from families interviewed throughout this process is that the resources do not currently fill all of the needs across the lifespan. Through this report, we identify the necessary resources at each stage throughout a lifetime and recommend new resources in the areas in which we are lacking.
A Lifetime of Key Transitions
As life unfolds for an individual with an autism spectrum disorder, the child and his or her family will face unique challenges at each key transition point across his or her lifetime. This is a journey for the entire family of a child with an ASD diagnosis. While the child will need therapy, care, and specialized education, caregivers will need support, both emotionally and financially, in navigating the system.
The timeline graphic labeled Figure 4 highlights common transition points that are especially important for persons with an ASD diagnosis.

04 A Lifetime of Key Transition Points

**EARLY DIAGNOSIS**
- Referral to physician specialist
- Referral to other medical specialists for comorbidity evaluations (if applicable)
- Referral to early intervention programs

**EARLY INTERVENTION**
- Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
- Application/referral to state waiver programs (if applicable)

**PRE-K-12 EDUCATION**
- Individual Educational Plan (IEP)
- Continued supplemental intervention and therapy
- Individual Transition Plan (ITP) in high school

**ADULT TRANSITION**
- Post-secondary education
- Career training
- Independent and supported living
To emphasize the importance of these transition points, most of the observations and recommendations included in this report are organized chronologically to coincide with key transitions on the timeline. The report observations and recommendations are organized into the following subparts:

01/ ASD Support Services & Navigation
02/ Early Childhood Diagnosis
03/ Medical Comorbidities
04/ Early Childhood Intervention
05/ Pre-K-12 Education
06/ Adult Transition
07/ State Support Services
08/ ASD Research & National Center of Excellence Recognition

Throughout this report, recommendations will be made to improve the infrastructure and resources necessary to fill the large voids in the Capital Region.
ASD Support Services & Navigation

FIRST RESPONDERS AND LAW ENFORCEMENT TRAINING
LEGAL PROFESSIONAL RESOURCES
ASD awareness and understanding are growing, as are the resources available in the Capital Region to serve the needs of citizens with an ASD diagnosis. There exists a core group of advocates in the Capital Region who are working relentlessly to raise community awareness and understanding of ASD, and energizing efforts to expand and strengthen the ASD resources and services infrastructure across Greater Baton Rouge.

However, across the dozens of individual interviews and group input meetings conducted as part of this assessment project (parents, advocates, early childhood educators, K-12 educators, post-secondary educators, health care professionals, public policy experts, and social service providers), the most pervasively expressed sentiment was this:

parents of children with an ASD diagnosis feel mostly alone when facing the lifelong task of navigating the fragmented and often inadequate ASD infrastructure of available medical, educational, and social supports to find and access resources best suited to the unique needs of their respective sons and daughters.
This challenge of “navigating the system” is often, for parents, a long, lonesome climb up a very steep mountain. This is largely because there really is no organized “system of ASD resources and services” that families can access – only fragmented pieces and parts, connected haphazardly (if at all) by word of mouth.

There is also no professional entity focused on creating a sustainable interface with all the key ASD stakeholder sectors – a convener/facilitator organization focused on connecting, strengthening, and building ASD resources and services throughout Greater Baton Rouge.

05 Key ASD Stakeholder Sectors

The Capital Region needs a permanent resource that can serve as a navigator for families with newly-diagnosed children, utilizing one-on-one case management techniques and leveraging the latest information technology to deliver sound (evidence-based) orientation and ongoing navigation services.

The Capital Region also needs a permanent resource that can serve as a convener and stakeholder interface, facilitating greater connection and collaboration among the ASD stakeholders, and helping lead consensus efforts to strengthen and build the ASD infrastructure in the Capital Region – leveraging strengths, filling service gaps, and avoiding wasteful duplication of effort.
The Capital Region could benefit greatly from a comprehensive ASD resource entity that can provide orientation and ongoing navigation services to the parents or guardians and serve as the interface and convening entity focused on strengthening the ASD infrastructure and facilitating easier family navigation of the system. This entity would function as a home base for families, serving in the following critical roles:

- **Family Orientation** – offer a comprehensive family orientation service for families with newly diagnosed children.

- **Family Navigation** – offer ongoing family navigation services that serve as a current and objective information source regarding ASD and available resources, and one-on-one navigation assistance across the key ASD stakeholder sectors (health care, early childhood intervention, Pre-K-12 education, social services and social interaction, post-secondary education and training, independent living, and employment).

- **Family Respite** – provide a comfortable, safe resource available to give parents (and other key family caregivers) brief intervals to refresh and recharge.

- **ASD Stakeholder Interface/Convener** – serve as a neutral convener of the many key ASD stakeholder organizations and sectors to foster greater understanding, network building, collaboration, innovation, advocacy, and problem solving.

- **ASD Infrastructure Development** – facilitate periodic strategic assessment of the ASD infrastructure in Greater Baton Rouge and the promotion of strategic needs.

- **ASD Public Policy** – facilitate ASD-focused public policy research and the promotion of evidence-based practices and innovations.

- **ASD Advocacy** – advocate for greater ASD awareness and support, including funding support, from local, state, and federal officials and policymakers.

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No two people on the autism spectrum are the same. The expression of characteristics, patterns of strengths and challenges, and severity of impairments differs widely across individuals on the autism spectrum. As a result, support and service needs vary greatly and continually change as individuals with autism age.

National Autism Indicators Report Transition into Young Adulthood, 2015
A.J. Drexel Autism Institute
SPOTLIGHT: AUTISM CONSORTIUM (BOSTON)

The Autism Consortium was founded in 2006 to connect families, donors and researchers to change the way ASD is understood and treated. Their network includes leading scientists, physicians, patients, and families working together in the search for treatments. The Consortium has grown to a network of researchers and clinicians from 16 elite institutions in the Boston area, along with a committed community of patients and families.

In order to facilitate such a network, the Autism Consortium funded autism resource specialists with backgrounds in social work and special education to support families seen at affiliated hospitals. These resource specialists serve as navigators for families trying to access support services in the Boston community. As part of their work, these resource specialists created a parent information book19 so that parents can access information outside of designated services hours. The resource specialists work with families from diagnosis through at least the first two years of intervention.

The Consortium hosts roundtable meetings for professionals and stakeholders, hosts parent education seminars, and gathers researchers together for symposiums. Their core principles are:

• Scientific collaboration accelerates research,

• ASD is a disorder that cannot wait for results to come from “business as usual,” and

• Patients and families are integral to understanding and treating ASD; they are part of the research team.

For more information about the Autism Consortium, visit www.autismconsortium.org.

19 http://www.autismconsortium.org/attachments/2015PIP.pdf
SPOTLIGHT: EXCEPTIONAL LIVES

Exceptional Lives is an organization based in Massachusetts and launched in 2013 to empower families and guide them through the complex world of accessing services and supports using technology. Exceptional Lives provides online guides, free to users, that help families navigate through difficult processes such as how to:

- Create an effective IEP
- Optimize their child’s health insurance
- Access state resources such as Medicaid waiver programs
- Obtain guardianship, or explore alternatives
- Access Social Security Insurance (SSI) and other disability benefits

In conjunction with the guides, Exceptional Lives maintains a robust online database of available resources and services in the community so family members can easily survey all of the available options on one website and contact those resources that best fit their child.

Because the guides can be accessed remotely, families are able to educate themselves from home on their own time. In this way, caregivers understand what resources are available and how they can best access them. If the process becomes stressful or confusing, Exceptional Lives offers 24/7 access to autism resource specialists who help families navigate through both the online resource and answer questions specific to that individual’s needs.

Over the past several months, the Baton Rouge Area Foundation has been working closely with the executive leadership of Exceptional Lives to explore the possibility of developing online guides, as well as a robust online resource database, tailored to Louisiana’s infrastructure of providers and system of state resources and laws. The Exceptional Lives team developed two Louisiana-specific pilot guides, and in March 2016, visited Baton Rouge to conduct focus groups with parents and providers to solicit feedback on the usefulness of the guides. The response was overwhelmingly positive. The Foundation is continuing to work with Exceptional Lives to implement a Capital Region-specific website and hopes to make this online tool available to families in the not too distant future.

For more information about Exceptional Lives, visit www.exceptionallives.org.
SPOTLIGHT: **CHARLIE’S PLACE**

Charlie’s Place Respite Center is a program for individuals with early to mild stage Alzheimer’s and dementia-related disorders designed to provide cognitive stimulation and social interaction while giving caregivers a much-needed break. While Charlie’s Place is focused on Alzheimer’s and related conditions, the model utilized in the Center could be adapted to those with an ASD diagnosis. Caregivers often need down time and centers like Charlie’s Place allow for a safe and supported environment to provide this reprieve.

The program offers a non-threatening, home-like experience, where participants can enjoy a purposeful, six-hour day with a host of activities to stimulate cognition and socialization. Offered activities included:

- Music and pet therapy
- Gardening
- Arts and crafts
- Spiritual activities
- Live entertainment
- Intergenerational activities
- Physical activities and exercising
- Integration of technology
- Games requiring mental participation and concentration
- Cooking with the “Charlie’s Place Culinary School”
- Social interaction with peers
- Periods of rest and relaxation

Charlies Place serves a ten-parish area with approximately 20,000 patients. The program serves 15 people per day at a cost of $65 per day per individual. These fees cover approximately 75% of operating costs with the remaining coming from fundraising efforts.

They have established collaborative partnerships with local beauty schools, higher education institutions, and other nonprofits in the area. Charlie’s Place strives for a staff to client ratio of 1:3, including volunteers who undergo extensive training.

For more information, visit [http://www.alzbr.org/charliesplace.cfm](http://www.alzbr.org/charliesplace.cfm).
FIRST RESPONDERS AND LAW ENFORCEMENT TRAINING

Citizens with an ASD diagnosis face a special risk when engaged by first responders and law enforcement officers if the engaging responder/officer does not recognize they are encountering a person with an ASD diagnosis, and therefore, misunderstand and misinterpret the citizen’s responding behavior. In worst case scenarios, a minor problem or issue can escalate to dangerous confrontation and tragedy.

In the Capital Region, there are several training resources available to law enforcement and first responders. The Arc of Louisiana, in conjunction with the Independent Living Research Utilization project, provides training for law enforcement agencies to help them identify individuals with developmental disabilities and communicate with them effectively. An ASD-specific one-hour module has been added to the training. The Capital Area Human Services District (CAHSD) also offers a Crisis Intervention Team training which helps law enforcement identify an individual who is developmentally disabled (including ASD), overcome communication barriers, and deescalate an interaction.

Prevent-Educate.org is an organization whose mission is to teach all first responders how to effectively interact with individuals with ASD. The training (Autism Awareness and Interaction Online Training Program) can be provided for firefighters, emergency medical technicians (EMT’s), paramedics, police officers, and other first responders. The training gives these professionals the tools they need to effectively communicate with individuals and reduce or eliminate dangerous behaviors. In Louisiana, this training is provided through the Louisiana Bureau of EMS.

The Louisiana Bureau of EMS offers five hours of continuing education credit to their state licensed professionals who successfully complete this training.
SPOTLIGHT: AUTISM IDENTIFICATION CARDS

In 2014, the state of Alabama passed legislation allowing its Department of Public Health, working closely with the Department of Public Safety (OMV), to issue Autism Identification Cards and then provide education to local and state law enforcement and first responders. This was the first state-recognized Autism Identification Card in the United States. The card explains that the person with autism may have difficulty communicating or understanding directions and may become agitated if touched or approached with loud sirens or lights. Though originally intended only for people with autism who have a driver’s license, the card has since been expanded to include children and adults with autism who do not have a driver’s license.²⁰

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²⁰ [Link](http://www.wsfa.com/story/29302557/autism-id-cards-helping-autistic-drivers-communicate); see also [Link](https://www.autism-alabama.org/what-is-autism/autism-driver-identification-card/).
LEGAL PROFESSIONAL RESOURCES

Parents of children and young adults with autism, as well as adult individuals with autism themselves, may encounter a number of issues along their journey that require legal assistance and/or advocacy to resolve. Parents, for example, often do not understand the full scope of their rights as they relate to the public education system, or may not understand their options when state waiver benefits for their child are reduced or changed. The scope of issues that parents and young adults often face include topics such as education rights and the IEP process; access to state benefits and waiver programs; access to Medicaid and reimbursement for autism-related treatments and therapies; powers of attorney and interdiction; legal issues related to financial status; advocacy for independent living supports, and many more. For any parent, but especially parents with too few resources to consult a private attorney, these issues can be overwhelming.

Based on conversations with parents and stakeholders, we have identified only one legal aid provider in the Capital Region that provides direct legal services for disability-related issues to individuals without the ability to pay: The Advocacy Center.

Federal law requires that a protection and advocacy system operate in every state to protect the rights of persons with mental or physical disabilities. The Advocacy Center of Louisiana carries out this mandate by providing legal and advocacy services to individuals with a disability and their family members. The organization, which is based in New Orleans but has a branch office in Baton Rouge, employs 14 full-time staff attorneys, as well as a number of additional client advocates, paralegals, social workers, and support personnel. The Center offers services, free of charge, to any Louisiana resident with a disability. The Center offers services related to several subject matters:

- **Special Education**: evaluations, appropriate IEP services, least restrictive environment, transition planning, inappropriate discipline

- **Access**: housing discrimination, physical accessibility, programmatic accessibility

- **Public Benefits**: Medicaid/Medicare, nursing home issues, personal care services to allow people to remain at home (including Waiver programs)

- **Self-Determination**: life planning issues, interdiction, challenges to clients’ rights to make decisions and choices

- **Community Integration**: children’s mental health system of care, home and community based services, housing, de-institutionalization

- **Institutional Rights**: abuse or neglect, restraint or seclusion, rights violations, illegal discharges

- **Employment & Rehabilitation**: Louisiana Rehabilitation Services, SSI/SSDI work incentives, employment barriers

- **Voting**: polling place accessibility, voter education, assistance in voting

More information about the Advocacy Center of Louisiana can be found at [http://advocacyla.org/](http://advocacyla.org/).
01 RECOMMENDATIONS

ASD SUPPORT SERVICES AND NAVIGATION
Parents and other caregivers of children with an ASD diagnosis often feel alone and sometimes overwhelmed in their lifelong task of navigating the fragmented support infrastructure in the Capital Region.

1. The Capital Region needs a comprehensive ASD support entity to provide orientation and ongoing navigation services to parents or guardians and serve as the interface and convening entity focused on strengthening the ASD infrastructure and facilitating easier citizen/family navigation of the system. This entity could be a reimagined, existing organization with more robust resources, an entirely new creation partnering with existing navigation resources, or a coalition of existing providers and resources, all working together. Dimensions of this entity when fully developed should include:

   a. A comprehensive, interactive website resource for families/caregivers and the full range of ASD stakeholder organizations that is a source of good information and facilitates connections to available resources. The Baton Rouge Area Foundation is committed to funding the initial website build-out and will partner with the proposed new organization or an existing local organization to ensure its long-term sustainability, as ongoing maintenance and updating of the website will be critical to its success. The Foundation’s work to date with Exceptional Lives to develop online guides and a resource database for families in the Capital Region should continue and be integrated into the work of the comprehensive ASD support entity recommended herein.

   b. A navigator for families with newly-diagnosed children that provides expert one-on-one case management services, ideally located in more than one location or geographic area, to provide comfort, to serve as a connection to widely recognized information sources, to facilitate family decision making, and to connect families to available resources and the ASD community.

   c. A high-quality respite program/service that provides families/caregivers needed support to rest and rejuvenate while their loved one is in an appropriate and safe setting. This could also include training for babysitters and other direct care providers.

   d. An interface and convening entity of ASD stakeholder organizations to facilitate ongoing collaborative needs assessment, planning, innovating, problem solving, and advocacy that connects policymakers, public agencies (state and local), community leaders, health care providers, early childhood providers and advocates, Pre-K-12 school systems, and employers. The interface should provide a collaborative environment for individual stakeholders to communicate on a regular basis, organize opportunities to create real policy change, establish an ongoing gap analysis for the Capital Region, and build an employer network.

2. The Louisiana Bureau of EMS and the Capital Area law enforcement agencies should design and promote public policy standards that require law enforcement and emergency first responders to complete training on how to recognize ASD citizens and appropriately communicate with and engage them. There are several tools and programs that have been developed that can be leveraged for this purpose.

3. The Louisiana Department of Health and Hospitals, the Louisiana Department of Public Safety, and the Louisiana State Police in collaboration with local law enforcement should design and implement an ASD identification card program.
Early Childhood Diagnosis

Medical Diagnosis

Early Diagnosis is Critical

Early Diagnosis Resources Available in the Capital Region
People on the spectrum are not a monolithic population exhibiting a uniform set of symptoms that require unvarying treatment regimens. Likewise, prognoses vary widely.

The broad range of ASD-related symptoms, conditions, and prognoses can leave parents of children with ASD with the impression that their child is, to a significant extent, an experiment of one.

This sentiment was repeatedly expressed by parents, educators, care providers, and advocates interviewed as part of this assessment project.

The wide-ranging nature of ASD challenges our ability to accurately diagnose ASD early in life – the all-important prerequisite to determining and supplying the types and amounts of interventional care required to achieve an optimal outcome. For ASD, as is true for many of our most pervasive medical conditions (diabetes, hypertension, cancer, heart disease, etc.), early diagnosis is the key to efficacious interventions that maximize outcomes.

We interviewed individuals and groups who are involved in the diagnosis and treatment of ASD in the Capital Region. We also spoke with representatives from local, state, and national organizations who had information related to ASD diagnosis and treatment. We also conducted a limited review of expert literature, including information available from the Centers for Disease Control (CDC), the National Institutes of Health Autism Research and Treatment Centers, and other organizations.
**EARLY DIAGNOSIS**
- Referral to physician specialist
- Referral to other medical specialists for comorbidity evaluations (if applicable)
- Referral to early intervention programs

**EARLY INTERVENTION**
- Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
- Application/referral to state waiver programs (if applicable)

**PRE-K-12 EDUCATION**
- Individual Educational Plan (IEP)
- Continued supplemental intervention and therapy
- Individual Transition Plan (ITP) in high school

**ADULT TRANSITION**
- Post-secondary education
- Career training
- Independent and supported living
MEDICAL DIAGNOSIS

In the U.S. health care system, a recognized medical diagnosis is the essential door opener for health insurance coverage and the eligibility determinations required to access other financial and service support programs. A medical diagnosis of ASD is made based upon criteria established in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders Fifth Edition) published in May 2013 by the American Psychiatric Association.

Under the previous version of the DSM (DSM-IV, published 1994), patients could be diagnosed with four separately defined pervasive developmental disorders (PDD): autistic disorder, Asperger’s disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder – not otherwise specified. Researchers found that these separate diagnoses were not consistently applied across different health care providers and treatment centers.

The revised diagnosis framework represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders. Anyone diagnosed with one of the four PDDs from the DSM-IV framework should still meet the criteria for ASD diagnosis in the new DSM-V framework or meet the criteria for another, more accurate DSM-V diagnosis. The DSM Work Group that developed the ASD diagnostic framework believes a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria or substantially changing the number of children being diagnosed.

The DSM-V criteria were tested in real-life clinical settings as part of DSM-V field trials, and analysis from that testing indicated that there would be no significant changes in the prevalence of the disorder as a result of the change in the diagnosis framework. More recently, the largest and most up-to-date study released in October 2012 issue of American Journal of Psychiatry provided the most comprehensive assessment of the DSM-V criteria for ASD based on symptom extraction from previously collected data. The study found that DSM-V criteria identified 91% of children with clinical DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses will retain their diagnosis of ASD using the new criteria.

The full-text of the DSM-V diagnostic criteria for ASD and the related diagnostic criteria for social communication disorder (SCD) is provided by Autism Speaks on its website. Autism Speaks is an international nonprofit organization focused on ASD advocacy.

22 ibid
**EARLY DIAGNOSIS IS CRITICAL**

Studies, including randomized ones (randomized clinical trials (RCT)), are showing that early diagnosis and intervention is beneficial and leads to significant improvement in cognition and behavior.\(^{24}\) Today, research has determined that ASD can be detected as young as 18 months and it is possible to **diagnose ASD correctly when a child is two to three years old**. Efforts are currently underway at the Marcus Autism Center in Atlanta (a NIH Autism Center of Excellence) to reliably detect symptoms in 12-month olds.\(^{25}\)

Unfortunately, many children with ASD are not diagnosed until the age of 5 or even after they begin elementary school. Minorities are typically diagnosed later than Caucasian children. The **median age of diagnosis in the United States is four years old**.\(^{26}\) Stakeholder interviews conducted as part of this assessment indicate our Capital Region children are no exception to these statistics. Stakeholders offered a variety of anecdotal rationales for the delay in diagnosis - from lack of access to primary care providers to parental avoidance to limited provider familiarity with ASD.

There is no medical test currently available to diagnose ASD. Diagnosis is based on behavior analysis by trained physicians and psychologists using behavior-based screening tools. Diagnoses are sometimes developed by larger evaluation teams that may also include speech therapists, behavior therapists, language experts, and other therapists.

Prior to medical diagnosis, parents and others who are in close contact with children are ideally positioned to make basic observations that raise “red flags” and warrant a professional evaluation. Autism Speaks offers the following list of “red flags” that may indicate risk for an ASD diagnosis:

- No big smiles or other warm, joyful expressions by six months or thereafter
- No back-and-forth sharing of sounds, smiles or other facial expressions by nine months
- No babbling by 12 months
- No back-and-forth gestures such as pointing, showing, reaching or waving by 12 months
- No words by 16 months
- No meaningful, two-word phrases (not including imitating or repeating) by 24 months
- Any loss of speech, babbling or social skills at any age

Autism Speaks also offers a basic tool for parents - the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-RTM) - on its website: [www.autismspeaks.org](http://www.autismspeaks.org). Caregivers, including parents and childcare providers, need to be trained to recognize the warning signs or red flags that indicate the need for a professional ASD assessment.

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25 For more information about the Marcus Autism Center in Atlanta and their research efforts, visit the Marcus Center website at [www.marcus.org](http://www.marcus.org).

**LOSING VALUABLE TIME**

Possible Age of Diagnosis: **between 2 - 3 years**

Current Median Age of Diagnosis: **4 years**
Early diagnosis of ASD by a medical professional is typically accomplished through a two-step process.

The first step is a basic developmental screening that can be conducted by a wide range of health care professionals including pediatricians, family practitioners, psychiatrists, psychologists, and other trained professionals. Screening is not the same as diagnosis. It identifies those children who may be at risk and who merit further evaluation. However, if there are concerns, referral for appropriate therapy services is essential even in the absence of a specific diagnosis.

In Louisiana, the EarlySteps program is designed to serve families with a child aged birth to 3 years old who has a developmental delay or a medical condition likely to result in a developmental delay. Eligibility for this state-run program requires either an established medical condition commonly associated with developmental delay or disability, or presence of a developmental delay established through the EarlySteps assessment battery. To access the EarlySteps assessment battery or to get more information about the program, parents/caregivers should call the System Point of Entry Office (SPOE) for their parish of residence. This program, managed by the Office for Citizens with Developmental Disabilities (OCDD) within the Louisiana Department of Health and Hospitals (DHH), also includes the screening of program participants for ASD beginning at 18 months. (EarlySteps is described in greater detail later in the State Support Services section of this report).

The American Academy of Pediatrics (AAP) specifically recommends that a child be screened for developmental delays and disabilities during well-child doctor visits at 9 months, 18 months, and 24 or 30 months. In addition, all children should be screened specifically for ASD at 18 months and 24 months. Extra screenings are recommended for high-risk children (those with pre-term birth, low birth weight, or with a sibling or parent with ASD) or those who may exhibit symptoms. A copy of the Surveillance and Screening Algorithm: Autism Spectrum Disorders (ASD) is provided by AAP on its website. Evidence gathered through our interviews with health care professionals, educators, advocates, and parents of children with an ASD diagnosis in the Capital Region indicates that the AAP-recommended standards for ASD screening and surveillance are not consistently utilized in the Capital Region – representing a significant opportunity to improve the early diagnosis of ASD in the Capital Region.

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27 For the System Point of Entry Office contact information or more information about Early Steps, visit the Louisiana Department of Health and Hospitals website at http://new.dhh.louisiana.gov/index.cfm/page/215.

The second step in the early diagnosis process is a comprehensive diagnostic evaluation that is typically provided by a much smaller community of specialists including developmental pediatricians, child neurologists, and child psychiatrists and psychologists. Again, evidence gathered through our interviews of stakeholders in the Capital Region indicates that comprehensive diagnostic evaluations for ASD are conducted by only a handful of specialists who are focused on ASD and other developmental disorders. The results from these interviews also suggest lengthy waiting lists to access these specialists, resulting in some families venturing outside the Capital Region to gain access to the qualified specialists they need.

The Louisiana Autism Spectrum and Related Disabilities Project (LASARD), housed in the Human Development Center of LSU Health Sciences Center in New Orleans, offers a number of educational opportunities targeted specifically at Louisiana physicians to increase rates of screening. LASARD has developed a series of webinars that can be viewed by practicing physicians for continuing educational credit. LASARD offers an ASD case trial to teach physicians what to look for in ASD cases and teaches seminars that discuss how to conduct ASD screenings and how to bill third-party insurers for ASD screenings. In addition, LASARD personnel meet regularly with pediatric residents at Tulane Medical School and LSU Medical School in New Orleans to discuss surveillance and screening practices.

An early diagnosis of ASD not only allows the family to access therapeutic and other support structures, but is also invaluable once the child starts schooling. Since most children are not diagnosed until they enter the school system, their access to school support is further delayed. A medical diagnosis is not required for the creation of an Individualized Education Program, but it is required for the school to bill private and commercial insurance and Medicaid for additional services and therapies provided in the classroom, such as speech therapy or ABA therapy. More information on this can be found in the Pre-K-12 Education section of this report.

Finally, while obtaining a diagnosis is critically important, comorbid medical conditions associated with ASD can often be a trying experience for parents. These comorbid conditions can include Attention Deficit Disorder (ADD), Attention Deficit/Hyperactivity Disorder (ADHD), gastrointestinal issues, sleep disorders, seizures, intellectual disability, and many others. More detailed information on these conditions and the steps physicians and caregivers need to take to best education and equip parents can be found in the Medical Comorbidities section of this report.
EARLY DIAGNOSIS RESOURCES AVAILABLE IN THE CAPITAL REGION

The following are significant early diagnosis providers currently available in the Capital Region. This listing is not intended to be an exhaustive list, as we have heard anecdotally that other physicians and psychologists in the region are performing comprehensive diagnostic evaluations. Additionally, screening is available at a variety of service providers as detailed in the Early Childhood Intervention section. Narrative descriptions for these providers can be found in the Key Providers and Organizations in the Capital Region section of this report.

- Baton Rouge Clinic Pediatric Neurology (2 pediatric neurologists)
- Our Lady of the Lake Pediatric Development and Therapy Center (1 developmental pediatrician, another joining in summer 2016)
- The Emerge Center for Communication, Behavior and Development (2 psychologists)

Resources are limited for physician specialists in Louisiana. Given the scarcity of these specialists trained to diagnosis in the Capital Region, it is not at all surprising to hear that parents are traveling as far as neighboring states in order to get an ASD diagnosis to access therapies and additional resources.
RECOMMENDATIONS

EARLY CHILDHOOD DIAGNOSIS
Evidence is mounting that shows an early diagnosis of ASD (beginning at 18 months) is possible, reliable, and significantly advantageous to the pursuit of optimal potential outcomes.

1. The Louisiana Chapter of the American Academy of Pediatrics (AAP) should lead an ongoing, focused campaign to endorse and encourage best practices in ASD treatments, particularly related to ASD screening and surveillance best practices and ongoing medical training.
   a. Promotion and distribution of AAP-developed guidelines, tools, and other collateral resources developed for pediatric health care professionals and new parents.
   b. Engagement with Louisiana medical schools/pediatric programs to identify and promote any new opportunities to better prepare pediatric residents for early diagnosis of ASD.
   c. Engagement with Louisiana medical schools/pediatric programs and physician clinics to identify and promote any new opportunities for ongoing training in comorbid conditions and best practices associated with the treatment of ASD.

2. Area providers, including the Baton Rouge Clinic, the Baton Rouge General, Lane Regional Medical Center, Ochsner Health System, Our Lady of the Lake Children’s Hospital, and Woman’s Hospital should lead an effort to build the cadre of pediatric physician specialists and psychologists needed in the Capital Region to offer all young children with ASD timely, local access to comprehensive diagnostic evaluations and treatment prescriptions. These hospitals should undertake a targeted campaign to recruit these specialists to the Capital Region and expand hospital resources to support and retain them.

3. A comprehensive, robust ASD stakeholder organization based in the Capital Region should design and execute a community education campaign focused on Learn the Signs of Autism, a practical guideline that can aid families and other caregivers in identifying early red flags that could warrant a formal evaluation. This campaign should include training sessions, awareness campaigns, and provide informational materials to the following targeted groups:
   a. Parents/Family caregivers
   b. Childcare providers
   c. Educators
   d. Social service and recreation organizations serving young children
   e. Churches
   f. Civic groups
   g. Other health care professionals (e.g., nurses, physician extenders, technicians)

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29 See Community Recommendation 1 on page 16.
4. The Louisiana Department of Health and Hospitals (DHH) should establish developmental screening performance metrics for its Healthy Louisiana (Medicaid managed care, formerly called Bayou Health) contracts that are consistent with Centers for Disease Control and Prevention (CDC) guidance.31

   a. Screening for developmental delays and disabilities during regular well-child doctor visits at:

      i. 9 months

      ii. 18 months

      iii. 24 or 30 months

      iv. Additional screening as needed if a child is at high risk for developmental problems due to pre-term birth, low birth weight or other reasons

   b. Screening for ASD during regular well-child doctor visits at:

      i. 18 months

      ii. 24 months

      iii. Additional screening as needed if a child is at high risk for ASD (e.g., having a sister, brother or other family member with ASD) or if behaviors sometimes associated with ASD are present

5. The Louisiana Department of Education (DOE) should establish a requirement, as a condition of state licensure, that all staff of licensed early learning centers be trained as part of the new employee orientation requirements (LA Title 28 Chapter 17.1719) to recognize the “red flags” that may indicate risk for an ASD diagnosis.

   The Louisiana Autism Spectrum and Related Disabilities Project (LASARD), a collaborative effort between the Louisiana State University Health Sciences Center Human Development Center and DOE, offers a one-hour training that illustrates “red flags” that may indicate a child has ASD. They also offer 12 hours of DOE approved training for caregivers regarding ASD detection and intervention. DOE may wish to leverage this existing resource to implement this new licensure requirement by allowing early learning center employees to be trained through this program.

Medical Comorbidities

ASD AND GASTROINTESTINAL DISORDERS
ASD AND SLEEP DISORDERS
ASD AND ANXIETY, ASD AND ATTENTION DEFICIT HYPERACTIVITY DISORDER
ASD AND SEIZURE DISORDERS
Because children with developmental disabilities (DD) will often meet the diagnostic criteria for more than one DD, making a definitive diagnosis can be challenging. Further, children with DDs, including ASD, frequently have co-occurring medical conditions that complicate the delivery of treatment and necessary interventions. Several studies have examined the link between ASD and comorbidities and have found varying prevalence estimates, but significant impacts.32 33

At the time of initial diagnosis of ASD, children should be screened for comorbid medical conditions and referred to a specialist for a full evaluation and treatment. The importance of identifying comorbid, health-related conditions associated with ASD are multiple. Many of the conditions can be treated, and if identified and managed, can result in an improved sense of well-being, more effective participation in educational and therapeutic programs, and improved quality of life for the child and the child’s family. In addition, identification of specific medical disorders may help physicians and researchers better understand medical conditions associated with ASD and develop more detailed protocols for assessment and treatment.34

Several of the most common and significant comorbid medical conditions are described in detail below. However, there are numerous other comorbidities that also add to the complexity of caring for a child with autism.

33 Bauman, Margaret L., “Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment,” 2010.
34 Ibid
According to a report completed by researchers at the CDC, after adjusting for a child’s sex, age, race/ethnicity, and mother’s education, children with autism were found to be:

- 1.6 times more likely than children without developmental disabilities to have asthma,
- 1.7 times more likely to have eczema or skin allergies,
- 2.4 times more likely to have food allergies,
- 17.8 times more likely to experience stuttering,
- 2.4 times more likely to have had more than three ear infections in the last 12 months, and
- 1.8 times more likely to have chronic severe headaches.

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ASD AND GASTROINTESTINAL DISORDERS

The exact prevalence estimate of ASD and gastrointestinal disorders, including gastroesophageal reflux disease (GERD), chronic constipation, diarrhea, celiac disease, or inflammatory bowel conditions is largely unknown, but estimates range from between 9% and 70% or higher.\(^{36}\) A National Health Interview Survey from 2006-2010 showed that children with ASD were 7.1 times more likely to have had frequent diarrhea or colitis within the last 12 months and 2.6 times more likely to have stomach or intestinal illness with vomiting or diarrhea within the past two weeks than children without any developmental delay.\(^{37}\) At present, the prevalence of gastrointestinal abnormalities in individuals with ASD is not fully understood.

Part of the difficulty of identifying comorbid medical conditions is that children with ASD may not exhibit symptoms in an easily recognizable manner. For example, children with gastrointestinal distress may tap their chest, apply pressure to their stomach, or act out in school. Diagnostic evaluations for patients with ASD and gastrointestinal symptoms therefore can be complex, especially when the patient presents with behavioral manifestations.

An expert panel convened in 2010 identified key guidelines regarding ASD and gastrointestinal distress and how care providers should approach treatment delivery.\(^{38}\) According to this panel, pediatricians and other primary care providers should be alert to potential nutritional problems in patients with ASD and should refer the patient for an evaluation by a nutritionist and/or dietician who is familiar with nutrition support for individuals with ASD to the extent that caregivers raise concerns about the patient’s diet. Children with ASD should be referred for consultation with a gastroenterologist specialist.

Anecdotal reports suggest there may be a subgroup of individuals with ASD who respond to dietary interventions, although additional data are needed before pediatricians and other professionals can recommend specific dietary modifications.

As noted above, children with ASD are 2.4 times more likely to have food allergies. As such, pediatricians and other primary caregivers should obtain a detailed history (including personal history of allergic disease, dietary history, and family history) to identify any potential associations between allergen exposure and gastrointestinal and/or behavioral symptoms. Involvement of specialists such as allergists and feeding therapists may be beneficial.

Clear guidelines for the management and treatment of ASD and gastrointestinal disorders are not universally accepted. However, the wide variation in prevalence rates of co-occurring gastrointestinal disorders in children with ASD and the vast array of research studies conducted to date suggest that caregivers and health care providers should be educated and trained on how to recognize both typical and atypical signs and symptoms of gastrointestinal disorders in individuals with ASD and that diagnosticians and primary medical providers should refer the patient to specialists if symptoms are identified. Our Lady of the Lake Children’s Hospital has a pediatric gastroenterology medical group in Baton Rouge.

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36 Bauman, Margaret L., “Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment,” 2010.
38 Buie, Timothy; Campbell, Daniel B.; et al, “Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals With ASDs: A Consensus Report,” 2010, http://pediatrics.aappublications.org/content/125/Supplement_1/S1
ASD AND SLEEP DISORDERS

Sleep disorders are one of the most prevalent co-occurring conditions for children with ASD. Often, sleep disorders manifest in children having difficulty falling asleep or staying asleep through the night, with some children experiencing nightmares, and other sleep disorders. The prevalence of sleep disorders varies from 40% to 80% of all children with ASD as compared to 30% of children without a developmental disability.39

Without appropriate intervention, sleep disorders can result in daytime drowsiness which affects overall health and well-being. In addition, without proper sleep, children cannot focus to benefit from therapeutic interventions, may become hyperactive, or struggle with maintaining attention. Studies have suggested that aggression, hyperactivity, emotional reactivity, and anxiety were exacerbated in children with ASD who also struggled from sleep disorders.40

All children with ASD should be screened for a potential sleep disturbance and pending the results of the screening, should be referred to a sleep specialist or neurologist. Currently, Our Lady of the Lake employs one pediatric trained sleep specialist and a second has recently been hired. Research related to the specific recommended treatment for sleep disorders shows varying levels of efficacy. Establishing a sleep program, using behavior interventions, and using pharmacologic interventions may be indicated depending on the child.41

39 Bauman, Margaret L., “Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment,” 2010.
41 Bauman, Margaret L., “Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment,” 2010.

ASD AND ANXIETY, ASD AND ATTENTION DEFICIT HYPERACTIVITY DISORDER

At least 30% of people with ASD also have an anxiety disorder which can include social phobia, separation anxiety, excessive worry, and obsessive compulsive disorder. Children with ASD and anxiety disorders should receive treatment like behavioral intervention and pharmaceutics.

The prevalence of attention deficit hyperactivity disorder (ADHD) in children with ASD is reported between 30% and 50%. Similarly, approximately 2/3 of children with ADHD show features of ASD.42

Recent research suggests that the “co-occurrence of ADHD and ASD is associated with a lower quality of life and poorer adaptive function than in any one of these conditions. Both disorders often include difficulties in attention, communication with peers, impulsivity, and various degrees of restlessness or hyperactivity. Both are more common in boys than in girls...”43 Children with ASD and ADHD are frequently treated with pharmaceuticals and behavioral intervention focused on social learning theory.

42 Leitner, Yael, "The Co-Occurrence of Autism and Attention Deficit Hyperactivity Disorder in Children – What Do We Know?,” 2014.
43 ibid
**ASD AND SEIZURE DISORDERS**

Children and adults with ASD experience seizures more frequently than their typically developing peers – 20 times more frequently, as reported by the National Health Interview Survey.\(^4^4\) Prevalence estimates of seizures in children with ASD range from 7% to 14% and in adults with ASD from 20% to 35%.\(^4^5\) All types of seizures – major motor, myoclonic, febrile, and complex partial – have been reported in association with ASD.

Challenges in identifying seizures in children with ASD abound, as atypical movements that would typically suggest the clinical manifestation of a seizure can be found in many children with ASD without seizures or with another co-occurring condition, such as gastrointestinal distress. Any child with ASD who exhibits behavior such as “staring spells, cessation of activity, eye fluttering, or eye deviation to one side, as well as behavioral changes associated with confusion or followed by fatigue or sleep should raise the suspicion of complex partial seizures, and should lead to further investigation.”\(^4^6\)

Although the research is not clear-cut in terms of the prevalence of the multiple medical comorbid conditions, evidence is clear that there are numerous medical conditions that present more often in children with ASD than they do in children without any developmental disability.

The identification and treatment of comorbid conditions is critical to the well-being of children with ASD, since the earlier these co-occurring diseases are diagnosed and treated, the more effectively a child with ASD can participate in educational and therapeutic interventions. Unfortunately, many of these comorbid conditions are often more difficult to recognize and diagnose in a child with ASD due to an inability to communicate discomfort and relay symptoms effectively.

Regardless of which type of specialist makes an initial ASD diagnosis for a child, all children should undergo a comprehensive diagnostic evaluation by a medical specialist such as a neurologist or developmental pediatrician trained to recognize medical comorbidities such as the ones described above. To the extent co-occurring conditions are identified, the child should be referred to additional specialists for further evaluation and treatment. Today, in the Capital Region, this process involves parents visiting and coordinating among numerous physicians and providers, which is not only time-consuming and confusing, but can also lead to inconsistent information and treatments. There is a lack of coordination among the initial diagnostician, a child’s primary treatment physician, specialists treating various comorbid medical conditions and a child’s therapists. Ideally, a child’s behavioral treatment plan should be developed, implemented, and changed as needed *in collaboration* with the child’s medical caregivers to ensure each of the treatment plans complement each other and to ensure there is open communication about how changes to one treatment plan may affect the child’s behavior or response to other types of treatments.

\(^4^4\) “Concurrent Medical Conditions and Health Care Use and Need among Children with Learning and Behavioral Developmental Disabilities,” National Health Interview Survey, 2006-2010.

\(^4^5\) Bauman, Margaret L., “Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment,” 2010.

\(^4^6\) ibid
SPOTLIGHT: A NEURODEVELOPMENTAL THERAPY CENTER & AUTISM TREATMENT CLINIC FOR BATON ROUGE, LA

The Our Lady of the Lake Pediatric Development & Treatment Center (PDTC) is leading an effort to open a Neurodevelopmental Therapy Center & Autism Treatment Clinic in Baton Rouge.

The goal is to develop a state-of-the-art, stand-alone pediatric neurodevelopmental and behavior diagnostic and treatment facility designed to assess the comprehensive health needs of children with behavior issues and neurodevelopmental disabilities, including ASD, by addressing their underlying co-morbid physical health conditions as a component in the overall diagnosis and treatment plan. This facility would focus on neurodevelopmental disabilities as an anchor for diagnosis, teaching, research, and multi-disciplinary assessments including social work, behavioral intervention, genetics testing, nutritional counseling, physical assessments for co-morbid physical and metabolic dysfunction, and therapeutic delivery (speech therapy, occupational therapy, and physical therapy).

This proposed center will provide outpatient, inpatient, and critical care services for the developmentally and intellectually disabled, as well as children with significant co-morbid health issues. The facility would be placed directly adjacent to the new Children’s Hospital so that services could be more easily integrated and to save operational costs, as well as reduce replication in services. The proposed facility would include six branches of operation:

• An Autism Center that would be a separate dedicated clinic focused on improving early diagnosis and treatment plans. The center will include parent education, as well as parent liaison/lay worker to assist with services and adult care transition. This center will also draw from clinics defined below, including hosting gastrointestinal and sleep medicine specialists to be integrally involved in care of patients on the autism spectrum.

• A Developmental Pediatrics/Rehabilitation Clinic to address developmental pediatrics, psychology services, and physiatry-physical medicine and rehabilitation physicians.

• A Neurology and Neurosurgery Clinic.

• A Genetics Clinic with a focus on personalized medical treatment plans and integrative health care.

• Pediatric Therapy Services, including therapeutic delivery of occupational, speech, and physical therapy.

• A Social Work and Community Liaison Division which will focus on educating parents and leading them through social services for which the child might be eligible. This division would assist with directing parents through paperwork and case management, as well as develop educational programming to enhance a continuum of care and provide marital and financial counseling so that families have an improved chance of retaining their nuclear function.

• Allied Medical Services to integrate with the existing Children’s Hospital services and provide necessary medical treatments for co-morbid health conditions present in the developmentally/intellectually delayed and behaviorally disturbed population.
Proposed Clinical Organizational Structure:

The Our Lady of the Lake Pediatric Development & Treatment Center envisions that this clinic would become a National Institute of Health Center of Excellence in this region in order to collaborate with entities like Pennington Biomedical Research Center and become a part of the Autism Treatment Network (ATN) system throughout the United States. As a recognized facility within this network, the center will more readily be able to access federal funds to support their ATN research and service activities. More information about NIH Centers of Excellence and the ATN can be found in the ASD Research and National Center of Excellence Recognition section of this report. Ultimately, this center would allow multiple care delivery models to occur under one roof and support families in seeking care for a child with comorbid medical conditions.
03 RECOMMENDATION

MEDICAL COMORBIDITIES
Children with ASD will frequently be diagnosed with comorbid medical conditions that will affect the child’s well-being and the efficacy of typical therapeutic interventions.

1. All children with ASD who present with symptoms of potential comorbid medical conditions should be referred to a physician specialist who can best determine the treatment regimen necessary.

The Baton Rouge community should support the creation of a designated neurodevelopmental center, like Our Lady of the Lake’s Pediatric Development and Therapy Center, that focuses on the treatment of medical comorbidities within an integrated developmental and behavioral care facility.
Early Childhood Intervention

THE CASE FOR INTENSIVE EARLY BEHAVIORAL INTERVENTION
APPLIED BEHAVIOR ANALYSIS (ABA) PROVIDERS
EARLY INTERVENTION RESOURCES AVAILABLE IN THE CAPITAL REGION
ABA IN LOUISIANA AND THE CAPITAL REGION
TRANSITION TO PRE-K THROUGH 12 EDUCATION
EARLY INTERVENTION

• Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
• Application/referral to state waiver programs (if applicable)
An accurate ASD diagnosis in early childhood creates the opportunity for a variety of early childhood interventions that are custom designed to meet the specific needs of the diagnosed child. Common interventions include: behavioral therapy, occupational therapy, speech and language therapy, auditory and sensory therapy, medical care to treat physical health issues which often co-exist with ASD, and social skills training through tools such as simulated classrooms to acclimate a child preparing for school.

These intervention efforts are primarily focused on improving skills and abilities that allow each individual to function as independently as possible in society and achieve his or her full potential. As mentioned in the previous section of this report, studies show that early diagnosis and intervention lead to significant improvement in cognition and behavior.

### EARLY DIAGNOSIS
- Referral to physician specialist
- Referral to other medical specialists for comorbidity evaluations (if applicable)
- Referral to early intervention programs

### EARLY INTERVENTION
- Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
- Application/referral to state waiver programs (if applicable)

### PRE-K-12 EDUCATION
- Individual Educational Plan (IEP)
- Continued supplemental intervention and therapy
- Individual Transition Plan (ITP) in high school

### ADULT TRANSITION
- Post-secondary education
- Career training
- Independent and supported living
A multitude of treatment interventions for ASD have been proposed in the professional and lay media. Anecdotally, families have found success in a number of these programs; however, the efficacy and safety of these interventions have not always been supported by scientific research and data. As has been discussed, ASD does not present the same in every child or adult. Each person will need a personalized intervention plan that includes the appropriate therapeutic interventions. We acknowledge the critical importance and large evidence base in support of speech therapy, physical therapy, and occupational therapy for many children with ASD. Interventions including ABA therapy, integrative behavioral and developmental programs, social skills programs, and picture exchange communication systems have seen moderate strength of evidence in support of their efficacy. We encourage parents to refer to resources that compile research on evidence-based interventions before embarking on innovative therapeutic models. The Association for Science in Autism Treatment compiles this information on their website.

For the purposes of this report, we have included a robust analysis of Applied Behavior Analysis (ABA) and its availability in the Capital Region. While other therapeutic interventions are critical for a young child with an ASD diagnosis, behavioral intervention – in particular, ABA therapy – despite reliable studies proving its effectiveness, is the least readily available early intervention tool in the Capital Region. Throughout the process of compiling this report, parents consistently voiced demand for wider availability and easier access to ABA therapy for their children. Today, reimbursement for ABA therapy through health insurance is mandated in Louisiana, providing a reliable avenue for families to access this intervention. Insurance companies should update their reimbursement mechanisms to include other evidence-based interventions as their efficacy is established.

ABA therapy is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree and to demonstrate that the interventions employed are responsible for the improvement in behavior. ABA therapy has been shown, when implemented effectively, to improve communication, social relationships, play, self-care, behavior in school, and employment performance for people who have ASD or other learning difficulties. ABA is widely recognized as a safe and effective treatment for ASD and has been endorsed by numerous state and federal agencies, as outlined below.

Studies have shown that ABA therapy is most beneficial when it can be applied to patients intensively and as soon as possible. Early intervention means programs that begin before the age of four. Some ABA therapy sessions involve one-on-one interaction between the behavior analyst and the participant. Group instruction can likewise prove useful. Intensive programs include 25-40 hours per week of ABA therapy, typically for one to three years. Productive ABA therapy continues for as long as necessary, sometimes into adulthood, but the level of intensity decreases substantially with age and behavioral improvement.

48 http://www.asatonline.org/for-parents/learn-more-about-specific-treatments/
49 Not all families will require or need 25-40 hours of intense ABA therapy. Some families may benefit from focused and short-term treatment approaches within ABA methodology.
THE CASE FOR INTENSIVE EARLY BEHAVIORAL INTERVENTION

The body of evidence to support early and intensive intervention is by no means complete, but the evidence is significant and growing. Significant literature suggests that early and intensive behavioral and developmental intervention – as much as 30+ hours per week – as well as comprehensive approaches that address numerous areas of functioning lead to greater improvements in cognitive performance, language skills, and adaptive behavior skills.\(^{50}\) Controlled trials have also shown ABA to be effective for improving social skills and language when provided for at least 25 to 40 hours per week for two years.\(^{51}\) Lower intensity level and parent driven intervention, especially behavioral, do not seem to have as strong a positive effect as more intensive interventions.\(^{52}\)

This evidence highlights the importance of adequate professional resources to serve the Capital Region’s early childhood behavioral intervention needs for children with an ASD diagnosis.


**APPLIED BEHAVIOR ANALYSIS (ABA) PROVIDERS**

In the U.S., ABA therapy is delivered through a three-tier system including the Board Certified Behavior Analyst® (BCBA® or BCBA-D®), Board Certified Assistant Behavior Analyst® (BCaBA®), and Registered Behavior Technician™ (RBT™).53

**Board Certified Behavior Analyst**
The BCBA and BCBA-D are independent practitioners who also may work as employees or independent contractors for an organization. The BCBA conducts descriptive and systematic behavioral assessments, including functional analyses, and provides behavior analytic interpretations of the results. The BCBA designs and supervises behavior analytic interventions. The BCBA is able to effectively develop and implement appropriate assessment and intervention methods for use in unfamiliar situations and for a range of cases. The BCBA seeks the consultation of more experienced practitioners when necessary. The BCBA teaches others to carry out ethical and effective behavior analytic interventions based on published research and designs and delivers instruction in behavior analysis. BCBAs supervise the work of Board Certified Assistant Behavior Analysts and others who implement behavior analytic interventions.54

A number of pathways exist to become certified as a BCBA with the national Behavior Analyst Certification Board. Each of these pathways has degree, training, and experience requirements.

- To satisfy the degree requirement, an applicant must have a master’s degree in an approved degree program, which may be in behavior analysis, natural science, education, human services, engineering, medicine, or another related field.

- To satisfy the training requirement, the applicant must have completed 225 hours of approved graduate-level instruction; one academic, full-time faculty appointment at a college or university teaching classes on behavior principles or conducting and researching behavior analysis; or have completed a doctoral degree in an approved field.

- To satisfy the experience requirement, the applicant must have completed 1,500 hours of supervised independent fieldwork, 1,000 hours of practicum, 750 hours of intensive practicum, or ten years of post-doctoral experience practicing behavior analysis.

53 In Louisiana, Medicaid enables licensed psychologists who practice ABA therapy within their scope of practice to bill for reimbursement without requiring a dual license in behavior analysis.
54 Definition from the Behavior Analyst Certification Board, [www.bacb.com](http://www.bacb.com).
Upon completing each of these three requirements, an applicant may apply for and take a certification exam administered by the national Behavior Analyst Certification Board. Upon successful completion of this exam, BCBAAs wishing to practice in Louisiana must apply for licensure with the Louisiana Behavior Analyst Board, pass the Louisiana Jurisprudence Exam, and complete a background screening.

The Behavior Analyst Certification Board defines a Board Certified Assistant Behavior Analyst as follows:

**Board Certified Assistant Behavior Analyst**

The BCaBA conducts descriptive behavioral assessments and is able to interpret the results and design ethical and effective behavior analytic interventions for clients. The BCaBA designs and oversees interventions in familiar cases (e.g., similar to those encountered during their training) that are consistent with the dimensions of applied behavior analysis. The BCaBA obtains technical direction from a BCBA for unfamiliar situations. The BCaBA is able to teach others to carry out interventions and supervise behavioral technicians once the BCaBA has demonstrated competency with the procedures involved under the direct supervision of a BCBA. The BCaBA may assist a BCBA with the design and delivery of introductory level instruction in behavior analysis. It is mandatory that each BCaBA practice under the supervision of a BCBA. Governmental entities, third-party insurance plans, and others utilizing BCaBAs must require this supervision.

To become certified as a BCaBA with the national Behavior Analyst Certification Board, an applicant must complete degree, coursework, and experience requirements.

- To satisfy the degree requirement, an applicant must have a bachelor’s degree in an approved degree program.
- To satisfy the coursework requirement, the applicant must have completed 135 hours of approved classroom instruction to satisfy the coursework requirement.
- To satisfy the experience requirement, the applicant must have completed 1,000 hours of supervised independent fieldwork, 670 hours of practicum, or 500 hours of intensive practicum.

Upon completing these requirements, an applicant may apply for and take a certification exam administered by the national Behavior Analyst Certification Board. The examination fee will be $125 beginning in 2016 (an increase from $100). Upon successful completion of the exam, BCaBAs wishing to practice in Louisiana must apply for certification with the Louisiana Behavior Analyst Board, pass the Louisiana Jurisprudence Exam, and complete a background screening.

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55 The Louisiana jurisprudence exam, issued by the board, covers the covering laws and rules governing the practice of behavior analysis in Louisiana.
The Behavior Analyst Certification Board defines a Registered Behavior Technician as follows:

**Registered Behavior Technician**

The RBT is a paraprofessional who practices under the close, ongoing supervision of a BCBA or BCaBA (“designated RBT supervisor”). The RBT is primarily responsible for the direct implementation of skill-acquisition and behavior-reduction plans developed by the supervisor. The RBT may also collect data and conduct certain types of assessments (e.g., stimulus preference assessments). The RBT does not design intervention or assessment plans. It is the responsibility of the designated RBT supervisor to determine which tasks an RBT may perform as a function of his or her training, experience, and competence. The designated RBT supervisor is ultimately responsible for the work performed by the RBT.57

RBTs do not have to be registered by the national Behavior Analyst Certification Board to practice in Louisiana. Most RBT’s are trained in-house by their hiring organizations. Requirements established by the national BACB include a high school diploma, completing a 40-hour training program conducted by a professional certified by the BACB, and passing the RBT Competency Assessment and examination. In Louisiana, the national RBT credential is not currently required to practice ABA; however, persons working in this capacity must be registered with the Louisiana Behavior Analyst Board as a Registered Line Technician (RLT) and pass a background screening.

ABA is a relatively young but rapidly growing therapy profession – the Behavior Analyst Certification Board was created in 1998. There is also limited national salary data available for BCBAs and BCaBAs through the Association of Professional Behavior Analysts (APBA). The data that does exist indicates an approximate BCBA salary range of $40,000 to $80,000 and an approximate BCaBA salary range of $20,000 to $60,000, with the majority between $40,000 and $60,000.58

**ABOUT THE LOUISIANA BEHAVIOR ANALYST BOARD**

The Louisiana Behavior Analyst Board was established by Act 351 of the 2013 Louisiana Legislative Session and is affiliated with the Louisiana Department of Health and Hospitals (like most other professional health care boards). This Act also included the Behavior Analyst Practice Act and “provide[d] for the licensure, certification and registration of individuals practicing ABA in the state of Louisiana.”59

The Louisiana Behavior Analyst Board is comprised of five voting members who are behavior analysts, serve between three and five year terms and cannot serve more than two consecutive and complete terms. The board members are nominated by the Louisiana Behavior Analysis Association, appointed by the Governor, and confirmed by the Senate. A sixth member of the board serves in an ex-officio and nonvoting capacity and is appointed by the Louisiana State Board of Examiners of Psychologists.

The board is housed in Baton Rouge and meets monthly. For more information about the board or the Practice Act, visit their website, [www.lababoard.org](http://www.lababoard.org).

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57 Definition from the Behavior Analyst Certification Board, [www.bacb.com](http://www.bacb.com).
LOUISIANA ABA EDUCATIONAL PROGRAMS

In Louisiana today, McNeese State University in Lake Charles, Louisiana State University in Baton Rouge, and Nicholls State University in Thibodaux offer BCBA educational programs.

The McNeese program started in 2008 and is a master’s-level program in psychology with a concentration in applied behavior analysis. The program, which currently has 30 students enrolled, includes a year-long internship. Approximately eight students graduate per year and the largest class ever (16 students) enrolled in the Fall of 2015. McNeese has recently received approval of a completely online master’s program which will be active in Fall 2016. McNeese is also implementing a graduate certificate program which allows students with a master’s degree in Education or Psychology to complete the BCBA-required concentration courses (approximately 40 credit hours) and qualifies them to take the national BCBA exam. This program will also be available in the Fall of 2016. The McNeese program graduates a combination of practitioners and researchers (80% practitioners).

The LSU Baton Rouge program is a doctorate-level program limited to candidates within the Psychology Department with a specialization in School Psychology. The program prepares students to develop interventions for behavior and academic problems and offers courses that have been approved by the Behavior Analyst Certification Board to fulfill the curriculum requirements for sitting for the national BCBA exam. This program is geared toward researchers and takes a minimum of four years to complete. LSU does not currently have a program geared toward training therapists to address the shortage seen in the Capital Region and nationally.

The Nicholls State program is a BCBA-approved masters-level program open to students of various backgrounds, but the program is housed in the Education Department. An estimated 75% of the cohort is from the Capital Region, suggesting demand for a similar program in Baton Rouge. The program can be completed fully online if students wish. Licensed teachers enrolled in the program (about 1/3 of their students) who want the BCBA skill set as a supplement to their teaching expertise typically do not sit for the BCBA exam upon completion of the program. These teachers utilize behavioral intervention techniques in their classrooms, but do not provide direct therapy. The remaining masters-level candidates do sit for the BCBA exam. Nicholls State is starting an undergraduate program in applied behavior analysis which will result in BCaBA and RBT training options. The Nicholls State program has partnerships in the Capital Region – Behavioral Intervention Group (BIG), HOPE Academy, and two school districts (Ascension and Livingston). These partnerships involve student practicum experience, connection with potential employers, and consulting services provided by students and professors in the program.
EARLY INTERVENTION RESOURCES AVAILABLE IN THE CAPITAL REGION

Stakeholder interviewees participating in this study expressed two general sentiments regarding the early childhood intervention resources currently available in the Capital Region.

First, the stakeholders unanimously agreed that the capacity of those intervention resources is wholly inadequate to meet current needs and demand.

Second, they expressed optimism that a relatively new positive momentum is present in the Capital Region with respect to early childhood ASD diagnosis and intervention.

Figure 6 is a sampling of significant early childhood intervention and therapeutic resources currently available in the Capital Region. Figure 6 is designed to identify important facts about each provider and the intervention services each provides, including:

- **Ages Served**: Age range of patients served.
- **Evaluation/Screening**: Initial evaluation/screening for ASD.
- **Offered Therapy**: Types of therapy available.
  - **ABA**: Applied Behavior Analysis
  - **PT**: Physical Therapy
  - **ST**: Speech Therapy
  - **OT**: Occupational Therapy
- **School Transition Support**: Services that facilitate family transition to Pre-K-12 education setting.
- **Location**: Where services are delivered (provider facility, home-based, or childcare setting).
- **Finance Model**: The payment options the provider accepts (Medicaid, Private Pay, Private/Commercial Insurance, Tuition).

This chart is not an exhaustive description of these agencies or their services. Narrative descriptions for these providers can be found in the Key Providers and Organizations in the Capital Region section of this report.
## Early Intervention Providers in the Capital Region

<table>
<thead>
<tr>
<th>Provider</th>
<th>Ages Served</th>
<th>Offered Therapy</th>
<th>Eval/Screen</th>
<th>School Transition</th>
<th>Location</th>
<th>Finance Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abilities Pediatric Therapy Services</td>
<td>Birth to young adults with developmental disabilities</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility (2 locations)</td>
<td>Private pay/Commercial</td>
</tr>
<tr>
<td>ABC</td>
<td>2-20 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>School</td>
<td>Private pay/Commercial</td>
</tr>
<tr>
<td>Arc of Baton Rouge</td>
<td>Birth through adulthood (birth to 3 years old intensive early intervention)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility/Childcare</td>
<td>Medicaid/Private pay</td>
</tr>
<tr>
<td>Baton Rouge General Pediatric Rehab/Therapy</td>
<td>0-18 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Private pay/Commercial/Commercial</td>
</tr>
<tr>
<td>BR Clinic</td>
<td>15 months - 11 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Private pay/Commercial</td>
</tr>
<tr>
<td>BIG</td>
<td>15 months - 11 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Medicaid/Private pay/Commercial</td>
</tr>
<tr>
<td>Bridges Learning Center</td>
<td>7-13 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>School</td>
<td>Medicaid/Private pay/Commercial</td>
</tr>
<tr>
<td>Butterfly Effects</td>
<td>2-21 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Home/Childcare</td>
<td>Private pay/Commercial</td>
</tr>
<tr>
<td>CAHSD</td>
<td>Birth through adulthood (2-5 years old intensive early intervention)</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Medicaid/Private pay/Commercial</td>
</tr>
<tr>
<td>CARD</td>
<td>All Ages</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>School/Home</td>
<td>Medicaid/Private pay/Commercial</td>
</tr>
<tr>
<td>Chesney Center Therapies</td>
<td>Birth and up</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Private pay/Commercial</td>
</tr>
<tr>
<td>Headstart/Early Headstart</td>
<td>Birth to 4 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>No charge for eligible families</td>
</tr>
<tr>
<td>The Emerge Center</td>
<td>18 months to 7 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Medicaid/Private pay/Commercial/Tuition</td>
</tr>
<tr>
<td>McMains Children’s Developmental Center</td>
<td>Birth to 18 years old</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Medicaid/Private pay/Commercial</td>
</tr>
<tr>
<td>NeuroTherapy</td>
<td>Birth and up</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Medicaid/Private pay/Commercial</td>
</tr>
<tr>
<td>One Step at a Time Behavioral Services</td>
<td>Birth and up</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Home/Childcare</td>
<td>Private pay/Commercial</td>
</tr>
<tr>
<td>Institution</td>
<td>Ages Served</td>
<td>Offered Therapy</td>
<td>Eval/Screen</td>
<td>School Transition</td>
<td>Location</td>
<td>Finance Model</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>OLOL Pediatric Development and Therapy Center</td>
<td>Birth to 16 years old</td>
<td>ABA PT ST OT</td>
<td>x</td>
<td>x</td>
<td>Facility</td>
<td>Medicaid Private pay Private/commercial</td>
</tr>
<tr>
<td>St. Lillian Academy (SLA)</td>
<td>3 years old and older</td>
<td></td>
<td></td>
<td>x</td>
<td>Facility</td>
<td>Tuition Financial Aid</td>
</tr>
<tr>
<td>Excellence in Speech Pathology (through SLA)</td>
<td>Birth and up</td>
<td></td>
<td></td>
<td>x</td>
<td>Facility</td>
<td>Private pay Private/Commercial Medicaid</td>
</tr>
<tr>
<td>Woman’s</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Facility</td>
<td></td>
</tr>
</tbody>
</table>
ABA IN LOUISIANA AND THE CAPITAL REGION

The case in support of intense early childhood intervention, in particular ABA therapy, for children that have been diagnosed with ASD is quite strong. In fact, there appears to be no significant alternative path recommended in the current body of ASD literature. The following question is therefore of great importance - Does the Capital Region possess the capacity of early childhood ABA services needed to optimally meet the needs of young children with an ASD diagnosis?

A definitive answer to this question is well beyond the scope of this assessment. Nonetheless, it is reasonable to conclude that current capacity in the Capital Region falls significantly short of demand/need. Here is why.

Approximately 150 BACB professionals are licensed in Louisiana, and roughly half of those licensees accept Medicaid patients.60 61

Interviewees participating in this community assessment estimate the number of BCBA’s practicing in the Capital Region is between 10 and 20 licensees. According to the national Behavior Analyst Certification Board, the appropriate caseload for behavior analysts is determined by the following factors:

- Complexity and needs of the clients in the caseload,
- Total treatment hours delivered to the clients in the caseload,
- Total case supervision and clinical direction required by caseload,
- Expertise and skills of the Behavior Analyst,
- Location and modality of supervision and treatment (for example, center vs. home, individual vs. group, telehealth vs. in vivo), and
- Availability of support staff for the Behavior Analyst (for example, a BCaBA).

The recommended caseload range for one Behavior Analyst supervising Focused treatment*:

- Without support of a BCaBA is 10-15 [clients] and
- With support of one BCaBA is 16-24 [clients].

The recommended caseload range for one Behavior Analyst supervising comprehensive treatment:

- Without support by a BCaBA is 6-12 [clients] and
- With support by one BCaBA is 12-16 [clients].

* Focused treatment for severe problem behavior is complex and requires considerably greater levels of case supervision, which will necessitate smaller caseloads.62

60 Licensure information is available on the Louisiana Behavior Analyst Board website, www.lababoard.org.
61 Information on the number of licensees serving Medicaid patients was gathered during a staff interview with Louisiana Department of Health and Hospitals.
Our 2030 Capital Region projections (see What is Autism Spectrum Disorder? section of this report) indicate the total number of individuals with an ASD diagnosis between the age of 0-21 will be approximately 3,500 (1 in 68) or 5,300 (1 in 45) with approximately 930 individuals (1 in 68) or 1,400 individuals (1 in 45) in the 0 to 4 years age range. These projections, combined with ABA capacity estimates, indicate the Capital Region alone may require 100 to 150 total BCBA’s to meet our 2030 ASD needs.

This gap is even larger than it appears because many of these providers serve children with other development delays and diagnoses in addition to children with an ASD diagnosis, spreading the available resources even more thinly. These estimates reveal an apparent gap between anticipated demand for services and current capacity – a gap that is consistent with reports of waiting lists and other anecdotal evidence collected from early intervention providers, advocates, and other ASD stakeholder interviewed as part this assessment.

The number of practicing BCBA’s in the Capital Region is the key limiting factor to providing needed ABA services.

The larger ABA providers in the Capital Region such as the Emerge Center and Center for Autism and Related Disorders (CARD) have long waiting lists of families who want access to their ABA services. The growing demand for ABA in the Capital Region has encouraged the establishment of additional ABA providers and programs such as Behavioral Intervention Group (BIG), Butterfly Effects, and Capital Area Human Services District (CAHSD). Each new BCBA added in a region offers a service delivery (therapy hours) multiplier because BCBA’s supervise multiple RBTs/RLTs, who are responsible for the direct implementation of the therapy plans developed and supervised by BCBA’s. Still, the available resources today are insufficient.
ABA providers in the Capital Region have expressed a desire to expand ABA capacity to meet growing demand for services, but most have had difficulty attracting BCBAs. Some providers interviewed also expressed a desire to educate and promote hard-working employees internally from RBT/RLT positions to BCaBAs and eventually to BCBAs. However, the lack of ABA educational opportunities in the Capital Region has largely prevented this type of organic growth.

Administrators of the Nicholls State program have expressed interest in collaborating with higher education institutions in the Capital Region to bring the masters-level and undergraduate program into the Capital Region, perhaps through a partnership with Louisiana State University, Southern University or Our Lady of the Lake College.

No BCaBA programs exist today in Louisiana. However, McNeese has developed coursework for a student with a Bachelor’s of Science in Psychology to be eligible to take the national exam. Nicholls is also currently developing an undergraduate program to allow students to sit for the BCaBA exam.

Baton Rouge Community College (BRCC) is working to create a Registered Behavior Technician (RBT) certificate program. This program is expected to provide the 40 regular hours of education required by the national board for the RBT credential.

In addition to having enough therapists to meet demand, providers need a financial model that works. Louisiana is one of 43 states with an autism health insurance mandate - requiring state-regulated insurance plans to provide benefits for recognized therapies (such as ABA). Additionally, Louisiana’s Medicaid program established coverage for ABA therapy in 2014 based on market-rate reimbursements. Governor John Bel Edwards has also committed to expanding Medicaid coverage in Louisiana as early as Summer 2016, which will allow a broader population to be covered. Nonetheless, currently only about 50% of ABA therapy providers in the Capital Region accept Medicaid reimbursement, despite the market-rate reimbursements available. Health care insurance coverage issues are discussed in greater detail in the State Support Services section of this report under Insurance Coverage.

A build out of needed ABA therapy capacity in Louisiana is realistic and can be greatly aided by appropriately leveraging the availability of the private/commercial insurance coverage mandate and the relatively new Medicaid coverage of ABA therapy in Louisiana. Existing key providers of early intervention services, including the Emerge Center and BIG, have proven that this reimbursement model can work. Each of these providers seek reimbursement for ABA and other types of therapy through private insurance and Medicaid to the fullest extent possible. These proven service delivery and financial models are sustainable and scalable.

Despite some recent additions to the Capital Region’s ABA therapy capacity, stakeholders interviewed as part of this assessment almost unanimously agree that current ABA capacity in the Region still does not come close to meeting the current need for services. Stakeholders also stated that the lack of ABA capacity is not a problem unique to Baton Rouge or Louisiana; it is a problem present in most communities across the U.S.
TRANSITION TO PRE-K THROUGH 12 EDUCATION

Early Intervention providers are a key piece of the coordination framework for parents. Entering the Pre-K-12 education environment is a significant transition for all children and their families. For children with an ASD diagnosis, this transition can be especially complicated and frustrating because families seldom feel that they have adequate information and the guidance necessary to confidently evaluate their available Pre-K-12 school options and select the most appropriate school environment.

Parents and caregivers of children with an ASD diagnosis face a number of important questions when transitioning their children into a Pre-K-12 school environment.

• What Pre-K-12 school options are available to accommodate children with ASD?

• Which of those school options offer my child the best opportunity to develop to his/her highest potential?

• What do I need to understand and do to maximize the effectiveness of my child’s Individualized Education Plan (IEP)?

• How do I appropriately integrate my child’s ongoing therapeutic service needs with his/her education?

• What financial support can I access to fund my child’s education?

Each Capital Region family must answer these questions in a Pre-K-12 school environment that includes public school options (including charter schools) and private school options (including voucher options to assist with tuition). Additionally, families must decide if their child is best served by a more inclusive (all students) versus exclusive (only students with disabilities) school setting.

This critical transition is made easier for families when their early intervention providers participate in transition planning and decision making. Key considerations for parents during this transition phase include: school environment and school fit options, transportation services to and from school, availability of therapeutic services, coordination with health care providers, and understanding the education diagnosis/IEP process. Early intervention providers in the Capital Region recognize this need, and more are offering school transition assistance, including coordination with Pre-K-12 schools and school systems.

Interviews throughout this process suggest that many parents found supportive transition services through their early intervention providers while others were unaware of how to access this critical resource. Educating parents on the importance of transition services and where these services are available should be a key role of the coordinating nonprofit or consortium of organizations referenced earlier in this report.
Early intervention services for children with an ASD diagnosis have proven effective - helping each child to achieve his or her optimal outcome. It is therefore critical that proven early intervention services are available and accessible to all in need.

1. Expand current early childhood intervention services capacity at both existing and potential new providers across the Capital Region to meet the population demand estimates, leveraging the sustainable and proven models (financial and service delivery) developed by the Capital Region’s existing early intervention service providers, including the Emerge Center and Behavioral Intervention Group.

2. Capital Region post-secondary educational institutions should establish ABA post-secondary education programs for Board Certified Behavior Analysts (BCBA), Board Certified Assistant Behavior Analysts (BCaBA), and Registered Behavioral Technicians (RBT) in the Capital Region. Nicholls State University has an established BCBA program and leadership from that program could collaborate to help establish similar post-secondary education programs in the Capital Region.

The BCBA program is an advanced degree program. Louisiana State University (LSU), Southern, and/or Our Lady of the Lake (OLOL) College should consider implementing this program on their respective campuses. The BCaBA program is an undergraduate-level program. LSU, Southern, and/or OLOL College should consider implementing this program on their respective campuses. The RBT training is a 40-hour program. Baton Rouge Community College and River Parishes Community College should consider implementing this program on their respective campuses.

3. All early childhood intervention providers should offer school transition services to facilitate an informed, practical transition for all families “graduating” from the early childhood intervention environment to a Pre-K-12 school environment. In particular, families need support navigating the following decisions:
   a. School environment and school fit options,
   b. Transportation services,
   c. Availability of therapeutic services,
   d. Coordination with health care providers, and
   e. Understanding the education diagnosis/Individualized Education Plan (IEP) process.
Pre-K-12 Education

PUBLIC EDUCATION: FEDERAL GUIDELINES
STATE FUNDING FOR EDUCATION
PRIVATE EDUCATION SCHOOLS
LOUISIANA’S NEW ABLE ACCOUNT SAVINGS PROGRAM
STATE STUDENT ACCOUNTABILITY/ACHIEVEMENT SYSTEM
TEACHERS AND LOCAL SCHOOL SYSTEMS
TRAINING RESOURCES
CAPITAL REGION PUBLIC SCHOOL SYSTEMS
ATTRIBUTES OF AN IDEAL SPECIAL EDUCATION INFRASTRUCTURE
PRE-K-12 EDUCATION

• Individual Educational Plan (IEP)
• Continued supplemental intervention and therapy
• Individual Transition Plan (ITP) in high school
In this section, we examine the basic federal regulations that govern how public school systems support children with disabilities and the rights that parents have to be involved in the process, Louisiana’s public education funding formula, the two largest Capital Region school systems (East Baton Rouge Parish Public School System and Ascension Public Schools), elements of an ideal modern public school system, and a sampling of private school options in the Capital Region.

**EARLY DIAGNOSIS**
- Referral to physician specialist
- Referral to other medical specialists for comorbidity evaluations (if applicable)
- Referral to early intervention programs

**EARLY INTERVENTION**
- Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
- Application/referral to state waiver programs (if applicable)

**PRE-K-12 EDUCATION**
- Individual Educational Plan (IEP)
- Continued supplemental intervention and therapy
- Individual Transition Plan (ITP) in high school

**ADULT TRANSITION**
- Post-secondary education
- Career training
- Independent and supported living
PUBLIC EDUCATION: FEDERAL GUIDELINES

Children with an ASD diagnosis can access special support services provided by the public education system through one of two general provisions of federal law – Part B of the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act. A general description of these two federal provisions is provided here.

PART B OF THE INDIVIDUALS WITH DISABILITIES ACT (IDEA)

Part B of the IDEA establishes standards and guides how special education and related services are made available to eligible students through public school systems.67

Special education is defined as specially designed instruction to meet the unique needs of a student with a disability.68 The law prescribes 14 diagnosed disabilities that determine eligibility for special education services. Autism, ADD, ADHD, specific learning disabilities, and speech or language impairments are all conditions that qualify a child for these services. Once a child has been determined eligible for special education services, the IDEA mandates that a team that includes the parent or guardian work collaboratively to develop a plan for services, called an Individualized Education Program (IEP). For parents, this IEP process is the most important mandate contained in the IDEA. The IDEA outlines a specific process that must be followed by local education agencies (LEAs), as well as the rights that parents have to be involved in the IEP process. The IEP is made up several important parts, including written descriptions of the student’s current level of academic and functional performance, customized student goals and objectives, descriptions of how progress toward goals will be measured, type and amount of special education services, need for assistive technology, need for behavior support, and a list of related services including type and amount.


Related services are defined in the law “as transportation and such developmental, corrective, and supportive services as are required to assist a child with a disability to benefit from special education.”69 Some examples of related services include: behavioral intervention, counseling, speech pathology, physical therapy, occupational therapy, and school health services. However, federal law specifically states that the services include those services listed in the law but are not limited to those listed. Services are determined based on each child’s individual needs. With respect to autism, it is important to note that while ABA therapy is not itself a “related service,” it is a type of behavioral intervention service and therefore can be considered a related service. In fact, in several states such as Connecticut, so many students are receiving ABA therapy as a related service that the state enacted a law mandating that ABA therapy be provided to any child with ASD if the IEP requires such services and establishing guidelines for how these ABA services must be delivered and supervised.70

69 34 CFR § 330.34 Related Services. See also Center for Parent Information Resources, “Special Education”, available online at www.parentcenterhub.org/repository/ep-specialeducation/#definition.

70 Ch. 164: Educational Opportunities § 10-76ii, Provision of Applied Behavior Analysis Services.
MEDICAL DIAGNOSIS AND SPECIAL EDUCATION ELIGIBILITY

A point of confusion and frustration for parents of a student with an ASD diagnosis is the fact that a medical diagnosis of ASD does not automatically qualify a student for special education and related services. Several parents interviewed in connection with preparing this report described being given inconsistent information from school officials and educators regarding the need for a medical diagnosis to qualify for special education services, obtain an IEP, and receive related services, either in a public school or a private school, to the extent a school district has agreed to do so. In many cases, parents are told they need a medical diagnosis, which given the shortage of specialty physicians providing ASD diagnoses in the Capital Region could take several weeks or months, only to be told later that the diagnosis is not sufficient to obtain an IEP.

As described below, special education eligibility is determined based upon an educational evaluation that determines if the student’s disability is severe enough (under IDEA guidelines) to require special education and related services. As such, not all children with an ASD diagnosis will be deemed eligible for special education and related services under the IDEA. However, this does not mean that a medical diagnosis of ASD is not an informative and useful document for parents – assuming they are comfortable sharing the information – to provide to school officials. Most importantly, in order for school systems to seek reimbursement from private and commercial insurance or Medicaid for related services, such as ABA therapy provided in an educational setting, the school must be able to submit documentation of “medical necessity.” Thus, parents who are interested in requesting behavioral intervention therapies such as ABA therapy as part of their child’s IEP related services should discuss obtaining a medical diagnosis for this purpose with school officials before or early in the IEP process.
THE IEP PROCESS
Under the IDEA, parents and guardians have a right to be involved in the development, implementation, and evaluation of their child’s IEP. Parents also have a right to invite other important parties such as therapists or counselors to IEP meetings. It is therefore important that families fully understand the IEP process and their rights.

The process mandated by the IDEA includes the following basic elements:

**Step 1**
Child is identified as possibly needing special education and related services. A school professional may ask that a child be evaluated to see if he or she has a disability, or parents may contact the child’s teacher or other school professional to ask that their child be evaluated.

**Step 2**
Child is evaluated. The evaluation results will be used to decide the child’s eligibility for special education and related services and to make decisions about appropriate educational programs. If parents disagree with the evaluation, they have the right to take their child for an Independent Educational Evaluation (IEE) and can ask the school system to pay for the IEE.

**Step 3**
Eligibility is decided. A group of qualified professionals and the parents review the child’s evaluation results and together, decide if the child is a “child with a disability” as defined by the IDEA. If a parent disagrees with the eligibility determination, the parent may ask for a hearing to challenge the decision.

**Step 4**
Child is found eligible for services. If the child is found to be “a child with a disability”, the child is eligible for special education and related services. Within 30 days of the eligibility determination, the IEP team must meet to write an IEP for the child.

**Step 5**
Individualized Education Program (IEP) meeting is scheduled. The IEP meeting is scheduled and run by the school system. Staff from the school must contact the participants, including parents; notify parents early enough to ensure they can attend; schedule the meeting at a time and place agreeable to the school and parents; tell the parents the purpose, time and location of the meeting, as well as who will attend; and notify the parents that they may invite others who have knowledge or special expertise about the child. The entire IEP team includes:

- The child’s parent or guardian,
- The child (when appropriate),
- A special education teacher or other special education provider,
- A general education teacher (when appropriate),
- A representative of the school system who is knowledgeable about specially designed instruction, curriculum, and the school system’s resources, and
- Others who the parent/guardian or the local school system wish to invite (i.e., therapists, physicians, and support navigators).
Step 6

IEP meeting is held and the IEP is written. The IEP team gathers to discuss the child’s needs and write the IEP. Before the school system can provide any services to the child, the parents must give consent. If parents do not agree with the IEP and/or placement, they can discuss their concerns with members of the IEP team and try to work out an agreement. If there is still disagreement, parents can request mediation or file a complaint with the state education agency and request a due process hearing.

Step 7

After the IEP is written, services are provided. Parents are given a copy of the IEP, and each of the child’s teachers and service providers must have access to the IEP and understand his or her specific responsibilities.

Step 8

Progress is measured and reported to parents. Progress toward annual goals must be measured and parents must be regularly informed of the child’s progress and whether that progress is enough for the child to achieve the goals by the end of the year.

Step 9

IEP is reviewed. IEPs are reviewed at least once per year, or more often if parents or the school request. The IEP must be revised if necessary, and parents, as IEP team members, must be invited to any meetings. Parents can request additional testing, independent evaluations, request mediation or a due process hearing, or file a complaint with the state education agency if they do not agree with decisions regarding revisions to the IEP.

Step 10

Child is reevaluated. A child must be reevaluated every three years, or more often if conditions warrant or if a parent or teacher requests a new evaluation.71

Figure 7 offers a general timeline, developed by Autism Speaks, of key steps in the IEP process.

71 http://www2.ed.gov/parents/needs/speced/iepguide/index.html; see also Center for Parent Information and Resources, 10 Basic Steps in Special Education, available online at www.parentcenterhub.org/repository/steps/.
More detailed information about each of these basic elements of the IDEA process is available through the Center for Parent Information and Resources, http://www.parentcenterhub.org/. Every state has at least one Parent Training and Information (PTI) center, operated by the Center for Parent Information and Resources, that offers families information about early intervention, the IDEA, school services, therapy, transportation, and much more. Many states also have a Community Parent Resource Center (CPRC), which offers the same type of support and training to parents of children with disabilities. Louisiana has one PTI, the Families Helping Families of Jefferson, in Harahan (201 Evans Rd., Bldg. 1, Ste. 100, (504) 888-9111), and one CPRC, the Pyramid Community Parent Resource Center, in New Orleans (3132 Napoleon Ave, (504) 218-8922). This CPRC serves the Greater New Orleans area. Additionally, the Louisiana Department of Education (DOE) has developed a guide, *Louisiana’s Educational Rights of Children with Disabilities, Special Education Processes + Procedural Safeguards*, to help parents navigate the special education system in Louisiana’s public schools.73

All public school systems in Louisiana are required to utilize the basic processes and procedures included in this guide. Louisiana’s regulatory guidance for pupil appraisal and IEPs for students with exceptionalities are available online through the Board of Elementary and Secondary Education (BESE) website:

- **BULLETIN 1508** – Pupil Appraisal Handbook, Revised May 200974
- **BULLETIN 1530** – Louisiana IEP Handbook for Students with Exceptionalities, Revised March 201575

Implementation of special education guidelines (federal and state) is the responsibility of local school districts. As a result, special education services vary from school system to school system based on local design and resources. Additionally, services are ideally customized to meet the unique needs of each child accessing special education services. However, as will be discussed later in this Section, there are certain important resources, such as federal IDEA funds, High-Cost Services funding, and third-party/Medicaid reimbursement, that are available to all school systems in order to enable them to offer the appropriate amount and type of special education services to students.

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72 Autism Speaks, “IEP Timeline,” figure available online at http://3.bp.blogspot.com/-Y2dIwyETbSQ/TnOIQ0K5xol/AAAAAAAALv0/lmS7znqM8dM/s640/IEP+Timeline.PNG


TRANSITION SERVICES

The IDEA requires that transition planning start and transition services be added to the IEP by the time a student reaches age sixteen, or earlier, if the IEP team decides it would be appropriate to do so. The IEP team, which includes the student and parents, develops the transition plan.

Transition services are a coordinated set of activities that promote movement from school to such post-school activities as post-secondary education, vocational training, employment, adult services, independent living and community participation. They must be based on the individual student’s needs, taking into account his or her preferences and interests. Transition services must include instruction, community experiences, and development of employment and other post school adult living objectives.

"Legal Requirement for Transition Components of the IEP”
by Barbara D. Bateman, PhD, JD

The word “coordinated” contained in the definition of transition services suggests that services should be planned in sync with one another in order to drive towards a result - full participation, independent living, and economic self-sufficiency to ensure that students with disabilities can lead productive and independent adult lives, to the maximum extent possible.

Developing an Individual Transition Plan (ITP) that adequately serves the uniqueness of an individual student is a challenging task given the broad scope of ASD and the diversity of potential co-occurring conditions. Obviously, the quality of ITPs is highly dependent on the knowledge and expertise of the plan developers (IEP team) and reasonable access to the resources and services required to successfully implement the ITP.

Provision of the transition services is the responsibility of the school system even though the plan may include participation by a variety of public agencies and/or private entities, including the Louisiana Rehabilitation Services (LRS) office. Specific transition resources offered through LRS are discussed in more detail in the Adult Transition section of this report.

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SECTION 504 OF THE REHABILITATION ACT

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination based upon disability. Disability is defined as a mental or physical impairment that substantially limits one or more major life activities such as self-care, manual tasks, walking, seeing, speaking, sitting, thinking, learning, breathing, concentrating, interacting with others, and working.

The definition of impairment is broader in Section 504 compared to the IDEA. Often, students with a disability who are not eligible for special education under IDEA guidelines can qualify for supportive accommodations under Section 504. The major differences between IDEA and Section 504 are in the flexibility of the procedures. For a child to be identified as eligible for services under Section 504, there are less specific procedural criteria that govern the requirements of the school personnel, whereas under IDEA a child must meet very specific criteria. The parental participation requirements are also much less detailed under Section 504.

To be protected under Section 504, a student must be determined to:

- Have a physical or mental impairment that substantially limits one or more major life activities; or
- Have a record of such an impairment; or
- Be regarded as having such an impairment.77

"Major life activities", as defined in the Section 504 regulations, include functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. This list is not exhaustive.

Under the IDEA, school districts are required to identify and evaluate any child suspected of having a disability. Section 504 does not have this requirement. However, anyone, including a parent or doctor, can refer a child for evaluation under Section 504, although a school district does not have to evaluate a child under Section 504 solely upon parental demand. The key is whether school district staff suspects that a child has a physical or mental impairment that substantially limits a major life activity and is in need of either regular education with supplementary services or special education and related services. A Section 504 evaluation draws on information from a number of sources and is documented in a written plan identified by knowledgeable individuals. However, the decisions do not require written consent of parents, only that parents be notified. There are no provisions requiring that the school district cover the cost of an independent evaluation. Rather than an IEP, a Section 504 plan is developed and must be reevaluated “periodically”.

In general, the accommodations provided to the student under a Section 504 plan are determined individually based upon the nature of the relevant disability conditions. Accommodations provided are designed to offer the qualified student a more equal opportunity to compete with the non-disabled students. Examples of accommodations include (but are not limited to):78

- Highlighted textbooks
- Extended time on tests or assignments
- Peer assistance with note taking
- Frequent feedback
- Extra set of textbooks for home use
- Computer aided instruction
- Enlarged print
- Positive reinforcements
- Behavior intervention plans
- Rearranging class schedules
- Visual aids
- Preferred seating assignments
- Taping lectures
- Oral tests

As with the IDEA, parents have certain due process rights under Section 504. If a parent disagrees with the identification, evaluation or placement of his or her child, the parent must be given an impartial hearing, although most details with the exception of a parent’s opportunity to participate with counsel are left to the discretion of the school.

78 Durheim, Mary. “A Parent’s Guide to Section 504 in Public Schools,” available online through GreatKids (GreatSchools) at www.greatschools.org/gk/articles/section-504-2/
STATE FUNDING FOR EDUCATION

Determination of whether a child qualifies for special education modifications is dependent on the IDEA process. This qualification determination dictates how funding from federal, state, and local sources will be allocated to the school serving the child.

Louisiana’s Minimum Foundation Program (MFP), combined with dedicated local revenues and other Louisiana Department of Education (DOE) sponsored programs, provide the financial resources for educating Louisiana’s public school students with special needs. Figure 8 details state and local per pupil funding for the East Baton Rouge (EBR) Parish Public School System.

The Louisiana DOE maintains robust information on its website about the state’s MFP Formula, including a detailed explanation of the calculations included in the formula. In general, local education agencies (LEAs) receive block grants from DOE proportional to the student population they serve as calculated by the MFP. Certain student characteristics, like special education students, gifted and talented students, and others, result in higher funding for an LEA through a multiplier. A school district serving students with special needs will receive additional funding based on a 1.5 MFP multiplier within their block grant. In practice, this 1.5 weight does not mean that every special education student receives 150% of the base per pupil funding amount. Rather, the weight is applied to the total number of students, resulting in special education students counting as 2.5 students for the LEA funding determination.

LEAs are responsible for the allocation of the total funding provided in their MFP block grant and few employ a differentiated formula. Rather, most LEAs spread the funding across all students. Although the total amount budgeted for special education must be spent on special education services, in practice, these funds are spread across the special education student population rather than individually on a student by student basis.

In 2011, the Cowen Institute for Public Education Initiatives at Tulane University analyzed the Louisiana MFP formula in a policy brief. This brief provides an explanation of how the formula works in practice. With the passage of Act 467 in 2015, the MFP allocations were changed for Type 1 and 2 charter schools to help ensure that additional MFP money allocated for special education students and other students in one of the “weighted categories” (gifted and talented, “at-risk” or career and technical units) in fact flows to schools who are educating those students. Rather than receiving the average per pupil amount as determined by the MFP formula, Type 1 and 2 charters who educate children with an IEP will now receive increased funding on a per pupil basis for those special education students. The chart below demonstrates this funding differentiation.

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79 https://www.louisianabelieves.com/funding/minimum-foundation-program
81 Type 1 charter schools are authorized by a local school board or local charter authorizer and Type 2 charter schools are authorized by BESE.
**PRE-K-12 EDUCATION | State Funding for Education**

**08 East Baton Rouge Parish Public School System**

- State and Local Allocation of Funding on a Per Pupil Basis

<table>
<thead>
<tr>
<th></th>
<th>2014-15</th>
<th>2015-16</th>
<th>2015-16</th>
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<tr>
<td>EBR School Per Pupil Amount (Average)</td>
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<td>$4,165</td>
<td>$4,248</td>
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<tr>
<td>Type 1 or 2 Charter within EBR with a District Building</td>
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<td>$2,957</td>
<td>$256</td>
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<td>EBR School Per Pupil Amount (Average)</td>
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<td>Type 1 or 2 Charter - Additional Funds</td>
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**MFP Allocation Per Pupil**

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<th>2014-15</th>
<th>2015-16</th>
<th>2015-16</th>
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<tr>
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<td>Special Ed Weight</td>
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<td>Level 2</td>
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<td>Level 3 HH and Mandate Cost</td>
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<td>$6,278</td>
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<tr>
<td>Low Income and ELL</td>
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<td>$1,183</td>
<td></td>
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<tr>
<td>Career and Technical Education</td>
<td>$1,183</td>
<td>$1,183</td>
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<tr>
<td>Gifted and Talented</td>
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**Local Revenue Representation Per Pupil**

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<th>2014-15</th>
<th>2015-16</th>
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<tr>
<td>Total Revenues Per Pupil</td>
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<td>$10,232</td>
<td>$10,526</td>
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**Additional Available Funding**

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<th>2015-16</th>
<th>2015-16</th>
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<td>Federal IDEA Funding**</td>
<td>$2,827</td>
<td>$2,827</td>
<td>$2,827</td>
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<tr>
<td>High Cost Services Allocation***</td>
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**Total Possible**

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<th></th>
<th>2014-15</th>
<th>2015-16</th>
<th>2015-16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Possible</td>
<td>$13,059</td>
<td>$13,059</td>
<td>$13,353</td>
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</tbody>
</table>

* Per 2015-16 Charter per Pupil Calculations, this is the amount if the school is in a district building; a school not in a district building is slightly higher.

**EBR reports 4,468 students with IEPs (11.7% of children in public schools) in 2014-2015; EBR received $12,631,355 in IDEA funding in 2014-2015 which is given as a block grant to the district. Per pupil costs estimated by dividing the number of students qualifying as special needs.

***High Cost Services (HCS) are available for school districts supporting students whose costs exceed 3x the state average per pupil cost of $11,113 ($33,339). For the 2014-15 Fiscal Year, the State allocated approximately $8.4M for HCS ($4M MFP + $4.4M IDEA). An additional $5.4 million was allocated for the 2015-2016 year.

*This number will vary as the local revenues will come from the school district in which the student resides, not in which the charter school is located.

The MFP Task Force, established by BESE in Spring 2013, evaluated the special education spending of all LEAs. On the whole, LEAs expend more money on special needs students than their state MFP weighted student funding requirement. During the 2012-2013 school year in East Baton Rouge Parish, for example, the parish was required by the state to spend $12.4 million on special education students. The parish spent an additional $44 million from its own local revenue sources in order to meet student needs. Across the state for the 2012-2013 school year, $312 million was mandated and provided by the state, and an additional $567 million was spent on special education from local revenue sources.82

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IDEA AND HIGH COST SERVICES FUNDING

Federal IDEA funds are provided to the state as a block grant. The amount is based on a 1997 formula adjusted for changes to the population of 3- to 21-year-olds and the number of children in poverty. DOE distributes IDEA funding to each LEA based on the same formula. LEAs then make their own determinations as to how the funding will be spent on special education students. States can choose to reserve a portion of the IDEA grant for High Cost Services (HCS).

HCS is intended to provide additional funding to schools because the state recognizes that it is a financial challenge for districts and charter schools to support some of the costlier services required to support students with special needs. HCS funds are only available for school districts supporting students whose costs exceed three times the state average per pupil cost of $11,113 ($33,339). HCS is currently funded through three sources: federal IDEA funds, state MFP funds before local district calculations occur, and other state funds including money from the general fund.

School districts can apply for HCS funding based on the number of eligible students they serve. Charter schools are also eligible to receive HCS funds - Type 1 charters through their associated school district and Type 2 charters as a local education agency (LEA) themselves. There is no limit on the number of eligible students for whom a district or charter school can apply for HCS funding. However, if Medicaid or insurance can pay for the services, such as ABA therapy, the services cannot be included in the HCS application.

Because funds requested from districts and charters generally exceed total HCS funds available, districts do not receive 100% of the HCS funds requested. Allocation of HCS funds to LEAs is based on the proportional impact to the LEA’s budget. For the 2014-2015 school year, all districts and schools whose application was approved were reimbursed 38% of the funds requested.

There was a backlog of $12.4 million in unfunded HCS requests from LEAs in the 2014-2015 school year.

For the 2015-16 school year, the available funds for HCS totaled $13.4 million, a $5.4 million increase over the 2014-2015 school year. The Louisiana Department of Education issues an annual report for High Cost Service Allocation, which is available on the Department’s website.83

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ESTABLISHING DIFFERENTIATED FUNDING FORMULAS

As noted earlier, Louisiana currently applies a 1.5 weight factor to student populations for each qualifying special education student, regardless of disability or accommodation(s). With the exception of the Recovery School District (RSD) in New Orleans, Louisiana does not utilize any medical or service need criteria to differentiate funding for individual special education students. Differentiated funding, which more and more states throughout the country are adopting, allocates money based on individual student needs - to ensure the right amount of money follows each student. The goal of this methodology is not only to provide a more fair and accurate distribution of funding, but also to ensure that schools have the financial resources to serve their neediest students.

Some states that have adopted differentiated funding formulas differentiate based on additional one-on-one hours required for each student, while other states differentiate funding based on a child’s medical diagnosis. Figure 9 illustrates how Arizona, Georgia, Iowa, Kentucky, and South Carolina differentiate special education funding.

09 Examples of States with Differentiated Funding

<table>
<thead>
<tr>
<th>State</th>
<th>Number of Categories for Special Education Funding</th>
<th>Range of Additional Funding</th>
<th>Basis of Weights</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona</td>
<td>11</td>
<td>0.003 to 7.947</td>
<td>Disability and Placement</td>
</tr>
<tr>
<td>Georgia</td>
<td>5</td>
<td>2.3960 to 5.8253</td>
<td>Disability, Services Required, and Placement</td>
</tr>
<tr>
<td>Iowa</td>
<td>5</td>
<td>0.72 to 2.74</td>
<td>Services Required</td>
</tr>
<tr>
<td>Kentucky</td>
<td>3</td>
<td>0.24 to 2.35</td>
<td>Disability</td>
</tr>
<tr>
<td>South Carolina</td>
<td>5</td>
<td>1.74 to 2.57</td>
<td>Disability</td>
</tr>
</tbody>
</table>

84 The Recovery School District, established in 2003, “is a special school district run by the Louisiana Department of Education that intervenes in the management of chronically low-performing schools.” There are currently 68 schools in the RSD in New Orleans. From Louisiana Department of Education website about Recovery School District, available online www.louisianabelieves.com/schools/recovery-school-district.

From 1973 to 1997, Florida provided special education funding to local districts based on a formula based on weighted program eligibility and minutes of direct service provided to students. But in 1997, the Florida legislature adopted a revised Exceptional Student Education funding model for statewide implementation. Under the new model, still in operation today, a document called the Matrix of Services is the cornerstone of funding determinations and is used to determine the cost factor for each special education student based on the decisions made by a student’s IEP team. The new funding model is based on both type and intensity of services provided and is intended to base school district funding upon the services actually provided to a special education student throughout the school day and across all settings, as documented on the Matrix of Services form.

The Matrix of Services form is divided into five sections called “Domains” that are used to group the types of services and five levels that are used to describe the nature and intensity of services within each domain. The five domains include:

1. Curriculum and Learning,
2. Social/Emotional Behavior,
3. Independent Functioning,
4. Health Care, and
5. Communication.

Each domain has five levels, ranging from Level 1 (lowest service level) to Level 5 (highest service level). The factors that are used to determine the levels are: frequency of the service provided; intensity of the service provided; and, in some cases, qualifications of the person providing the service. Costs increase with each succeeding higher level. The total number of points, determined by adding together scores for each domain and applicable special considerations points, results in a rating of Support Level 1 (251), Support Level 2 (252), Support Level 3 (253), Support Level 4 (254), or Support Level 5 (255). At least two special education personnel (teachers, coordinators, specialists, therapists) must complete the Matrix of Services form after initial IEP meeting, after an interim IEP meeting if services are changed, and annually for any student with a Support Level of 254 or 255. Students with a Support Level of 251-253 do not have to have another matrix completed unless new services provided move them to a level 254 or 255.

Each year, the Florida legislature sets funding amounts for the various matrix service levels. Cost factors (weights) are assigned to each of the two highest support levels (254 and 255) to determine the amount of funding districts will receive for these students. With the exception of students participating in the McKay Scholarship for Students with Disabilities Program, students scoring 251-253 receive special education funding based only on their grade group, without regard to the level of service provided. But for students with a score of 254 or 255, the base per pupil amount is multiplied by the assigned cost factor to determine the total amount of special education funding provided to the district. For the 2014-15 school year, the cost factors applied to ESE Support Levels 4 (254) and 5 (255) were 3.548 and 5.104, respectively, and total funding for the 254 and 255 support levels was approximately $14,000 and $21,000, respectively. Educators at one of Florida’s autism charter schools indicated that most children with an autism diagnosis fall receive a 254 or 255 support level since most of these students need regularly scheduled occupational or physical therapy; a direct, specialized instruction and/or curriculum for the majority of learning activities; and a highly structured individualized behavioral intervention plan.

Despite Louisiana’s reluctance to embrace differentiated funding on a statewide basis, the RSD in New Orleans is nonetheless at the forefront of differentiated funding for students with disabilities. The RSD historically differentiated based on diagnosis alone; however, after noticing that students with the same diagnosis often need different levels of intervention, they have now moved to a funding formula based on disability diagnosis and total weekly service minutes. Figure 10 illustrates the differentiated funding formula used by the RSD.

10 RSD Differentiated Funding Formulas

<table>
<thead>
<tr>
<th>Approx. Additional Funding per Pupil</th>
<th>Tier 1</th>
<th>Tier 2</th>
<th>Tier 3</th>
<th>Tier 4</th>
<th>Tier 5</th>
</tr>
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<tr>
<td>$1,500</td>
<td>$8,000</td>
<td>$13,000</td>
<td>$15,000</td>
<td>$20,000</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disability Diagnosis</th>
<th>Total Weekly Service Minutes</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Tier 1</td>
</tr>
<tr>
<td>Autism</td>
<td>Below 421</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>Below 421</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>Below 1261</td>
</tr>
<tr>
<td>Speech/Language</td>
<td>All</td>
</tr>
</tbody>
</table>

A comparison of two students, both with an autism diagnosis, demonstrates how the funding formula helps direct funding appropriately to those students who need it the most.

**STUDENT A**

Diagnosis: Autism  
Total Weekly Service Minutes: 1,650  
Approximate Additional Funding: $20,000  

Student A requires a full day, small group instruction in a pull out learning environment with designated adult support.

**STUDENT B**

Diagnosis: Autism  
Total Weekly Service Minutes: 135  
Approximate Additional Funding: $13,000  

Student B thrives in a regular classroom environment with appropriate supports and technology.

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87 ibid
SPOTLIGHT: NHS HUMAN SERVICES SCHOOLS

NHS is a nonprofit organization that provides innovative solutions to support the unique needs of the individuals they serve by striving to create a caring and responsive environment that promotes the highest standards of integrity and quality.

The NHS Education and Autism Division focuses on the continuum of care throughout the lifespan. The core, fundamental principles of Applied Behavior Analysis (ABA) are incorporated into a specialized approach across all NHS service offerings.

Early Childhood Education - Provides early intensive behavioral interventions (EIBI) to both neurotypical children and those with developmental delays building the framework for later success in school, the workplace and the community. The high-quality early childhood education services NHS offers minimize the long-term impact of a child with a developmental delay or other diagnosis.

• Childcare
• Preschool
• Pre-K Readiness
• Award-Winning Curriculum

Education - NHS blends behavioral expertise and education to provide a nurturing environment in their licensed private academic schools for students with an Autism or Emotional Support Diagnosis. Their goal is to instill confidence and build skills so each student reaches their fullest potential and transition to a least restrictive environment.

• Transition Services
• Consultation
• Gender-Responsive Programming
• Behavior Modification

Autism Services - NHS has a team of Board Certified Behavior Analysts (BCBAs) and other skilled clinicians and support staff to provide therapy for individuals with an Autism diagnosis. Their programs are tailored to meet specific goals of each individual child.

Adult Autism Services - As students transition into adulthood, NHS provides specialized activities designed to enhance skill development and independent living for adults with an autism diagnosis. In addition, NHS provides integrated housing services in community settings which those with a diagnosis live alongside typically developing residents.

Ancillary Services - The Education and Autism Division also has the expertise to provide specialized comprehensive speech, occupational, and physical therapy services across the lifespan. Through the integration of individualized therapy, NHS will develop goals and a customized treatment plan of selective interventions based on evidence-based practices.

Recruiting - Highly qualified staff are the cornerstone in providing quality educational and autism services. NHS has entire team of specialized recruiters to ensure hiring managers consider only the best candidates for employment.

NHS has met with many stakeholders in the Capital Region and is interested in expanding their programming into school districts in the Capital Region. More information on NHS can be found at http://www.nhsonline.org/. 
POTENTIAL MFP CHANGES

In 2013, the Louisiana Board of Elementary and Secondary Education (BESE) convened the Minimum Foundation Program (MFP) Task Force to consider revisions to the state’s MFP formula. The Task Force includes members from the Legislature, local school boards, superintendents, teachers, parents, and community and education organizations. The Task Force offered several recommendations for changes to the MFP for the 2015-16 school year.

Among the recommendations, the Task Force suggested an increase of the MFP per pupil base funding amount, an increase to the state’s High Cost Services funds, and a more in-depth study of the principles underlying the MFP formula. The Task Force recommendations are available on the Louisiana Department of Education website. Additional information on the MFP allocation information is also available on Louisiana Department of Education website (DOE). On its website, DOE identifies MFP allocations for each of Louisiana’s local education agencies (LEAs).

Louisiana State University (LSU) was engaged by BESE and DOE to conduct the in-depth study of the MFP formula as recommended by the MFP Task Force. The purpose of this more detailed study is to identify alternative allocation approaches to certain components of the MFP formula simplifying the methodology and, where possible, continuing to maintain the equity and efficiency of the allocations. The study was originally intended to be presented to the incoming Governor, Legislature, and BESE in 2016 as they outlined future education and fiscal policies. However, due to state budget shortfalls, it is not certain the contract with LSU will materialize, and as such, LSU has not yet been authorized to begin its work.

88 [http://bese.louisiana.gov/documents-resources/newsroom/2014/01/06/mfp-task-force-recommendations](http://bese.louisiana.gov/documents-resources/newsroom/2014/01/06/mfp-task-force-recommendations)
89 [www.louisianabelieves.com/resources/library/minimum-foundation-program](www.louisianabelieves.com/resources/library/minimum-foundation-program)
PRIVATE EDUCATION SCHOOLS

Private schools, unlike public school systems, do not operate under any broad regulatory obligation to serve students with exceptionalities, including ASD. Historically, there have been limited private school options in the Capital Region for students with exceptionalities. Many private schools simply did not possess the resources necessary to serve these students. However, this circumstance is gradually changing for the better as the list of private school options available grows. The following is a list of private school options currently available:

- Behavioral Intervention Group (BIG)
- Diocese of Baton Rouge Catholic Schools
- The Dunham School – McKay Academic Center for Excellence
- The Emerge Center
- Greater Baton Rouge Hope Academy
- St. Lillian Academy

Information about each school is provided in the Key Providers and Organizations in the Capital Region section of this report. In addition to these schools, there are numerous examples in the Capital Region of private schools that accept very small numbers of students with an ASD diagnosis on a case-by-case basis.

State funding available to private schools in Louisiana includes three programs.

1. Louisiana Scholarship Program
2. School Choice Program for Certain Students with Exceptionalities
3. Tuition Donation Rebate Program (STO Program)
EXISTING STUDENT CHOICE PROGRAMS

Louisiana has established the following specific programs that facilitate access to educational options and allow families greater opportunity to select a school environment that best meets their child’s need. These programs provide greater access to private school options.

1. **Louisiana Scholarship Program**: Formerly named the Student Scholarships for Education Excellence Program, a participating private school receives a voucher amount of the school’s tuition plus an incremental amount based on the cost to educate the school’s students, up to the maximum per pupil MFP amount for the school district in which the private school is located. The average scholarship amount for the 2015-2016 school year was $5,856 per student. To be eligible for a scholarship, students must have a family income that does not exceed 250% ($60,750 for a family of four) of the federal poverty guidelines and must be entering kindergarten or enrolled in a public school with a C, D, or F grade.90

   More than 3,200 students statewide applied for the Louisiana Scholarship Program for the 2015-16 school year and approximately 1,700 students accepted a scholarship and enrolled in a participating state-approved private school.91 Within East Baton Rouge, more than 1,200 students applied for the program for the 2015-16 school year and approximately 250 students accepted a scholarship.92

2. **School Choice Program for Certain Students with Exceptionalities**: Students with disabilities in some school districts may be eligible for the School Choice Program, which provides families with tuition assistance to attend eligible participating schools that offer special needs programs. Students wishing to attend a nonpublic school in parishes with a population of 190,000 or more are eligible for this program. In the Capital Region, East Baton Rouge Parish is the only parish that qualifies.

   Participating private schools must be eligible to receive state funding. For the 2015-2016 school year, participating private schools in East Baton Rouge Parish include: Greater Baton Rouge Hope Academy, Our Lady of Mercy, St. Louis King of France, St. Michael the Archangel High School, Redemptorist Elementary School, and The Dunham School. Statewide, more than 400 students applied for assistance through this program for the 2015-16 school year, and approximately 360 students accepted an award.93 Within East Baton Rouge, approximately 115 students applied and approximately 100 accepted an award.94

   Tuition assistance is 50% of the state per pupil funding for the student’s school district (approximately $2,200) and cannot exceed the cost of the private school tuition. Families are responsible for paying the difference if tuition exceeds that amount.95

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90 Louisiana Department of Education, [https://www.louisianabelieves.com/schools/louisiana-scholarship-program](https://www.louisianabelieves.com/schools/louisiana-scholarship-program)

91 ibid

92 ibid

93 ibid

94 ibid

95 Louisiana Department of Education, [https://www.louisianabelieves.com/schools/school-choice-for-students-with-disabilities](https://www.louisianabelieves.com/schools/school-choice-for-students-with-disabilities)
3. **Tuition Donation Rebate Program**\textsuperscript{96} The Tuition Donation Rebate Program empowers low-income Louisiana families with the financial resources to choose the school that will best prepare their children for college and careers. This program provides rebates to Louisiana state taxpayers, including corporate taxpayers, who donate to School Tuition Organizations (STOs), tax-exempt, not-for-profit organizations. STOs use these donations to provide scholarships to students in low-income families.

To be eligible for a scholarship, a student must have a family income that does not exceed 250% of the federal poverty line and must be entering kindergarten or must already be enrolled in a Louisiana public school, or enrolled in the Louisiana Scholarship Program. Students apply directly to STOs for scholarships. Once the student receives a scholarship, the student can then apply directly to the nonpublic school of the student’s choice for enrollment.

School Tuition Organizations determine the amount of the scholarship. Scholarship amounts cannot exceed the lesser of either the school’s tuition and mandatory fees or 80% of the state average per pupil funding for elementary and middle school students (approximately $4,000) and 90% of the state average per pupil funding for high school students (approximately $4,500). Parents must pay the difference of any tuition and fees not covered by the scholarship.

Louisiana currently has three School Tuition Organizations participating in the Tuition Donation Rebate Program.

- Arete Scholars Louisiana
- ACE Scholarships Louisiana
- New Schools for Baton Rouge Excellence Scholarship Fund\textsuperscript{97}

\textsuperscript{96} Louisiana Department of Education. [https://www.louisianabelieves.com/schools/tuition-donation-rebate-program](https://www.louisianabelieves.com/schools/tuition-donation-rebate-program).

\textsuperscript{97} Ibid.
LOUISIANA’S NEW ABLE ACCOUNT SAVINGS PROGRAM

The Louisiana Legislature passed the Achieving a Better Life Experience in Louisiana Act (Louisiana ABLE Act) in 2014 establishing a savings account program for financing of qualified expenses of persons with disabilities who meet either of the following criteria:

• Have a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months, or

• Are blind.

The ABLE program is intended to be treated in the same manner as a qualified tuition program defined in Section 529 of the federal Internal Revenue Code, and is being designed to function much like Louisiana’s existing Student Tuition Assistance and Revenue Trust Program (START) that can be used to reimburse higher education expenses.

A wide range of qualified disability expenses can be paid from an ABLE account including: assistive technology and personal support services, education expenses including tuition for preschool through postsecondary education, employment support expenses related to obtaining and maintaining employment, health and prevention and wellness expenses, housing expenses for primary residence, transportation expenses, and other miscellaneous expenses.

The ABLE program will be administered by the Louisiana Office of Student Financial Assistance (LOSFA).
SPOTLIGHT: EDUCATION SAVINGS ACCOUNTS

The Education Savings Account (ESA) is a new innovation in Pre-K-12 education that provides qualified families the opportunity to direct the educational funding (provided by the state) to the schools, courses, programs, and other relevant services they deem most appropriate to meet the needs of their child. The monies placed in an ESA are managed directly by the parents under state-established guidelines and oversight. ESAs currently exist in the states of Arizona and Florida. The following are ESA program summaries for both states.

ARIZONA’S EMPOWERMENT SCHOLARSHIP ACCOUNT (ESA) PROGRAM
The Arizona Empowerment Scholarship Program began five years ago to provide broader educational opportunities for children with disabilities. Sometimes referred to as “School Choice 2.0”, the ESA choice model constitutes an important refinement of the original school choice concept. Rather than a state-funded coupon that parents can use to cover costs at a public or private school, an ESA is literally an account controlled by parents. Participating Arizona parents sign an agreement with the state and in return receive an account with 90% of the funds that their public school would have received. Parents can use these funds in a variety of ways – private school tuition, certified private tutors, licensed therapists, individual public or private school courses, community college tuition, online programs, etc. ESA parents have an incentive to judge service providers by both quality and cost, as one of the allowable uses of funds is to save funds for future higher education expenses in a federal education savings account. Parents access funds through use of a restricted debit card with state officials continually monitoring and auditing accounts.

Currently, the program serves approximately 2,200 schoolchildren, and current regulations cap program enrollment at 5,500 students. However, those caps expire at the end of 2019, and legislative efforts are currently underway to expand the program to all of the state’s 1.1 million public school children.

Minimum Qualifications:

1. Reside in the state of Arizona

2. Meet one of the following criteria:
   a. Enrolled in an Arizona public or charter school full time for the first 100 days of the previous fiscal year
   b. Received a School Tuition Organization (STO) scholarship for displaced and disabled students
   c. Eligible for kindergarten or preschool

3. AND Be identified in one of the approved student populations
   a. Child with a disability
   b. Child who is a ward of the juvenile court and is residing in prospective permanent placement foster care
   c. Child who is a ward of the juvenile court and who achieved permanency through adoption
   d. Child who is the sibling of a current ESA recipient
   e. Child who attended a public school assigned a letter grade of “D” or “F” for the first 100 days of the school year
   f. Child with an active duty military parent

98 http://www.azed.gov/esa/
How It Works:

• Parents sign a contract saying they are responsible for their child’s education and waive the public school’s Free and Appropriate Public Education (FAPE) requirement

• Child must withdraw from public school and enroll in a private school, home school, or online curriculum program

• 90% of state allocated funding for the child’s education is placed in a bank account for the parents to use

• Parents receive a debit card and pay for services directly using this account

• Debit cards will only work on approved expenses

• Parents submit a quarterly report to the Department of Education as back-up for the approved expenses

Funding Amount:

• Funding amounts vary depending on disability, grade level, and school district. Children with Autism in this program typically receive between $20,000 and $25,000

• There is no financial cap on the program. Currently, 1,300 of the 220,000 eligible students are participating in the program

• Program is administered by the Department of Education and Treasurer’s office

Approved Funding:

1. Tuition and fees at a nongovernmental (private) school for Pre-K-12

2. Required textbooks

3. Tutoring services from an accredited provider

4. Services provided by a public school including individual classes and extracurricular programs

5. Approved curriculum, generally defined as a complete course of study for a particular content area or grade level

6. Tuition and fees for a private online learning program

7. Fees for nationally standardized norm-referenced achievement tests, advanced placement exams, or any exam related to post-secondary admissions

8. Tuition, books, and fees at an eligible postsecondary institution in the state of Arizona

9. Educational therapies or services from a licensed or accredited practitioner or provider, including ABA therapy, as determined by the parent

10. Services/aide from a licensed or accredited paraprofessional

11. Funds remaining in the account can be rolled over into a 529 account for future college expenses
SPOTLIGHT: EDUCATION SAVINGS ACCOUNTS

FLORIDA’S PERSONAL LEARNING SCHOLARSHIP ACCOUNT (PLSA) PROGRAM

Florida’s Personal Learning Scholarships Accounts Program is a newly created program administered by state-approved nonprofit Scholarship Funding Organizations that, like Arizona’s ESA Program, is designed to provide the option for a parent to better meet the individual educational needs of his or her eligible child. The PLSA provides eligible students a scholarship that can be used to purchase approved services or products. To participate, parents must apply to one of the nonprofit scholarship funding organizations that are administering the program. Parents initially pay for approved educational services and then are reimbursed. Funding provided through the program can pay for everything from instructional materials to curriculum to approved specialized services and therapies such as ABA therapy. The amount of a child’s PLSA is dependent on a number of different factors, including grade level, county of residence, and a student’s individual level of need. The average for the 2015-16 school year is approximately $10,000. Like Arizona’s program, a child enrolled in the PLSA program may not receive a PLSA and attend public school at the same time, unless it is to receive contracted services.

Nearly 3,900 Florida students have PLSAs today. Enrollment in the program is capped based on the amount of funds allocated by the state legislature. However, in 2015, the Florida legislature appropriated approximately $53.4 million for the program, which is enough to help more than 5,000 students.

Minimum Qualifications:

1. Reside in the state of Florida

2. AND Be identified in one of the approved student populations:
   a. Child with an IEP
   b. Child with a diagnosis of autism, down syndrome, intellectual disability, Prader-Willi syndrome, spina-bifida, Williams syndrome
   c. Kindergartners who are considered high risk

Requirements of Private School Providers:

1. Located in the state of Florida

2. Comply with requirements for private school participating in the state school choice scholarship program

3. Provide to the eligible nonprofit scholarship-funding organization all documentation required for the student’s participation, including the private school’s and student’s fee schedules

4. Be academically accountable to the parent for meeting the educational needs of the student

5. Employ or contract with teachers who have regular and direct contact with each student receiving a scholarship under this section at the school’s physical location

6. Annually contract with an independent CPA to perform a report of the results to the scholarship-funding organization

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99 http://www.fldoe.org/schools/school-choice/k-12-school/shar

100 See https://www.stepupforstudents.org/for-parents/spe

How It Works:

- Parents sign a contract saying they are responsible for their child’s education and waive the public school’s Free and Appropriate Public Education (FAPE) requirement
- Child must withdraw from public school and enroll in a private school, homeschool, or online curriculum program
- 90% of state allocated funding for the child’s education is reserved for expenses related to the child’s education as chosen by the parent
- Parents pay for approved services out of pocket and submit reimbursement requests electronically as expenses are incurred to the nonprofit agency approved by the state to administer the program (Scholarship Agency)

Funding Amount:

- Funding amounts vary depending on disability, grade level, and school district.
- Average anticipated funding was $10,000 per child for the 2015-2016 school year. Official numbers have not been released.
- 3,900 students are currently enrolled with funding to support up to 5,000 students
- Program is administered by an approved nonprofit agency, the Scholarship Agency for the state.

Approved Funding:

1. Tuition and fees at a nongovernmental (private) school for PK-12
2. Tutoring services from an accredited provider
3. Approved curriculum, generally defined as a complete course of study for a particular content area or grade level
4. Tuition and fees for a private online learning program
5. Tuition, books, and fees at an eligible postsecondary institution in the state of Arizona
6. Educational therapies or services from a licensed or accredited practitioner or provider, including ABA therapy, as determined by the parent
7. Services/aide from a licensed or accredited paraprofessional

These programs have seen great success in Arizona and Florida achieving high levels of satisfaction from the families utilizing this funding mechanism. ESAs could be implemented in Louisiana; however, families would be required to leave the public school system – including charter schools - and coordinate private schooling or homeschooling coupled with therapies on their own.
**SCHOOL CHOICE OPTIONS**

New Schools for Baton Rouge, a Capital Region nonprofit launched in 2012 for the purpose of catalyzing the creation of a new network of excellent schools, developed the following comparative summary of nonpublic and public charter school options, including requirements and opportunities to serve students with exceptionalities (like students with ASD). Many different factors determine whether or not a school should incorporate as a nonpublic or public charter school. These factors are heightened when discussing the needs of a school focused on special education. More information on Louisiana charter schools can be found on DOE’s website[^1] and Bulletin 126 outlines the laws surrounding charter schools in Louisiana.[^2]

**Authorization for Charter Public Schools** - In Louisiana, there are five separate types of charter authorizations.

- All charter schools are 501c3 nonprofits governed by a nonprofit board.

- There are five types of charters in Louisiana:

  - **Type 1**: Local school board authorizes a new start school
  
  - **Type 1B**: Local authorizer authorizes a new start school
  
  - **Type 2**: BESE authorizes a new start school
  
  - **Type 3**: Local school board converts an existing school. Note that a nonpublic school may not convert to a charter.
  
  - **Type 3B**: The RSD returns an existing school to the local school board
  
  - **Type 4**: BESE authorizes either a new start school or conversion school upon application by the local school board
  
  - **Type 5**: BESE authorizes a school under jurisdiction of the RSD

[^1]: [https://www.louisianabelieves.com/schools/charter-schools](https://www.louisianabelieves.com/schools/charter-schools)

**Funding: Nonpublic vs. Charter Public** - The funding sources for nonpublic schools and public charters are varied. The funding outlined below demonstrates anticipated funding for schools serving students with special needs.

Funding sources available to nonpublic schools include:

- Louisiana Scholarship Program: amount equals the school’s tuition and fees or per pupil funding in the district where the student lives, whichever is less.\(^{103}\) The statewide average in 2015-2016 is $5,856.\(^{104}\)

- Tuition Donation Rebate Program: amounts cannot exceed the school’s tuition and fees or 80% of state per pupil funding.\(^{105}\) Amount for 2016-2017 will be $4,156.80 for students in kindergarten through 8th grade and $4,676.40 for students in 9th through 12th grade.

- School Choice Program for Certain Students with Exceptionalities: approximately $2,200\(^{106}\)

- Tuition\(^{107}\)

- Fundraised dollars

- Medicaid or insurance refund for covered services and/or therapies

Funding sources available to charter public schools include:

- Public funds: local, state, and federal funds equal an estimated $15,526 per student\(^{108}\)

- Per pupil facility funding for Type 2 charters in private facility: approximately $920 per student

- Fundraised dollars

- Medicaid or insurance refund for covered services and/or therapies

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\(^{106}\) A student may only benefit from one of the first three sources of funding, in a given year.

\(^{107}\) If a nonpublic school accepts scholarship for a student, tuition cannot be charged in addition to that amount.

\(^{108}\) See explanation of the Louisiana MFP calculation on pages 142-143.
Curriculum and Accountability – The variances in curricular control and accountability requirements include the following.

Nonpublic schools:

- Full autonomy over curriculum.
- Students participating in the Louisiana Scholarship Program must take all state assessments.
- Students participating in the Tuition Donation Rebate Program must take state assessments in English language arts and math, during 3rd through 8th grade and certain end of course exams in 9th through 12th grade.
- Students on school choice program scholarship are not required to take state assessments.

Charter Public Schools:

- Full autonomy over curriculum.
- A formal renewal process after five years and annual review for provisions of Charter School Performance Contract. Compact asks charters to set and meet targets for academic performance, financial health, and organizational items such as enrollment, facilities, governance, discipline, health, and safety
- Students must take all state assessments.
Student Enrollment – Nonpublic schools and charter public schools have different guidelines for enrolling their student population. Nonpublic schools establish their own constraints over student admission and enrollment. However, the guidelines for student enrollment in a charter public school include the following:

- Charters are open enrollment public schools. However, a school may “have admission requirements that are consistent with the school’s role, scope, and mission”, as approved by the authorizer.

- A charter public school could write an admission preference for students with special needs into the charter application.

- The school could seek students with special needs through marketing and student recruitment efforts.

- A charter public school student population must include 85% of the school district’s average population of at-risk and special needs students. As an example, if a school district population has 10% students with special needs, a charter school should serve a student population of which 8.5% have special needs.

Board of Directors Code of Ethics Requirements – In a nonpublic school, there is no code of ethics requirement for Board members. In a charter public school, however, there are several requirements of the Board members, including:

- Board members must submit financial disclosure statement annually.

- Board members cannot be members of the same immediate family and potential family benefits from a proposed action must be disclosed.

- 60% of board members must reside in the community where the school is located, and

- Board members must develop and follow an annual training program.

Auxiliary Services: Transportation and Food Services – A nonpublic school has full discretion to charge for auxiliary services such as transportation and food services. Guidelines for charter public schools include:

- Generally, charters must provide transportation, which is often a high-cost expense. However, there are transportation waivers available for Type 2 charters with a mission of serving students with exceptionalities, where the transportation requirement would create a substantial financial burden.

- Charter public schools must provide free or reduced lunch to students who qualify.

Other General Charter Public School Requirements – There are a number of other additional rules and regulations charter schools must comply with. Two significant requirements include:

- Charter schools must follow open meeting law requirements, and

- Charter schools must comply with all provisions of the federal IDEA.111

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109 There are some stipulations for nonpublic schools enrolling students in the Louisiana Scholarship Program or the Tuition Donation Rebate Program.

110 Louisiana Division of Administration, Bulletin 126, Ch. 27, Sec. 2705.A.

111 See additional information on IDEA on page 134.
Sampling of Charter Schools in the US Focused on Students who are Developmentally Disabled

The following is a sampling of innovative charter schools throughout the US that are focused on serving students who are developmentally disabled, including those with an ASD diagnosis. Descriptions for each school were taken from the respective websites.

Arizona Autism Charter School (Phoenix, Arizona)
The Arizona Autism Charter School is the first tuition-free, public charter school in Arizona that specifically focuses on the educational needs of children with autism. The school has the mission to educate students with autism and related disorders using evidence-based strategies grounded in the principles of Applied Behavior Analysis (ABA) delivered by highly trained teachers and staff. Educational curriculum is delivered via ABA techniques. Classrooms are multi-grade and group students by ability and need. All teachers and staff are supervised by BCBAs. Today, the school is limited to grades K-6, but the school is authorized to grow up to grade 8 and plans to add an additional grade each year. There are currently 108 students enrolled. Class sizes are limited to a maximum of nine students and have a student to staff ratio of 3 to 1. The Arizona Autism Charter School also provides fee-based after school programming.112 The school’s operations are funded almost exclusively from public funds. Arizona’s base per-pupil funding ranks among the lowest in the country, at approximately $8,000. However, it’s tiered funding formula for students with disabilities allows a charter to receive an additional nearly $20,000 to educate a student with autism.

Charterhouse School (Richmond, Virginia)
Charterhouse School is an educational institution located in Richmond and Edinburg, VA, that serves the needs of students with autism and other neurological differences, emotional disabilities, learning disabilities, intellectual disabilities, developmental disabilities, and other health impairments. The Charterhouse approach focuses on a student’s individual academic, behavioral, social, and emotional needs while addressing the four needs of the “Circle of Courage” – belonging, independence, mastery, and generosity. Founded in 1979, Charterhouse School educates elementary, middle, and high school students ages six to 22 and has an average student to teacher ratio of 8 to 1. The school offers both residential and non-residential services, as well as more mainstream classrooms and specialized classrooms for students with autism or other neurological disorders. Within the autism program, behavioral specialists are present throughout a student’s day, recording behavioral and social observations as needed. Students participate in weekly support groups facilitated by the school counselor and receive individual therapy as needed. These services help students develop the skills they need to reflect and self-regulate.113 Today, the Charterhouse School serves 39 students (27 day students, 12 overnight residential students). Charterhouse is not a traditional public charter school. Rather, it is a private day school that enrolls students referred by the public school system whose IEP indicates they cannot be appropriately educated in the traditional public school setting. Charterhouse receives approximately $242 per day from the Local Education Agency (LEA) for each student with autism or another intellectual disability.

112 For more information, visit the Arizona Autism Charter School website at www.autismcharter.org
113 For more information, visit the Charterhouse School website at www.charthouseschool.org
The Hope Center for Autism (Stuart, Florida)
The Hope Center for Autism is a Florida public charter school with the mission to open doors for people affected by autism and related disabilities. The Hope Center for Autism offers a curriculum based on ABA. The student to teacher ratio is 2 to 1, and each student receives one on one instruction on a daily basis. All educational plans are overseen by a BCBA and implemented by a teacher certified in Exceptional Student Education and experienced therapists and paraprofessionals. The Hope Center for Autism accepts students in grades Pre-K through grade two who reside in Martin County, FL, and have been determined eligible for Exceptional Education Services by the Martin County School District.114

114 For more information, visit the Hope Center for Autism website at www.hopecenterforautism.org.

New York Center for Autism Charter School (New York, New York)
The NYC Autism Charter School is the only public charter school in New York State devoted solely to children with autism. The NYC Autism Charter School is co-located in East Harlem with P.S./IS 50, providing students the opportunity to interact with developing peers in the East Harlem community. The educational program offers individualized and evidence-based instruction rooted in ABA and one to one teacher to student ratio in most classrooms. The faculty provides 30 hours of intensive ABA instruction to students every week. The school serves approximately 32 students and receives approximately $62,000 in public funds per student. Additional funding is provided by private donations which total close to $20,000 per student.115

115 For more information, visit the New York Center for Autism Charter School website at www.nycacharterschool.org/home.

Florida Autism Center of Excellence (Tampa, Florida)
The Florida Autism Center of Excellence (FACE) is a public charter school located in Tampa, FL that offers successful educational programs for children and young adults with ASD. FACE serves children with ASD from ages three to 22 in Pre-K through grade 12 and is open to residents in Hillsborough, Pinellas, Polk, Manatee, and Sarasota counties. FACE implements ABA principles to help students gain the academic, social, language, behavioral, vocational, and life skills they need to help them become independent later in life. FACE utilizes ABPathfinder, an autism therapy management tool, to aid staff in defining and administering individualized ABA programs.116

116 For more information, visit the Florida Autism Center of Excellence website at http://www.faceprogram.org/.
Palm Beach School for Autism (Lake Worth, Florida)

Palm Beach School for Autism is a tuition-free public charter school, located in Lake Worth, Florida, that serves children from pre-school through grade 12 on the autism spectrum in Palm Beach County. The Palm Beach School for Autism has the mission to provide a developmentally appropriate education using intensive behavioral strategies for students with ASD and related disabilities. The foundation of the educational program is the application of ABA and other therapies infused with innovative learning methods that include sensory integration, hands on learning, team collaboration, individualized instruction, achievement portfolios, and language based instruction. The school currently serves approximately 280 students. Students seeking to enroll must have an IEP from a public school district that identifies the student as having ASD. Once the IEP is provided to the Palm Beach School, school staff conduct an additional intake and assessment to determine the unique set of programs and resources necessary to educate the student. The amount of state funding for each student is based on the student’s Matrix Score. As discussed in the Spotlight: The Florida Exceptional Student Education Program, in Florida, the Matrix of Services is the document used to determine the cost factor for exceptional education students based on the decisions made by the IEP team. Scores range from 251 to 255 and most children with autism score 254 or 255, qualifying the most high-cost students for up to approximately $20,000 in state funding. The school also receives federal IDEA funds for each student. The combination of state and federal funding is not enough to cover the complete cost of educating the school’s students, so fundraising, grants and private donations are also pursued.

St. Coletta Charter School (Washington D.C.)

St. Coletta of Greater Washington operates a public charter school and a private school, co-located in the District of Columbia. St. Coletta has the mission to serve children and adults with intellectual disabilities and to support their families. Students served are between the ages of three and 22 years and must be diagnosed with an intellectual disability, autism, or multiple disabilities and have a minimum of 24.5 hours of special education services on their IEP. They must also have a secondary disabling condition such as speech language disorder, vision or hearing impairment, orthopedic impairment, health impairment or behavior disorder. St. Coletta’s approach to teaching children with autism incorporates various approaches including picture communication, sensory diets, positive behavior intervention, and management of environments based on the TEACCH program.

St. Coletta serves approximately 250 students each year. They receive approximately $35,000 per student from public funding sources, bill Medicaid for most therapy services, and have a full-time grants staffer who works in development.

St. Coletta also offers adults the opportunity to participate in vocational and pre-vocational training, supported employments, life skills training, and community integration. The adult program, located in Old Town Alexandria and North Bethesda, focuses on developing life skills through community integration.

For more information, visit the Palm Beach School for Autism website at [www.pbsfa.org](http://www.pbsfa.org).

For more information, visit the St. Coletta Charter School website at [www.stcoletta.org](http://www.stcoletta.org).
As with the unique mix of services and supports necessary to help a child with autism reach his or her full potential, the specific type of school and educational setting and curriculum that will help a child with autism maximize his or her educational experience will be different for each child. There is long-standing and robust debate among parents, policymakers and advocates concerning whether mainstream education or education in a more exclusive setting is most advantageous for children with developmental disabilities. The recommendations contained in this report, including the recommendation to establish a charter school focused on children with autism, are not intended to suggest that an exclusive educational environment will be right for all, or even most, children. Parents unquestionably are the most qualified decision makers when it comes to choosing the type of school setting and environment that are right for his or her child, and there is no one-size-fits-all answer. To that end, in light of the staggering number of children in the Capital Region projected to be on the autism spectrum by 2030, the authors of this report conclude there is a need for a host of different educational options for parents to choose from. A specialized charter school for children with autism is simply one option among many. Additionally, the recommendation for a specialized charter school is not intended to relieve local public school systems in the Capital Region from their obligation to provide appropriate services and supports to children on the autism spectrum.
SPOTLIGHT: A FEASIBILITY STUDY FOR A SPECIALIZED ELEMENTARY SCHOOL IN THE CAPITAL REGION

Over the past several years, The Emerge Center (Emerge) has become one of Baton Rouge’s leading nonprofit organizations dedicated to optimizing independent communication and social interaction skills, and it remains poised for continued and sustainable growth, expansion, and success. A potential area for expansion is elementary education for children with autism in the Baton Rouge area.

During the fall of 2015, Emerge engaged Emergent Method, a Baton Rouge-based strategy and management consulting firm, to conduct a feasibility study to assess opportunities to expand current interdisciplinary services and potentially create a school that would serve children with autism and related disorders. The objectives of the feasibility study were to develop a program and curriculum model that would build upon the strengths of Emerge’s ABA therapy program, determine the potential population of students the school would serve, explore different options for creating a school (public versus private), and develop a financial model that would account for potential revenue sources as well as expenses. Coleman Partners Architects was engaged to develop a master plan for the current facility and site to support any such expansion.

In February 2016, the first phase of feasibility study was completed. The findings of the study have determined that a therapeutic school for children with Autism at Emerge is feasible. Based on this preliminary information, the Emerge Board of Directors has voted to move forward with a planning phase as the next step. During this phase, Emerge’s Board of Directors will continue to assess and take a prudent approach in analyzing the model and determining philanthropy and funding opportunities. The Board of Directors of the Emerge Center will operate under the guiding principle that this programmatic growth must supplement the current strengths of Emerge as well as continue to assess any potential risks to existing programming.
STATE STUDENT ACCOUNTABILITY/ACHIEVEMENT SYSTEM

Student accountability for school performance is complex, ever evolving, and linked with federal standards which mandate that all students participate in state accountability systems and large-scale testing systems. The Louisiana Department of Education, in collaboration with stakeholders and policy advocates, continues to refine the state’s accountability system, including the development of alternative and appropriate accountability assessments for students with disabilities.

LAA 1

Louisiana students with the most significant cognitive disabilities are eligible to take the Louisiana Educational Assessment Program (LEAP) Alternate Assessment, Level 1 (LAA 1), an alternate assessment for students who have Individualized Education Programs (IEPs) and meet specific criteria. Under the LAA 1, students in grades 3 through 8 and 10th grade are assessed in English language arts and mathematics; students in grades 4 and 8 are also assessed in science. Students in 11th grade are assessed in science only. Students who take the LAA 1 may receive a Career Diploma through an alternate pathway or a Certificate of Achievement.

Louisiana’s state accountability system for high school (9th to 12th grade) includes four equally weighted components – high school ACT score, End-of-Course (EOC) assessments, cohort graduation rate, and the graduation index. Federal law requires all students to be included in the denominator for calculating the graduation rate and graduation index. Students who are eligible for the LAA 1 and receive a Career Diploma are included in the graduation index numerator. However, students that receive a Certificate of Achievement are not included in the numerator.

More information on the LAA 1 can be found on DOE’s website: http://www.louisianabelieves.com/assessment/alternate-assessments.

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120 The federal standards that mandate state accountability systems are the Individuals with Disabilities Education Act (IDEA) and No Child Left Behind Act.
121 www.doa.la.gov/osr/lac/28v97/28v97.doc
**ACT 833 OF THE 2014 LOUISIANA LEGISLATIVE SESSION**

In an effort to further recognize performance of schools serving students with exceptionalities, Act 833 of the 2014 Louisiana Legislative Session provided an additional alternative for students with exceptionalities within the state accountability system, including grade promotion, pursuing a career major curriculum, graduation criteria, diploma eligibility, and monitoring and corrective action for school systems with high rates of students with exceptionalities performing below expected levels.

The general purpose of Act 833 is to make certain “students with exceptionalities shall be afforded the same opportunities to pursue a high school diploma and to exit with all course credits, honors, and financial awards as other students.”122 Additionally the Act ensures “A student with an exceptionality... who successfully completes the requirements of his Individualized Education Program, including performance on any assessment required for graduation determined appropriate by his Individualized Education Program team, shall be issued a high school diploma.”123

Act 833 creates another opportunity for students with exceptionalities in Louisiana public schools to achieve a high school diploma and for their schools to receive accountability credit for their performance. A summary of Act 833 can be found on the Louisiana Developmental Disabilities Council (LaDDC) website.124

**THE ACCOUNTABILITY CONSTRAINTS OF FEDERAL LAW**

Louisiana’s efforts to extend the opportunity for a high school diploma to students with exceptionalities are ultimately constrained by the federal definitions previously included in the No Child Left Behind legislation and is now superseded by the Every Student Succeeds Act (ESSA). With the passage of the ESSA, schools will still be held accountable for student performance; however, states will have more autonomy to determine standards and intervention protocol. Louisiana is actively engaged with policy makers on the federal and state level to promote more inclusive definitions and standards for the reauthorization of this federal policy. A summary of the ESSA and its impact in Louisiana is available on the LaDDC website.125

123 ibid
124 [http://www.laddc.org/content.cfm?id=563](http://www.laddc.org/content.cfm?id=563)
TEACHERS AND LOCAL SCHOOL SYSTEMS

Typically, teachers not certified as special education instructors receive limited exposure to working with this unique population. Even special education instructors who receive extensive training need ongoing education and support to stay up to date on changing best practices. Professional development and support for teachers includes behavioral intervention training and tools, access to behavioral intervention experts for classroom support, and continuing education opportunities focused on classroom techniques for students with an ASD diagnosis. The following information describes the available resources in the Capital Region.

TRAINING RESOURCES

Nicholls State University
As mentioned previously in this report, the Nicholls State University BCBA Program, housed in the University's Education Department, is a two-and-a-half-year program that provides the education to become a certified BCBA. While the students in the program are not all teachers, the program is geared towards both special education and regular education teachers to train them in behavior analysis techniques so these individuals can be used as ABA resources within their home institutions.

Ascension Public Schools has taken advantage of the Nicholls State BCBA program and currently employs three teachers who have graduated from the Nicholls State program. These teachers are leveraged as resources around the school district in a “train-the-trainer” model. They are called into classrooms when students have behavioral outbursts and work closely with the everyday teachers. They teach these teachers techniques for managing the child’s behavior to prevent future outbursts and encourage a learning environment. These experts can also be leveraged for IEP and Individual Transition Plan (ITP) development and counseling.

The East Baton Rouge Parish School System has not worked with Nicholls State. Previously, a single Program Specialist provided expert support for all teachers in the system serving ASD students. However, this staff person has left the school system and no plan for replacement has been identified.

Calcasieu Parish School System has adopted a model to support educators and administrators in managing children with ASD. Calcasieu Parish has on staff a group of behavioral specialists who are supervised by a BCBA. Each specialist oversees a few schools and can be called upon to support teachers for Individual Education Programs (IEPs), transition planning, and behavioral issues. These behavioral specialists can be called in by teachers for consultation and can act as case managers for students as they progress through school.
Louisiana Autism Spectrum and Related Disabilities (LASARD) Project
In addition to the LASARD Project’s educational materials for physicians, referenced in the Early Childhood Diagnosis section of this report, LASARD also engages in efforts to improve educational practices and outcomes for students with ASD and related disabilities and to develop statewide capacity to provide high-quality educational programs for these students. LASARD provides free online training modules, professional development opportunities, and technical assistance statewide. The Autism Training Modules are a nine-part professional development electronic modules available online 24 hours a day, 7 days a week through the LASARD website - www.hdc.lsuhsc.edu/lasard.

LASARD will also provide contract support to school systems upon request on a case-by-case basis. The Baker, Ascension Parish, and St. Helena Parish school systems from the Capital Region have taken advantage of LASARD’s contract support services. The East Baton Rouge Parish school system has not.

LASARD also provides support free of charge to ten “partner” school systems (including charter schools) selected through an application process each year. Each partner commits to creating and supporting up to three teams of educators, administrators, therapists, family members, and paraprofessionals. LASARD provides each team three days of training in the areas of environment, communication, curriculum and instruction, collaboration, inclusive practices, behavior, social interaction, and transition.

After training, teams create action plans to improve one or more of these areas within their respective schools. LASARD also provides regular follow up meetings and targeted development assistance for all teams. St. Helena Parish School System is the only Capital Region system that has been accepted by LASARD as a partner for the 2015-16 school year.

Additionally, LASARD provides professional development to any school district that requests assistance, regardless of whether the district is a “partner” district. During the 2014-15 school year, LSARAD provided a workshop at the City of Baker schools, but no other district in the Capital Region requested professional development assistance. LASARD also offers web-based professional development tools that may be accessed by anyone and hosts training opportunities and events around the state on a variety of topics including adult transition, behavior in the classroom, and social interaction. See Pre-K-12 Education section for more information. Anecdotal evidence from study interviews indicates LASARD is an underutilized resource. LASARD leadership acknowledged that with more funding from the Louisiana Department of Education, the organization could serve more districts through intensive technical assistance (as provided to LASARD’s partner districts), but stated that even with free supports available today, no districts in the Capital Region have applied for services.
Interviews were conducted with two of the largest school systems in the Capital Region – the East Baton Rouge Parish School System and the Ascension Public Schools – for the purpose of understanding how these local systems serve special education students, including those with an ASD diagnosis.

Ascension Public Schools and East Baton Rouge Parish School systems, like all public school systems in the US, utilize the prescribed federal guidelines and processes to serve all special education students including students with an ASD diagnosis who also meet special education criteria. As described earlier in this section, the centerpiece of the federal special education guidelines is an IEP developed by a team that typically includes education professionals, the family, health care professionals, and other relevant experts.
ASCENSION PUBLIC SCHOOLS SYSTEM

In the Ascension Public Schools system, IEPs are reviewed and updated once per year on or before the anniversary date of the previous IEP - unless the student’s anniversary date falls within the September/October timeframe. Updates for those students are completed toward the end of the previous school year.

Officials from the Ascension Public Schools system interviewed as part of this assessment identified the following specifics of their special education infrastructure as key components of their program.

• An organizational culture that emphasizes problem-solving and student success over mere compliance with federal and state requirements.

• An elaborate, structured six-step process to evaluate and remedy poor student performance prior to referral for a special education eligibility assessment. This process utilizes a team approach referred to as the Professional Learning Community (PLC) which includes the child’s teacher(s), other grade level teachers, speech therapist, counselor, special education staff, and trained facilitators. The exact members of the team are individualized based on the needs of the student. The school system’s PLC Problem-Solving Flow Chart is provided in Appendix C of this report.

• An emphasis on providing elaborate transition support services for students including grade-to-grade, school-to-school, and school-to-adult world/work transitions.

• A system-level Applied Behavior Analysis (ABA) expert to serve as a resource across the school system. The school system also leverages a close working relationship with the ABA educational program at Nicholls State University. Additionally, the system has teachers trained in a variety of other behavioral intervention techniques. The school system does not currently leverage insurance reimbursement for ABA therapy.

• The school system offers several health care services including speech therapy, physical therapy, occupational therapy and nursing services. The school system is enrolled as a Medicaid provider allowing for Medicaid reimbursement of these services for eligible students.

School system officials identified the following as potential improvements of the Ascension Public Schools special education program:

• A need for better coordination between private student evaluators, health care professionals, and the school system.

• Guidebook resources and other simple tools and collaterals that facilitate greater family understanding and more efficient navigation of the special education infrastructure.

We spoke with several families and stakeholders who indicated that Ascension Parish has demonstrated a commitment to special education students that has seen success.
EAST BATON ROUGE PARISH PUBLIC SCHOOL SYSTEM

In the East Baton Rouge Parish Public Schools System, IEPs are reviewed and updated annually. The update process is initiated by the school system approximately 60 days prior to expiration and the IEP meeting is conducted at least 30 days prior to expiration.

Officials from the East Baton Rouge Parish Public School System interviewed as part of this assessment identified the following specifics of their special education infrastructure as key components of their program.

- A focus on getting families connected to and interfacing with the available early intervention resources including the Early Steps program resources.

- An elaborate multidisciplinary infrastructure to support pre-appraisal interventions, the pupil appraisal function and IEP development. Copies of the school system’s key pre-appraisal intervention documents are provided as Appendix D of this report.

- ASD-exclusive classrooms, including approximately thirty-three elementary classes, ten middle school classes, and five high school classes.

- Health care services including speech therapy, physical therapy, and occupational therapy. The East Baton Rouge Parish Public School System does not currently offer ABA therapy to students.

School system officials also identified significant needs to improve the East Baton Rouge Parish special education program (to serve students with an ASD diagnosis):

- Guidebook resources and other simple tools and collaterals that facilitate greater family understanding and more efficient navigation of the special education infrastructure.

- A system of ongoing ASD-specific training for teachers, therapists, school administrators, and other relevant school system staff.

- ABA therapy resources and expertise to support ongoing ASD-specific staff development and to provide ABA therapy as appropriate.

- More and better adapted educational resources/materials for ASD students - age, grade, and skill level appropriate.

- A more effective transition services function, including more effective student training, greater family engagement, and a more robust interface with external transition resources.

We heard from parents and stakeholders that the East Baton Rouge Parish Public School System has room for improvement in terms of delivering special education support services, particularly to students with an ASD diagnosis. With the departure of the school system’s ASD specialist, parents no longer have access to a dedicated and knowledgeable resource. With the recent change in school system administration, East Baton Rouge Parish Public School System is primed for implementation of best practices in special education.
Approximately 20 years ago, the Calcasieu Parish School System began developing what is now a robust support infrastructure for students with an ASD diagnosis. This system-level infrastructure includes:

- Two full-time education professionals and experts dedicated exclusively to supporting students with an ASD diagnosis by working with school administrators and special education teachers and general education teachers in the classroom. These individuals are educators who have completed special training and ongoing development to maintain an expertise in supporting ASD students. These educators provide ongoing teacher training and serve as resources to the schools and the classrooms.

- Speech therapists, occupational therapists, physical therapists, and ABA therapists who are engaged to work with teachers. The school system does not currently seek insurance reimbursements for ABA therapy, but utilizes behavioral intervention techniques in the classroom. If there is a need, the school system works with external groups, like the McNeese Autism Program, to bring more specialized techniques into the classroom.

- The school system has engaged a BCBA from Indiana University to serve as a consultant to the system, working with the system to design the ASD programs and services. She also visits the system during the year to provide ongoing development.

- A strong collaborative relationship with families, outside health care providers (including therapists), transition/workforce development resources available through the state (Louisiana Rehabilitation Services), local providers, the local community and technical college, and local employers.

- Transportation services leveraged to maximize utilization of existing training programs available across the school system for older students in the transitional phase of the IEP.

Calcasieu has been identified as one of the better school systems in Louisiana for children with an ASD diagnosis.
Although many school systems are not offering ABA therapy or ABA techniques in the classroom, some in the state have incorporated models that do utilize these services. For example, St. James Parish consults with an ABA therapy provider for classroom behavior intervention techniques and Assumption Parish works directly with outside agencies to provide ABA services.

Families can push their school districts to work with existing service providers and entities to more easily facilitate the provision of ABA therapy.

The school district can establish a memorandum of understanding with these organizations who can then provide therapy in the school setting.
The following is a list of attributes of an “ideal” special education infrastructure to best serve public school students with an ASD diagnosis. This list was developed from research conducted throughout this assessment, including interviews with education professionals, medical professionals, advocates, and other stakeholders.

The ideal infrastructure is focused on achieving maximum student potential through a collaborative, professional effort that leverages all available resources. The ideal infrastructure is also transparent and easy to navigate by caregivers, and driven by innovation and continuous improvement.

**Attributes of an Ideal Special Education Infrastructure**

- **Student/Parent-centered Design**
  A high-quality special education system is designed around the needs of the student and the parents, not the organizational structures and staff of the school system bureaucracy. Student/Parent-centered design means families are provided the information and tools they require to clearly understand and efficiently navigate all relevant requirements, responsibilities, processes, and timelines that collectively comprise the special education function.

  Perhaps the most important component of the design is how the school system approaches the Individualized Education Plan (IEP), including the Individual Transition Plan (ITP). The development and ongoing management of a student’s IEP/ITP should reflect ASD-specific evidence based practices and real collaborative input from all relevant contributors – educational experts, medical experts, behavioral experts, workforce experts, and the family.

  Student/Parent-centered design also requires an inventory of easy-to-use tools (hardcopy and digital) that facilitate family understanding, collaboration, and satisfaction. Examples of tools that school systems should develop to facilitate good student/parent navigation of the special education function include:

  - Special education how-to guidebooks for parents,
  - Parental responsibility check sheets and timelines,
  - Simple graphical flowcharts that help explain key special education processes,
  - Experts and counselors easily available to parents for consultation,
  - A robust webpage and digital helpline, and
  - Survey instruments to measure family satisfaction.
• Collaborative Culture
ASD is an umbrella diagnostic label for a complex array of medical and behavioral conditions found in varying combinations and concentrations from person to person. ASD is recognized as a lifelong disorder without a cure, and expert research focused on understanding and addressing ASD is relatively limited and still evolving. Together, these facts significantly challenge public school systems to gain the knowledge and insights necessary to understand how to best serve each student with an ASD diagnosis.

Federal and state regulations provide a solid framework to make sure every school system follows basic requirements and standards for student eligibility, individualized education planning, and student performance measurement. However, compliance with regulations will not alone provide students and families with the service and support they need. The uniqueness of each student with an ASD diagnosis is best understood and addressed through true collaboration - the culture for which must be developed and continuously nurtured by the special education department of the school system.

Recognized collaborative partners should include: the family (including the student when appropriate), physicians and other relevant health care providers (such as psychologists, clinical social workers, therapists, etc.), education experts including special education experts and educators with ASD-specific expertise, and other relevant student/family support resource providers.

• ASD Expertise
The expanse and complexity of the different conditions that are included in the broad definition of Autism Spectrum Disorder warrants school system investments that provide ASD-specific expertise including:

- A recognized lead ASD expert at the school system level,

- System-level ASD expert resources available for special education eligibility evaluations, IEP/ITP development and classroom support,

- Incorporation of evidence-based practices and therapies that represent current best practices for students with an ASD diagnosis, including ABA therapy and ABA techniques and strategies for the classroom, and

- Ongoing continuing education of staff and periodic evaluation of the school system’s relevant staffing/service delivery model.
• Comprehensive Transition Planning and Support Services
The journey through Pre-K-12 education includes numerous significant transitions that students and families must successfully manage, including grade-to-grade transitions, school-to-school transitions, and the transition out of the secondary (high school) school environment. These transitions can be traumatic for any student and they can be especially so for students with an ASD diagnosis. School systems can make these transitions less daunting for students with an ASD diagnosis (and their families) by providing a comprehensive set of transition planning and support services.

Grade-to-grade and school-to-school transitions can be facilitated by student and family orientation sessions and collateral materials, and preliminary visits that offer environmental orientation and acclimation. The transition out of the high school environment is guided by the student’s Individual Transition Plan, but also ideally includes the active ongoing engagement of community resources external to the school system, including workforce development resources, the full array of available independent living resources, postsecondary education providers, and cooperative employers from the public and private sectors.

• Determination to Leverage Available Resources
Public school systems typically operate under significant financial pressures that do not allow for the internal development of all support services and resources needed to optimize outcomes for students with an ASD diagnosis. Such financial constraints compel school systems focused on optimizing student outcomes to leverage all appropriate resources available through public agencies, nonprofit organizations, and the private sector. Examples of external resources that can be leveraged to support students with an ASD diagnosis include:

- Third-party health care insurance reimbursement (including Medicaid) to provide needed health care services including appropriate therapies such as ABA therapy,

- Transition planning/guidance and workforce development resources available through the Louisiana Workforce Commission, especially Louisiana Rehabilitation Services (LRS), and

- Services, expertise, and other resources available from the relevant public agencies, nonprofit service providers, and advocacy organizations operating in the Capital Region, such as LASARD. These services can include therapy providers like speech therapy, occupational therapy, physical therapy, and ABA therapy, as well as training materials for teachers and expertise regarding transition planning and access to available supports for families.
05 RECOMMENDATIONS
PRE-K-12 EDUCATION
Federal and state laws provide an elaborate framework to guide how public school systems serve students who qualify for special education support due to an ASD diagnosis. However, appropriate implementation of federal and state guidelines requires transparent and accessible processes and programs, adequate resources, and ASD-specific expertise.

1. Public school systems in the Capital Region should conduct an independent assessment of their special education system as it relates to serving students with an ASD diagnosis for the purpose of organizational and operational redesigns to improve quality of system performance. Following the findings of this assessment, the recommendations should be implemented. The ideal system attributes include:
   a. Student/Parent-centered design
   b. Collaborative culture
   c. ASD expertise (including ABA therapy experts and a dedicated ASD expert to support staff development and coordinate service delivery)
   d. Comprehensive transition planning and support services
   e. Determination to leverage available resources

2. Public education systems and private schools should develop the organizational and operational infrastructure needed to leverage third party reimbursement, including private/commercial insurance and Medicaid reimbursement, of ABA and other relevant therapies and health care services.

3. The Louisiana Legislature should support the following changes to education funding:
   a. Increase the Minimum Foundation Program (MFP) base per pupil funding by 2.75% as recommended by the MFP Task Force,
   b. Implement a differentiated or tiered MFP for special education students based upon disability diagnosis and levels of intervention, similar to the differentiated funding model currently utilized by the Recovery School District in New Orleans, and
   c. Increase the funds set aside for High Cost Services by at least $7 million in addition to the $5.4 million allocated for the 2015-2016 school year, totaling approximately $21 million, as recommended by the MFP Task Force.
4. The Louisiana Department of Education should continue to work with policymakers on the state and federal levels to maximize the opportunities for students with exceptionalities to be included in the state accountability system.

5. In addition to the Emerge Center, relevant ASD community stakeholders should conduct a feasibility study for the establishment of an East Baton Rouge-based charter school serving Pre-K-6 or Pre-K-12 students with ASD and related disorders. This charter school and study should analyze the breadth of disabilities and disorders the school could service and does not need to be exclusive in nature, but could provide inclusive education to both typical and non-typical children. The feasibility study should include:

   a. Required demand for viability
   b. Transportation to potentially extend reach beyond East Baton Rouge
   c. Funding
   d. Accountability standards

6. The Louisiana Department of Education should establish a state-level ASD champion/expert to consult with local school systems, advocate for best practices, assist with troubleshooting and problem solving, and understand available resources, connect school systems to those resources, and serve as a liaison with other appropriate state agencies (i.e., DHH, LWC, DCFS).
Adult Transition

HIGH SCHOOL TRANSITION SERVICES

LOUISIANA REHABILITATION SERVICES

TRANSITION AND ADULT RESOURCES IN THE CAPITAL REGION

POST-SECONDARY EDUCATION SUPPORT SERVICES IN THE CAPITAL REGION

FUNDING FOR POST-SECONDARY PROGRAMS

PROGRESSIVE EMPLOYER EXAMPLES

A COMPREHENSIVE TRANSITION SERVICES MODEL
The Adult Transition component of this community assessment project is focused on understanding the resources available to individuals with an ASD diagnosis who are transitioning out of the secondary school setting. Specific topics addressed include: transition services provided through public school systems, post-secondary education and workforce training opportunities, employment, housing/living arrangements, independent living skills, adult support services, and social and community participation.

**EARLY DIAGNOSIS**
- Referral to physician specialist
- Referral to other medical specialists for comorbidity evaluations (if applicable)
- Referral to early intervention programs

**EARLY INTERVENTION**
- Intensive therapeutic intervention, including ABA therapy and other evidence-based interventions
- Application/referral to state waiver programs (if applicable)

**PRE-K-12 EDUCATION**
- Individual Educational Plan (IEP)
- Continued supplemental intervention and therapy
- Individual Transition Plan (ITP) in high school

**ADULT TRANSITION**
- Post-Secondary education
- Career training
- Independent and supported living
As mentioned earlier in this report, ASD is a lifelong condition without any known cure that studies indicate does not significantly shorten an individual's life span. ASD is also sometimes associated with intellectual disability, motor coordination difficulties, and attention and physical health challenges (for example, sleep and gastrointestinal problems). Given the complexity of ASD, the transition from a secondary school environment to the “adult world” is a critical juncture in the lives of young adults on the spectrum.

Drexel University produced a report in 2015 entitled National Autism Indicators Report: Transition into Young Adulthood that analyzed key outcomes after high school, including education, employment, living arrangements, and social and community participation. The report is primarily based on analyses of data from the National Longitudinal Transition Study-2 (NLTS2), a national study that captured the experiences of youth who received special education from the time they were in high school into adulthood.

Young adults with autism have a difficult time following high school for almost any outcome you choose – working, continuing school, living independently, socializing and participating in the community, and staying healthy and safe. To complicate matters, many of these youth begin their journey into adulthood by stepping off a services cliff. Access to needed supports and services drops off dramatically after high school – with too many having no help at all.

- from the executive summary of the National Autism Indicators Report: Transition into Young Adulthood

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The following data points depicted in Figure 11 from the National Autism Indicators Report: Transition into Young Adulthood clearly show

“... we are not succeeding as a nation in helping autistic adults to thrive to the best of their abilities and attain a high quality of life.”

11 What Happened After High School Across Key Outcomes

<table>
<thead>
<tr>
<th>What happened after high school across key outcomes?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>Attended any postsecondary education</td>
</tr>
<tr>
<td>36%</td>
</tr>
<tr>
<td>Ever attended 2 or 4 year college, or vocational/technical school</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
</tr>
<tr>
<td>Had a job for pay</td>
</tr>
<tr>
<td>58%</td>
</tr>
<tr>
<td>Ever had a job for pay outside of the home</td>
</tr>
<tr>
<td><strong>Living Arrangements</strong></td>
</tr>
<tr>
<td>Lived independently</td>
</tr>
<tr>
<td>19%</td>
</tr>
<tr>
<td>Ever lived away from parents without supervision</td>
</tr>
<tr>
<td><strong>Social &amp; Community Participation</strong></td>
</tr>
<tr>
<td>Any socialization</td>
</tr>
<tr>
<td>76%</td>
</tr>
<tr>
<td>Ever (in the past year) saw friends, called friends, or was invited to activities</td>
</tr>
<tr>
<td><strong>Access to Services</strong></td>
</tr>
<tr>
<td>Received any services</td>
</tr>
<tr>
<td>74%</td>
</tr>
<tr>
<td>Ever received at least one service after high school</td>
</tr>
<tr>
<td><strong>Health and Safety</strong></td>
</tr>
<tr>
<td>Co-occurring conditions</td>
</tr>
<tr>
<td>60%</td>
</tr>
<tr>
<td>of adolescents had two or more additional health or mental health conditions.</td>
</tr>
<tr>
<td><strong>Attended any college</strong></td>
</tr>
<tr>
<td>30%</td>
</tr>
<tr>
<td>Ever attended 2- or 4-year college</td>
</tr>
<tr>
<td><strong>Had a job soon after high school</strong></td>
</tr>
<tr>
<td>32%</td>
</tr>
<tr>
<td>Ever had a job for pay outside of the home within the first two years after leaving high school</td>
</tr>
<tr>
<td><strong>Lived apart from parents</strong></td>
</tr>
<tr>
<td>31%</td>
</tr>
<tr>
<td>Ever lived away from parents with or without supervision</td>
</tr>
<tr>
<td><strong>Any community participation</strong></td>
</tr>
<tr>
<td>68%</td>
</tr>
<tr>
<td>Ever (in the past year) was involved in volunteer activities, community activities, or took classes or lessons</td>
</tr>
<tr>
<td><strong>Received vocational services</strong></td>
</tr>
<tr>
<td>37%</td>
</tr>
<tr>
<td>Ever received any vocational services or job training after high school</td>
</tr>
<tr>
<td><strong>Bullying victimization</strong></td>
</tr>
<tr>
<td>47%</td>
</tr>
<tr>
<td>of youth were victims of bullying during high school</td>
</tr>
</tbody>
</table>
HIGH SCHOOL TRANSITION SERVICES

As mentioned in the Pre-K-12 Education section of this report, school systems are required to begin including transition services in a student’s Individualized Education Program (IEP) beginning at age 16. Stakeholders interviewed as part of this assessment project commonly expressed dissatisfaction with at least one or more components of the high school transition and/or adult services available in the Capital Region - a sentiment that appears consistent with available national outcomes research results for the transition to the young adulthood period.

This dissatisfaction is also consistent with the shock families across the U.S. commonly experience when the special education support services provided through high school abruptly come to an end due to the lack of an intellectual disability – a basic requirement to qualify for many adult special support services.
LOUISIANA REHABILITATION SERVICES

Louisiana Rehabilitation Services (LRS) is a state office of the Louisiana Workforce Commission that "assists persons with disabilities in their desire 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." Programs offered by LRS include independent living support, vocational rehabilitation services, and employer placement services.

INDEPENDENT LIVING PROGRAM
The Independent Living program "allows individuals to have the option to choose to live or remain in their home or community setting, with emphasis on community based supports and services. This includes such services as information and referral sources, independent living skills training, peer support, system and individual advocacy, and other independent living services."

To be eligible for this program, individuals:

- Must have a significant physical, mental, cognitive or sensory impairment that impedes or substantially limits their ability to function independently in the family or the community; and
- Must be able to benefit from independent living services by improving their ability to function, continue functioning, or move toward functioning independently within the family or the community.

In Baton Rouge, the LRS Independent Living Center is located at 3233 South Sherwood Forest Blvd., Suite 101A (225) 753-4772. Applications for Independent Living services must be submitted through this office. Determinations regarding Independent Living benefits are made by the Independent Living Center’s Independent Living Specialist. Medical documentation is helpful, but applicants do not need documentation in hand to apply for benefits. The Independent Living Center works with all types of disabilities, including Autism. The type of benefits and services provided are individualized depending on the individual’s need for services.

LRS administers support services for independent living through a 90% federal-10% state match program. The 10% state match funds do not necessarily have to come from the State. In fact, local tax dollars, donations from a nonprofit organization, or other types of funding can also serve as the state match. Each year, Louisiana receives a notice of the State’s Independent Living program grant award from the federal Department of Health and Human Services (DHHS) based on a formula that takes into account population and per capita income. The amount of the grant is based on a formula determined by DHHS. Louisiana is currently drawing down the maximum amount of Independent Living funds available. During the 2014-15 Fiscal Year, 4,783 individuals received Independent Living services, which include the five core services.

More information about LRS’ Independent Living Program can be found at http://www.laworks.net/WorkforceDev/LRS/LRS_Living.asp.

130 ibid
131 When a plan for Independent Living services is completed on an individual, a medical diagnosis from the attending doctor is obtained. That diagnosis forms the basis for this determination.
132 Louisiana Workforce Commission, Louisiana Rehabilitative Services, Independent Living Program available online at www.laworks.net/WorkforceDev/LRS/LRS_Living.asp.
VOCATIONAL REHABILITATION SERVICES

Vocational Rehabilitation Services "provides comprehensive rehabilitation services that go far beyond those found in routine job training programs. This frequently includes work evaluation and job readiness services; assessment for and provision of assistive technology, such as customized computer interfaces for persons with physical or sensory disabilities; job counseling services, and medical and therapeutic services."\(^{133}\)

Applications are accepted at the time an individual with a disability reaches or nears the minimum age of legal employability. To be eligible for this program, the individual must:

- Have a physical or mental disability which for the individual constitutes or results in a substantial impediment to employment; and
- Be able to benefit from vocational rehabilitation services in terms of employment; and
- Require vocational rehabilitation services to prepare for, enter, engage in, or retain gainful employment.\(^{134}\)

Since 1988, this program has been administered by Order of Selection - meaning that priority for services must be given to citizens in Louisiana with the most significant disabilities.\(^{135}\)

Funding for Vocational Rehabilitation services requires an approximately 20% state match in order to draw down federal funds. Because the Louisiana Workforce Commission has been unable to provide adequate state matching funds during the past several fiscal years, the agency has been forced to leave significant federal dollars for vocational rehabilitation services on the table. For any given year, if Louisiana fails to draw down a portion of the total amount awarded to the state by the federal government, those dollars are re-allocated and lost to Louisiana forever; they cannot be carried over to the following year.

The following is an excerpt from the Louisiana Legislative Auditors’ report on LRS issued in March 2015.

**Funding**

The Vocational Rehabilitation Program is funded with 78.7% federal funds. The state provides 21.3% of funds through the state General Fund, local government funds from school districts that contract with LRS to provide vocational rehabilitation services, and funds from other entities such as nonprofits that contract with LRS to provide vocational rehabilitation services. Total federal funding available for Louisiana in federal fiscal year 2014 was $53.1 million. However, since LRS contributed only $8.1 million as the state share, it only received approximately $35.5 million of federal contributions. According to LRS, since the state did not appropriate more funding for the state’s share, LRS was not able to draw down the remaining $17.6 million available in federal contributions. LRS has been unable to use all allocated federal funds each year for the past four fiscal years.\(^{136}\)

\(^{133}\) Louisiana Workforce Commission, Louisiana Rehabilitative Services, Vocational Rehabilitative Services Program website, available online at [www.laworks.net/workforceDev/LRS/LRS_Rehabilitation.asp](http://www.laworks.net/workforceDev/LRS/LRS_Rehabilitation.asp).

\(^{134}\) Ibid.

\(^{135}\) Ibid.

In Fiscal Year 2014-15, the situation worsened. Louisiana failed to draw down approximately $19.1 million in additional federal funds due to a lack of state match funds. As of November 30, 2014, there were 12,672 individuals receiving vocational rehabilitation services and 137 individuals on the waiting list to receive services. The situation is not projected to improve for 2016. Out of a total state award of $55.2 million, LRS officials report that Louisiana will likely draw down approximately $32 million, leaving over $21 million on the table.

The Louisiana Workforce Commission administers the federal regulations of the Workforce Innovation and Opportunity Act (WIOA), which places a new emphasis on high school transition services for special education and Section 504 students. For several years, LRS has been entering into third-party agreements with parish school systems (for example, Grant Parish) to hire transition program coordinators. Federal WIOA funds pay 80% of the transition coordinator cost and the parish school system provides the 20% funding match. However, no school systems in the Capital Region are currently utilizing this resource. Leadership from LRS reported that several years ago, contact was made with the Special Education Director of the East Baton Rouge (EBR) Parish Public School System regarding the opportunity for this type of third-party cooperative agreement for transition services. However, the EBR Parish Public School System did not pursue the opportunity. LRS is still actively pursuing opportunities to provide pre-employment transition services (PETS) to students in public high schools, including those in EBR Parish, through cooperative arrangements with fee-for-service providers or by placing LRS counselors in the schools.

As evident by the numbers described above, LRS administrators interviewed as part of this assessment project confirmed that Louisiana does not draw down the full amount of available federal funding for Louisiana Rehabilitation Services programs due to lack of state match dollars.
**EMPLOYER SERVICES**

Employer Services "offer[s] a cost-effective alternative to advertising for job candidates and can save employers time and money. LRS offers placement services for job ready individuals to help employers achieve their goals."\(^{137}\) This program matches qualified vocational rehabilitation program participants with employers.

The LRS services offered to businesses include:

<table>
<thead>
<tr>
<th>Employment Services</th>
<th>Personnel Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Prescreening of applicants based on essential job requirements</td>
<td>• Recruiting</td>
</tr>
<tr>
<td>• On-site job trainer and support services</td>
<td>• Affirmative action planning</td>
</tr>
<tr>
<td>• Job restructuring/work site adjustment</td>
<td>• Work force diversity consultation</td>
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<tr>
<td>• Accessibility survey of complete work site</td>
<td>• Reasonable accommodation support</td>
</tr>
<tr>
<td>• Assistive technology; devices and specialized equipment to assist in job success</td>
<td>• Employee assistance and/or advisory program</td>
</tr>
<tr>
<td>• Follow-up services</td>
<td></td>
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</tbody>
</table>

**Financial Incentives**

- **Job Retention** - Minimize the cost of training new employees by maintaining valued workers who have become disabled through work-related injuries.

- **Business Tax Incentives** - If you own or operate a business, you should be aware of two tax incentives for hiring workers with disabilities:
  - **Deduction for Removal of Barriers** - You may be eligible to deduct expenses for making a facility or vehicle used in your business more accessible to persons with disabilities.
  - **Accessibility Credit** - An eligible small business which pays or incurs expenses for providing access to persons with disabilities is allowed a tax credit.\(^ {138}\)

\(^{137}\) ibid

\(^{138}\) Louisiana Workforce Commission, Louisiana Rehabilitative Services, Employer Services webpage available online at [www.laworks.net/WorkforceDev/LRS/LRS_EmployerServices.asp](http://www.laworks.net/WorkforceDev/LRS/LRS_EmployerServices.asp)
The Program for Successful Employment (PSE) at Bossier Parish Community College was started in January of 2014. PSE is a two-year vocational program for adults with cognitive disabilities and/or ASD. The program combines academic and job skills training on BPCC’s campus and in regional businesses. By the end of the program, students find paid employment in a job focused on their interests and strengths.

The program’s operations are funded through LRS via a school-sponsored local match (~23%) with federal funding (~78%). Additionally, PSE received funding from A Kid’s Choice Foundation to offer a specialized vocational literacy class to PSE students to increase their reading levels and better prepare them for the workplace. PSE is based on standards and benchmarks outlined at thinkcollege.net.

First-year students participate in job sampling with employers in the area and soft skills training. After completing the first year, students accept a full-time job, take courses for credit at the community college, or continue on with support from the program. All students leave the program with a certificate and, if applicable, an industry specific certificate (i.e., culinary arts). Classes are currently limited to 10-15 students and application requirements are outlined on their website. More information can be found at www.bpcc.edu/pse.
TRANSITION AND ADULT RESOURCES IN THE CAPITAL REGION

The following is a sampling of resources available in the Capital Region for adults and those transitioning from high school to the adult world. More information about each of the organizations can be found in the Key Providers and Organizations in the Capital Region section of this report.

- Capital Area Human Services District
- Community Opportunities - The Arc of East Ascension
- Gateway Transition Center, Inc.
- Port City Enterprises
- The Arc of Baton Rouge
- Volunteers of America Greater Baton Rouge
POST-SECONDARY EDUCATION SUPPORT SERVICES IN THE CAPITAL REGION

The following is a list of support services available at Capital Region institutions of post-secondary education.

## LOUISIANA STATE UNIVERSITY OFFICE OF DISABILITY SERVICES

Louisiana State University Office of Disability Services (LSUODS) is a university office whose mission is to provide appropriate auxiliary aids, services, and support programs for students with disabilities in an effort to increase the quality of the learning and living environment, diversity, inclusiveness of the university, and effectiveness of programs and services that support student success.

LSUODS assists students in becoming self-advocating, high achieving, and productive members of society, works with LSU administration on the development and revision of policies and procedures relevant to students with disabilities, and serves as a resource for disability-related information for the campus community. Services provided by LSUODS include intake, assessment of needs on campus, and facilitation of auxiliary aids and services when appropriate.139

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## SOUTHERN UNIVERSITY OFFICE OF DISABILITY SERVICES

Southern University Office of Disability Services (SUODS) is a university office that assists students in meeting their unique academic/educational, personal, vocational, and social needs that would otherwise prove to be an obstacle to educational pursuits. SUODS provides academic accommodations to students on the basis of documented disabilities including large print handouts, interpreters, extended time for examinations, scribes, academic counseling, audio taping, and note takers.140

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## OUR LADY OF THE LAKE COLLEGE OFFICE OF STUDENT SERVICES

Our Lady of the Lake College Office of Student Services (OLOLOSS) is a college office that is committed to providing a holistic approach to personal, academic, and career counseling for students. In addition, OLOLOSS is dedicated to promoting the self-advocacy of students and is committed to working with the College Administration in the development and revision of policies and procedures relevant to student life at the College. Services provided through OLOLOSS include counseling services, disability accommodations, career counseling, academic counseling and peer tutoring, and student development services.141

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139 For more information, visit the LSUODS website at http://students.lsu.edu/disability.

140 For more information, visit the SUODS website at http://www.su.edu/index.cfm/page/13/n/29.

141 For more information, visit the OLOLOSS website at http://www.ololcollege.edu/catalog/Student_Support_Services.html.
Baton Rouge Community College Office of Disability Services (BRCCODS) is a college office that ensures equal access to all campus programs and activities and promotes full participation in campus life for individuals with disabilities. Services offered by BRCCODS are provided collaboratively to empower students to advocate for themselves and assume responsibility for their academic outcomes and personal goals. Accommodations provided include extended time for in-class assignments and examinations, consideration for absences, tape recorded lectures, readers, scribes, distraction reduced environments, test taking alternatives, note takers, and communication facilitators.142

River Parishes Community College Office of Counseling Services (RPCCOCS) is a college office that coordinates academic accommodations for students with disabilities. RPCCOCS is dedicated to service excellence in the provision of comprehensive and flexible accommodation plans that contribute to the successful academic endeavors of qualified students who have disabilities. Accommodations are provided for students who document an evidence of a physical disability or systemic illness, deafness or hearing deficiency, blindness or visual impairment, psychological disability, Attention Deficit/Hyperactivity Disorder, specific learning disability, or temporary medical condition.143

142 For more information, visit the BRCCODS website at http://www.mybrcc.edu/disability_services/.

143 For more information, visit the RPCCOCS website at http://www.rpcc.edu/uploads/documentationGuidelines.pdf.
These institution-centric support services, although valuable, must be successfully navigated, which can be difficult and/or intimidating for some students and their families. It is the responsibility of the student to ensure the accommodations are met, which includes having the appropriate paperwork outlining their specific needs. Additionally, students with an ASD diagnosis often need support above and beyond traditional post-secondary disability services. Anecdotally, parents and young adults with autism shared that the services provided at post-secondary institutions in the Capital Region are hard to access, often inadequate, and do not help students achieve their full potential.

Post-secondary institutions recognized for their support services for students with an ASD diagnosis were listed in a 2011 article, “10 Impressive Special College Programs for Students with Autism.” No Capital Region schools were included in this list.144

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SPOTLIGHT: THE UNIVERSITY OF ALABAMA, ASD COLLEGE TRANSITION AND SUPPORT PROGRAM (UA-ACTS)

“The UA-ACTS program provides individualized services to help students develop appropriate skills for self-advocacy, daily living, and social interactions that will contribute to their success as an independent adult. UA-ACTS seeks to provide support for the transition into a large, traditional university campus and to guide students towards achieving their goals for the future. Also, the program seeks to promote awareness and understanding of ASDs throughout the campus community through education, training, and collaborations with University programs, faculty, staff, and students.”

Additionally, the program interacts with other campus offices that offer supportive services, including Office of Disability Services (ODS), Center for Teaching and Learning (CTL), and Residential Life.

The UA-ACTS program was started in 2006 and today serves approximately 20 students during any given semester. Students must apply to be part of the program and are selected for enrollment after interviewing with UA-ACTS staff. Currently, the program, which is housed within the university’s Psychology Department, is run by 4-5 full-time staff members, including a program director who is a licensed clinical psychologist, an assistant program director with a PhD, two graduate clinical psychologist students, and 10-15 undergraduate volunteers. The program includes therapist-mentors who meet with each UA-ACTS student three times per week to provide services in academics, social skills, and daily living. Mentors also work throughout the students’ time in the program to help students identify career interests, write resumés, and prepare for interviews. Mentors also speak with students’ family member contact each week to update the family on any issues that might affect the student’s enrollment in the program or academic progress. The UA-ACTS program brochure lists the following specific activities for UA-ACTS students:

ACADEMICS

• One session per week focused on academics, including organization and planning of study time, using classroom attendance efficiently, prioritizing of assignments, preparation for exams, etc.

• Regular communication with instructors, including monthly progress reports and individual meetings as needed regarding student strengths and weaknesses in the classroom.

• Guidance to help students become self-advocates to ensure academic success, including requesting appropriate accommodations from ODS and using campus services, such as the CTL writing center and math lab.

145 The University of Alabama, ASD College Transition and Support Program website, https://autism-clinic.ua.edu/uaacts/
SOCIAL AND DAILY LIVING SKILLS

- One session per week focusing on the social aspects of college life, including interacting with instructors and classmates, roommates, dating, etc.

- Regular communication with parents/caregivers regarding their student’s progress and relevant concerns, including monthly update letters.

- Weekly “check ins” for daily living skills, including meeting in the dorm room and checking for cleanliness, etc.

- Assisting students with the skills needed to find jobs after college (e.g., finding work-related experiences while in college, interview skills, accessing campus resources related to job-finding).

- Regular contact with residential life personnel, including RAs, dorm director, etc. to give information about ASD, provide support and education, and obtain information about needs in the dorm setting.

- A representative from the program is on call in case of an emergency. This number is available to only parents and students.

EMOTIONAL AND PSYCHOLOGICAL WELL-BEING

- Provision of counseling services as needed to identify appropriate coping strategies to manage symptoms of anxiety and/or depression.

- Consultation with psychiatrists on campus for students and families who would prefer that psychiatric medications be managed locally.146

The UA-ACTS program does not receive any university or other state funding. It is funded solely by enrolled student fees. The current fee is $3,600 per semester, excluding the summer semester, which costs slightly less.

146 For more information on services, visit the UA-ACTS Program Brochure available online at www.autism-clinic.ua.edu/uaacts/UAACTSbrochure.pdf.
FUNDING FOR POST-SECONDARY PROGRAMS

Students with intellectual disabilities, including autism, can receive federal grants to attend approved programs at colleges and universities throughout the United States. Students at these “Comprehensive Transition and Post-Secondary (CTP)” programs focus on academic, vocational and independent living skills. These programs are designed to support students with intellectual disabilities who want to continue academic, career, and independent living instruction to prepare for gainful employment. Students in the programs must participate, for at least half of the program, in regular enrollment courses with non-disabled students or participate in an internship or work-based training with non-disabled students.

Funding for these programs is directed through the Federal Pell Grants, Federal Supplemental Educational Opportunity Grants, and Federal Work-Study programs. In order to qualify for one or more of these grant opportunities, an individual must:

- Be enrolled or accepted in an approved Comprehensive Transition and Post-Secondary Program for students with intellectual disabilities at an institution of higher education (a college or career school) that participates in the federal student aid programs;

- Maintain satisfactory academic progress; and

- Meet the basic federal student aid eligibility requirements, except that the student is not required to have a high school diploma or GED and is not required to be pursuing a degree or certificate.

Today, 39 colleges and universities across 16 states have schools that offer CTP programs. Notably, not a single Louisiana college, university or vocational/career school offers a CTP program.

In fact, the closest states with a CTP program are Georgia (Kennesaw State University in Kennesaw, GA) and Florida (Southeastern University in Lakeland, FL and Florida Panhandle Technical College in Chipley, FL). The U.S. Department of Education has issued guidance to assist colleges and universities with launching a CTP.

147 A full description of CTP programs, including a list of existing programs, is available online at https://studentaid.ed.gov/sa/eligibility/intellectual-disabilities#ctp-programs.

148 http://www.thinkcollege.net/topics/becoming-a-comprehensive-transition-program.
SPOTLIGHT: UNIVERSITY OF LOUISIANA AT LAFAYETTE LEARNING IS FOR EVERYONE (UL LIFE) PROGRAM

The UL LIFE program is a highly personalized program for young adults with intellectual disabilities. By combining academic, social, and career development skills at the college level, young adults with intellectual disabilities can become thriving members of the community.

The UL Life program offers a two year Basic program that incorporates functional academics, independent daily living skills, employment, social/leisure skills, and health/wellness skills in a public university setting with the goal of producing self-sufficient young adults. In addition, the UL LIFE program offers a four year Advanced program for students who have demonstrated the ability to safely navigate certain areas on campus independently, sustain employment, and socially integrate during the Basic program. The Advanced program progresses with an emphasis on workplace experience, community integration, and independent academic time with transitionally reduced support. Students who successful complete the Basic or Advanced program receive a corresponding certificate of post-secondary completion.

The UL LIFE program has three major components: academic growth, career development, and community involvement.

ACADEMIC GROWTH
LIFE students participate in functional academic classes within the LIFE program as well as audit general university courses in their area of interest. Students audit at least two university courses per semester.

CAREER DEVELOPMENT
All LIFE students receive career instruction throughout their time in the program. Students begin their first semester by taking a career exploration course taught by LIFE staff. All LIFE students will begin an on-campus internship their fourth semester accompanied by a job coach.

COMMUNITY INVOLVEMENT
LIFE students are required to spend a certain amount of time each month outside of school volunteering, taking classes, or participating in community events.

Acceptance to the UL Life program is based on an individual’s academic, social, communication, and career needs. The program accepts four students per year.

The program is currently working to become a CTP program. For more information, visit: http://academicaffairs.louisiana.edu/initiatives/ul-life-program.
SPOTLIGHT: UNIVERSITY OF SOUTH CAROLINA, CAROLINA LIFE PROGRAM

The University of South Carolina’s CarolinaLIFE program is a college-based, inclusive, certificate program for students with diverse learning needs. The goal of the program is to “support[] students in reaching their personal goals and prepare[] them to become productive community members by providing inclusive and individualized experiences in academics, employment, independent living, and community involvement.” Students enrolled in the program receive experiences in four main areas: academics, employment, independent living, and community life. Students live in university housing and participate in all aspects of student life in order to better prepare them for adult life within the community.

Academics
Students take 15 credit hours of coursework each semester, which includes auditing regular university classes as well as taking CarolinaLIFE classes that provide small-group instruction on subjects like personal finance and career exploration. Students must also participate in at least three hours of individual academic lab sessions each week with an academic coach.

Employment
Students take classes in career exploration and skill development, and starting sophomore year, are required to either work or intern at a jobsite with support from a job coach, if needed.

Independent Living
Students live on campus in apartment-style housing with other university students. CarolinaLIFE resident mentors work throughout the week to help students with independent living skills and provide assistance with transportation, laundry, budgeting, shopping, and cooking.

Community Involvement
Students are encouraged to participate in university student organizations and social events. Social mentors are available to students who want additional support accessing the campus and community.

Students applying to the CarolinaLIFE program do not need a regular high-school diploma. A non-academic track diploma (certificate of achievement) or certificate of attendance is sufficient. The student must be 18 to 23 years old (or in the last year of a public school program), have a cognitive assessment with documented intellectual disability, and demonstrate interest and desire in pursuing educational, employment, and life experiences through post-secondary education. The cost of the CarolinaLIFE program, including housing, is approximately $16,000 per semester for a non-South Carolina resident. However, because the program has been approved as a CTP program, a number of financial assistance options are available for students, including South Carolina Vocational Rehabilitation (up to $1,850/semester); Federal Pell Grant, Work-Study and Federal Supplemental Education Opportunity Grants (up to $5,500/year), and College Transition Connection SC Need-Based Grants (up to eight semesters of funding).
SPOTLIGHT: THE OHIO STATE UNIVERSITY TRANSITION OPTIONS IN POSTSECONDARY SETTINGS (TOPS) PROGRAM

The TOPS Program at The Ohio State University is a certified Comprehensive Transition and Post-secondary (CTP) program that offers individuals ages 18 and older with both an intellectual and developmental disability a unique opportunity to engage in Ohio State academic coursework and work experiences while developing independent living skills and participating in campus and community organizations, social activities, and events. The program offers two tracks - a 2-year or 4-year certificate program - that focus on four basic transition areas: Academics, Employment, Independent Living, and Self-Determination & Student Development. The TOPS program is not a degree granting program but rather a catalyst for employment and/or a bridge to degree granting programs.

The 2-Year Certificate of Completion Track is a 60-hour program for students who seek to obtain basic transition skills in preparation for enrolling in a degree program, or for students who want to focus primarily on professional employment skills. Over the course of the program, students construct an electronic portfolio - a multi-media presentation that is eventually given to employers to assist students in marketing their skills in a specific job cluster. The portfolio contains elements that depict the knowledge and skills of each student. The 4-Year Generalized Studies Certificate Track is a 120-hour program for students who wish to gain general knowledge of and professional employment skills in a specific career cluster.

- The Academics program of each of the two tracks focuses on academic access and lifelong learning through auditing Ohio State inclusive courses and program Student Learning Communities that support students' personal and career goals. Students may also choose to enroll in credit-bearing courses at Columbus State Community College (CSCC). Each student can enroll in up to two inclusive courses (or four credit hours) per semester. Students are supported by: (1) a full-time TOPS Educational Advisor, who coordinates with university faculty and academic advisors, assists students with course selection and sequencing, and evaluates/monitors student performance on a weekly basis, and (2) TOPS Educational Coaches, trained OSU interns whose responsibilities include providing students with support and accommodations as necessary. TOPS students can also take advantage of the TOPS Academic Center for study and goal-planning needs.

- The Employment program area focuses on career development and job readiness through unpaid and paid internships using a Project SEARCH model, with the goal of obtaining and sustaining competitive, permanent employment. Students participate regularly in job fairs, job shadows, informational interviews, and job search classes. Employment experiences are aligned with student interests, skills and goals as closely as possible; initial placements place a stronger focus on learning/enhancing soft skills. TOPS students typically engage in internships that are 3-15 weeks long, and 8-15 hours per week. Students are supported by: (1) a Disability Career Specialists, whose responsibilities include job development, on-the-job training and supports, training for job sites and stakeholders, and reporting, and (2) TOPS Job Coaches, who provide on-the-job training and supports to students.

149 Intellectual disability is defined as a disability characterized by significant limitations both in intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. Intellectual disability is one type in a larger universe of many types of developmental disabilities (American Association on Intellectual and Developmental Disabilities, 2013).
• The **Independent Living** program area focuses on activities in which students learn and practice skills required to live independently, make healthy choices, and socialize successfully. The program area also focuses on campus membership and support for participation in campus and community organizations, activities and events. Some TOPS students choose to commute, while others live in off-campus university apartments. The program is currently working to secure on-campus dormitory housing for TOPS students. Students are supported by: (1) a TOPS Residential Coordinator, whose responsibilities include facilitating social activities for TOPS students, teaching independent living skills, and engaging in active recruitment, and (2) TOPS Social Coaches, trained OSU interns who provide support during TOPS social activities.

• The **Self-Determination & Student Development** program area focuses on advocacy and community service through student-directed, person-centered planning, mentoring, and volunteering. Students are in charge of scheduling and running their Person-Centered Planning (PCP) Meetings, where they meet with various stakeholders to review progress, develop goals and actions steps, as well as identify necessary supports. Students also develop Self-Advocacy Plans in preparation for their PCP meetings, which serves as a summary of their personal characteristics, program experiences, and transition goals.

The TOPS program currently serves 12 students, but can and hopes to grow to 50 students in the near future. Approximately half of those 12 students have a diagnosis of ASD. Tuition for the program is approximately $15,000/year. However, because the program has been credentialed by the U.S. Department of Education as a CTP, students eligible for financial aid such as Pell grants or Federal Supplemental Educational Opportunity grants can use those funds to offset tuition costs.

With no CTP Program located in Louisiana or any of the surrounding states, universities and community colleges in the Capital Region have a unique opportunity to launch this type of program and attract students with various types of intellectual and developmental disabilities from a wide geographic area. Robust coordination between each university’s disability/student services offices, admissions offices, and student-aid offices will be necessary to design and launch a CTP program. There should also be open communication and coordination among institutions since one can envision a CTP program that includes both community and technical college courses and services, as well as university courses and services.

With federal grant dollars available to help students access these valuable CTP programs to better prepare them for independent living and employment, Capital Region post-secondary institutions should respond with opportunities.

PROGRESSIVE EMPLOYER EXAMPLES

Gaining reasonable access to appropriate internships, jobs and careers is a challenge for many adults on the spectrum. Even with a completed credential (high school, college, or vocational training), individuals with an ASD diagnosis often have difficulty obtaining and maintaining employment. Part of this difficulty stems from a fear of employers that an individual with an ASD diagnosis may be an imposition or a safety hazard. Often, employers are not aware of the benefits of hiring an individual with an ASD diagnosis such as the ability to maintain extreme focus in the workplace, a perfectionist attitude towards their work, and a diversity in problem-solving that can support innovation.

The federal government has made efforts to address this situation by creating both mandates and incentives to hiring disabled employees. In 2013, the Department of Labor updated regulations to Section 503 of the Rehabilitation Act of 1973 to require that federal contractors set a goal of having people with disabilities make up at least 7% of their workforce. In addition, the Internal Revenue Service offers a Work Opportunity Credit that provides eligible employers with a tax credit of up to 40% of the first $6,000 of first-year wages provided that an employee has been certified as disabled.

The following are a few examples of large companies that have chosen to embrace the workforce potential that individuals with ASD offer.

- Walgreens

Walgreens, one of the largest drugstore chains in the United States, has introduced an innovative program that hires people with disabilities, including individuals with an ASD diagnosis, and allows them to work as equals with people without disabilities and enjoy the same benefits and opportunities for advancement. At the Walgreens distribution center in Anderson, South Carolina, 42% of the 275 employees have a disclosed disability. Walgreens managers have worked to improve workstation designs to make jobs easier for both disabled and non-disabled workers. As a result, the company has experienced an overall 20% higher rate of efficiency across the site.

- The Federal Home Loan Mortgage Corporation (Freddie Mac)

The Federal Home Loan Mortgage Corporation (Freddie Mac), the government-sponsored mortgage loan company, partners with The Autistic Self Advocacy Network to hire interns and college graduates for jobs in IT, Finance, and Investments & Capital Markets. Freddie Mac has also adopted a policy stating, “Harnessing the unique skills of people on the autism spectrum has the potential to strengthen our business and make us more competitive.”


• **SAP**

SAP, the multi-national software corporation, has partnered with Specialisterne, a Denmark based company that helps people with ASD find employment, to create a hiring program called Autism at Work. Autism at Work participants have been found to excel at innovating and creating new products and improving the quality of existing products. SAP has a goal of having 1% of its entire workforce comprised of employees with an ASD diagnosis.154

• **Microsoft**

Microsoft, a multi-national technology company, has also partnered with Specialisterne to start a pilot program to hire people with autism in full-time positions in their corporate headquarters. The program launched in May of 2015 and began with 10 full-time positions. The company is invested in increasing the diversity of its workforce and intends to expand the program in the future.

While these large employers should be commended for their efforts, smaller, local businesses can also successfully employ people with an ASD diagnosis. In Parkland, Florida, a father and son co-founded a car wash dedicated to the empowerment of individuals with autism. The car wash has been wildly successful with 100% customer satisfaction and impressive efficiency. The company washes 500 cars per day (equating to 150,000 per year) and has 92 associates with an autism spectrum disorder diagnosis. The car wash is scalable and has been replicated in communities around the country. For more information, visit: [www.risingtidecarwash.com](http://www.risingtidecarwash.com).

In Princeton, New Jersey, the Hyatt Regency Princeton joined with Eden Autism Services, a local nonprofit engaged in educating individuals with autism and training family members, professionals, and educators in best practices, to place Eden’s participants at the hotel, working under the supervision of job coaches. The hotel’s General Manager, was amazed at how the experience served not only the employees with autism, but engaged all of the hotel’s employees and enriched the entire work culture: “There’s a certain pride of ownership that happens - a pride in seeing the development in these individuals. The growth is clearly evident and it makes everyone feel good... People with disabilities, including autism, can be very dependable employees. They’ve never been given a chance, and when they are, they’re very loyal.”155

And in Marysville, Ohio, UCO Industries, a 501c3 providing employment services to people with developmental disabilities, partnered with Honda to become a Tier 1 Supplier for Honda vehicle owner manual kits.156 The organization’s approximately 125 employees, 70-80 of whom have a developmental disability, assemble the owner manuals and provide them to all of Honda’s plants in North America for distribution. In 2015, employees at UCO produced nearly 1.5 million manuals for distribution. Employees with developmental disabilities are provided with additional support as needed, including counselors and therapists.


A COMPREHENSIVE TRANSITION SERVICES MODEL

Having invested much time and resources into ensuring their child receives the most effective and appropriate education in high school, many parents unfortunately find themselves back at square one when their young adult turns 18 and/or completes high school. In Baton Rouge, as in many other small and medium-sized towns throughout the U.S., there are very few support services available to help young adults on the spectrum and their families navigate the challenges of post-secondary education, career development and job placement, and/or independent living.

Employers across the country, large and small, have proven that young adults on the autism spectrum bring unique skills and talents to the workplace that can add tremendous value not only to an employer’s business culture, but also to its bottom line. However, today in Baton Rouge, these young adults are often forced to move back in with their parents, navigate post-secondary education programs on their own or not at all, and miss out on valuable opportunities to utilize their unique skills in the workplace.

COLLEGE LIVING EXPERIENCE (CLE)

In February of 2015, staff from the Baton Rouge Area Foundation travelled to Denver, Colorado to meet with leadership and students from College Living Experience (CLE). CLE is a for-profit organization that has been providing post-secondary supports to students with autism, Asperger’s Syndrome, ADHD, and other varying exceptionalities since 1989. Today, CLE operates at six locations throughout the country (Denver, Colorado; Austin, Texas; Costa Mesa and Monterey, California; Washington, D.C.; and Fort Lauderdale, Florida).

Most students who enroll at CLE have received a high school diploma or certificate, are interested in pursuing some type of 2- or 4-year academic or vocational degree and/or job training program, and have the capability – with support – to live and work independently. The CLE team at each location offers services to students in four primary areas: academics, independent living, social skills, and career development. Students, and their families, are supported by a full-service support team that tailors the array of services to each student’s unique needs and capabilities.

Academics

Through partnerships with numerous local community colleges, 2- and 4-year colleges, and technical/vocational programs, students at CLE, with guidance from CLE staff, are able to enroll in a program that best suits their educational needs. CLE pulls together the needed resources:

- Individual and group content-specific tutoring by trained professional staff
- Instruction across environments, including on campus, community, and CLE’s quiet tutoring and study hall rooms
- Coaching in self-advocacy
- Support in executive functions that impact learning including time management, organization, planning, and prioritizing
- Anonymity for students wanting to avoid peers knowing their disability
- Regular parent communication to keep abreast of updates and challenges that cannot be accessed through direct campus communication

For more information about College Living Experience, visit www.experiencecle.com.
Career Development
Through partnerships with local employers, CLE is able to place students in internships and part-time or full-time jobs that fit the student’s interests and skills. An individualized employment path is developed for each student, and CLE’s services include everything from job coaching to soft and hard skill instruction, support at building a resume, job searching, and education on community awareness. The CLE career development team works closely with students and community employment partners to provide appropriate opportunities, including:

- Volunteer placement
- Job shadowing
- Paid or unpaid internships
- Part-time and full-time employment

Independent Living
Students at CLE also master the skills required to live independently during their college transition program. More importantly, they acquire the judgment to make sound decisions about daily life, including budgeting, keeping their apartment in order, and shopping for themselves. In Denver, students live in an apartment building located adjacent to the CLE office and local community college campus in downtown. Students live with a roommate, and an RA on each floor checks in on students as needed. CLE staff also work with each student one-on-one as needed to ensure they develop the skills of financial management, personal hygiene, health and wellness, and navigating public transportation. From grocery shopping to managing a bank account, CLE students are guided through each step of their transition to independence.

Social Skills
Finally, CLE’s support team provides opportunities for students to be comfortable in and even thrive in social situations so that students can develop appropriate, fulfilling relationships with peers and adults and apply these skills to experience success in academic, independent living, and career development settings. CLE staff facilitate a variety of social activities every week that are geared toward developing specific social skills, in a real world setting, while having fun at the same time. Activities range from cultural performances, local entertainment and attractions, to just eating out or seeing a movie.
AT A GLANCE: CLE DENVER, COLORADO PROGRAM

**Location**
Downtown Denver, centrally located three blocks from University of Colorado at Denver, Denver Community College, and Metropolitan College of Denver, and one block from CLE independent living apartment complex and multiple public transportation options

**Student Body**
Approximately 40 students from throughout the United States and the world

**Admissions**
Rolling admissions process; nine of ten students who apply are accepted

**Average Duration of Program**
Three to four years

**Partner Institutions**
Community College of Denver, Metropolitan College of Denver, University of Colorado at Denver, University of Denver, Regis University, Colorado Christian University, Art Institute of Colorado, Emily Griffith Opportunity School, Community College of Aurora, Arapahoe Community College

**Staff**
Approximately 10-15 part-time and full-time staff members, including Director Sharon Heller and Coordinators for each of the four service areas (Academics, Career Development, Independent Living, Social Skills)

**Cost**
$43,500/year for residential CLE services and $32,500 for non-residential services. This cost does not include costs of approximately $1,800/month for housing, money for social and extracurricular activities, or cost of tuition for academic or vocational programs. With these expenses, the total cost could reach up to $55-60,000/year. New students require a $75 application fee and a one-time new student fee of $1,500. CLE does not receive insurance or Medicaid reimbursement for services, but some families do receive financial assistance through state vocational rehabilitation programs.
**CLE SUMMER PROGRAM**

In addition to the year-round, full-time CLE program, CLE also offers pre-college programs during the summer months for high school students. Various programs and camps, ranging from a few days to several weeks, are offered at CLE campuses throughout the country. In Austin, Texas, for example, CLE offers a 5-day Game Design Camp designed to give students an opportunity to participate in the exciting production of their own video game while developing personal and team participation skills. The cost of the program is $1,500 and space is limited to 15 students. CLE also offers 2-week summer career exploration camps at several locations. These programs are designed to help students prepare for future employment and gain real world work experience. Students are placed in a number of volunteer positions and receive job coaching while having fun with their peers.

More information about CLE’s summer programs is available at [http://experiencecle.com/enrichment-programs-for-teens/](http://experiencecle.com/enrichment-programs-for-teens/).

**INDEPENDENT LIVING EXPERIENCE (ILE)**

The Independent Living Experience (ILE), currently operating in seven states, is a sister company of CLE whose main goal is to aid young adults in developing skills needed to find and maintain employment, live independently, and create social networks. ILE helps clients develop skills to secure and maintain housing, manage money and finances, search for and apply for jobs, prepare for interviews, and make and maintain personal relationships. In addition, ILE works with local employers to develop strategies to hire, train, evaluate, accommodate, and maintain employees with disabilities. Typically, ILE programs can be implemented when as few as three to five individuals in a region request the service. The cost for ILE is $6,000 for a contract that includes 100 hours of supports and services. The supports are meant to be flexible and serve the client according to their current needs. In some cases, clients will go through hours very quickly due to a change in life such as a new living space, changing/getting a job, or some type of personal crisis. ILE staff will incorporate virtual supports for clients who may not have an immediate social network in order to expose them to the opportunity to develop friendships.

More information about ILE is available at [www.independentlivingexperience.com](http://www.independentlivingexperience.com).
A CLE/ILE-TYPE COMPREHENSIVE TRANSITION SERVICES MODEL IN SOUTH LOUISIANA?

Baton Rouge Area Foundation staff has discussed with CLE leadership the possibility of bringing CLE and ILE to South Louisiana. Ongoing conversations suggest that CLE leadership is very interested in bringing its programs to South Louisiana. During these preliminary conservations, CLE staff has highlighted three critical areas in evaluating whether a geographic area could support a CLE program:

1. Strong post-secondary institutions such as community colleges, 2 and 4-year colleges and technical colleges who are willing to partner with CLE and collaborate to serve CLE students;

2. Sufficient housing facilities to accommodate CLE students, preferably located close to a community college or other academic institution; and

3. Well-established and efficient transportation options.

CLE in South Louisiana may take a different form than their other programs around the country given unique characteristics in our community. For example, CLE may first pursue a multi-week summer program where students could experience college life before enrolling in post-secondary institutions. Conversations with CLE are ongoing.

Louisiana State University and the Baton Rouge Community College have expressed support for and interest in bringing the type of services that CLE offers to their campuses. In Denver, CLE programs tap into technical training programs for their students, such as automotive technician certification programs. Partnerships between the public and private sectors and academic institutions designed to serve students in unique ways and better equip them for today’s workforce needs are already underway in Baton Rouge. For example, several months ago, construction began on the new Baton Rouge Community College’s Center of Excellence for Transportation Technology. The Automotive Training Center - a partnership between the State, East Baton Rouge Parish Public School System, and BRCC - will train college and high school students to work as automotive technicians and give them a chance to develop these high-demand skills while simultaneously pursing a traditional high school or post-secondary degree. Leveraging partnerships such as these and facilitating new partnerships not just with post-secondary and technical colleges, but also with the leadership in the business community, will be necessary to support a robust transition program such as CLE in South Louisiana.

While CLE would be a great asset to our community, not all families will be able to afford their services nor could CLE meet the capacity demands of our entire community. Further, not every young adult will pursue post-secondary education. Programs like Gateway Transition Center (described in the Key Providers and Organizations in the Capital Region section of this report) are working to incorporate the principals of organizations like CLE into programs based here and designed to meet the needs experienced by Baton Rouge families. Having organizations like Gateway working in our community is a major step forward since we have not had many available resources in terms of transition, independent living, and post-secondary services. Multiple, different providers will be needed to address all the needs in our community.
SPOTLIGHT: ST. ANDREW’S VILLAGE

St. Andrew’s Village will be a faith-based, mixed-use community in Abita Springs, Louisiana, where adults with all degrees of developmental disabilities and non-disabled individuals can live, work, worship, and socialize. Saint Andrew’s Village will initially offer adult day services only for the developmentally disabled anticipated to open in 2017. The program will have capacity to serve 20-40 individuals in its initial year. Fundraising efforts and donations are intended to cover the majority of program expenses. Funding for the facility is in place and construction is expected to begin in 2016.

The facility design includes several large classrooms for post-secondary education, life skills training, vocational training and a job placement program. A basketball/volleyball court, fitness area for individual exercise and classes, art studio and stage for performances are also part of the building plan. The Villagers of Saint Andrew’s will experience an array of activities, opportunities in business enterprise, and social events. The long-term vision for St. Andrew’s also includes adding housing so that individuals in the program can live independently at the campus.

For more information about St. Andrew’s Village, visit their website at www.standrewsvillage.org.
ATTRIBUTES OF AN IDEAL ADULT TRANSITION SUPPORT SERVICES INFRASTRUCTURE

Across the country, young adults with ASD who are leaving the high school environment and entering a post-secondary education environment and/or the larger adult world must face the well-documented and much dreaded “services cliff” – the loss of many of the services and supports available to high school students. It is an unnecessarily perilous and often bewildering time for these young adults and their parents. Parents, service providers, and advocates interviewed as part of this assessment project were almost unanimous in identifying this transition period as the weakest link in the Capital Region’s ASD supports infrastructure. The two most common complaints were (1) a real deficit of needed resources and (2) the fragmentation of available resources.

The establishment of a comprehensive transition support services enterprise in Baton Rouge for young adults with ASD (and related disorders) would add supports not currently available in the Capital Region and facilitate a more effective utilization of existing adult support resources. Additionally, some support services could be provided on a regional basis such that all of South Louisiana benefits from their implementation. The following is a list of attributes of an “ideal” adult transition support services infrastructure to best serve individuals with an ASD diagnosis and their families. This list was developed from research conducted throughout this assessment, including interviews with education professionals, advocates, and other stakeholders.

| **INTERFACE WITH PRE-K-12 SCHOOL SYSTEMS, POST-SECONDARY INSTITUTIONS, EMPLOYERS, AND ASD STAKEHOLDER ORGANIZATIONS** |
| **ACCESS TO HEALTH CARE RESOURCES (OCDD AND CAHSD PROGRAMS AND BENEFITS)** |
| **INDEPENDENT LIVING SKILLS** |
| **POST-SECONDARY EDUCATION CONSULTING SUPPORT** |
| **WORK READY SKILLS** |
| **JOB TRAINING AND PLACEMENT** |
| **WIDE ARRAY OF HOUSING ISSUES** |
| **TRANSPORTATION** |
| **SOCIAL ENGAGEMENT** |
| **LEGAL ASSISTANCE** |
ADULT TRANSITION | Recommendations

06

RECOMMENDATIONS

ADULT TRANSITION
Individuals with an ASD diagnosis (in the Capital Region and around the nation) face perhaps the greatest deficit in needed services and other infrastructure support when they transition out of the secondary education environment and into the adult world. The following recommendations are designed to fundamentally improve the availability of vital services and infrastructure in the Capital Region.

1. Local school systems, post-secondary institutions, and the state should access the full amount of federal funding for transition, vocational rehabilitation, and employment services by providing the required local or state match. In light of the current state budget constraints, the Louisiana Workforce Commission, Louisiana Rehabilitation Services (LRS), local school systems, the Louisiana Community and Technical College System, and other Capital Region post-secondary institutions should form a working group to explore and pursue alternative sources of matching funds to support LRS programs and make recommendations to the Governor and State Legislature.

2. Post-secondary institutions in the Capital Region should invest resources in designing and implementing a comprehensive, inclusive program to support students with diverse learning needs and intellectual disabilities. The program should include not only academic components to help students achieve a certificate or degree, but also employment, independent living, and community involvement support to assist students learn how to live independently and gain employment. The Disability Services offices should work closely with Financial Aid offices within these institutions to have the program approved as a Comprehensive Transition and Post-Secondary (CTP) program so that students eligible for federal assistance such as Pell Grants and Work-Study programs can deploy these funding options.

3. A working group that includes community leaders, business organizations, local and state education, health care and workforce officials, among others, should be established to govern a project dedicated to the establishment of a sustainable enterprise in the Capital Region that offers comprehensive transition support services to young adults with ASD and related disorders. Dimensions of this service hub model should include:

   a. Interface with Pre-K-12 school systems, post-secondary institutions, employers, and ASD stakeholder organizations
   b. Access to health care resources (OCDD and CAHSD programs and benefits)
   c. Support for developing independent living skills
   d. Post-secondary education support, including interfacing with post-secondary disability services offices and facilitating partnerships between private-sector support providers and post-secondary institutions
   e. Programs for development of job-readiness skills
   f. Job training and placement programs, including interface with Louisiana Rehabilitation Services and engagement with area employers and business organizations
   g. Wide array of housing options
   h. Transportation options
   i. Social skills and activities
   j. Legal assistance
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.

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.\textsuperscript{159} The Louisiana insurance coverage mandate was established in 2008 through legislation authored by Representative Franklin Foil of Baton Rouge.\textsuperscript{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.\textsuperscript{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:\textsuperscript{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

\textsuperscript{159} \url{https://www.autismspeaks.org/state-initiatives}
\textsuperscript{160} Act 648, Regular Session, 2008, (Louisiana, 2008), \url{http://www.legis.la.gov/legis/BillInfo.aspx?s=08RS&b=ACT648&sbi=y}
\textsuperscript{162} For a complete listing of available services, visit Louisiana Department of Health and Hospitals website at \url{http://new.dhh.louisiana.gov/index.cfm/page/522}
**STATE SUPPORT SERVICES | Insurance Coverage**

**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, 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. 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.

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.

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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 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.”

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.

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.

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.
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.

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 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 disabled\textsuperscript{170} and meet the ICF/DD\textsuperscript{171} 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:\textsuperscript{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.

\textsuperscript{170} Louisiana Developmental Disability Law, LA RS 28:451.1-28:455.2
\textsuperscript{171} ICF/DD – Intermediate Care Facility for the Developmental Disability.
\textsuperscript{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. 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.

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](http://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](http://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, meet Louisiana’s definition of developmentally disabled and meet the ICF/DD 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:

- 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.

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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 28:451-28:455.2
177 ICF/DD – Intermediate Care Facility for the Developmental Disability
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. 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. 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/provweb/Providermanuals/manuals/NOW/NOW.pdf
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/263](http://www.dhh.state.la.us/index.cfm/page/263).
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/DD\textsuperscript{183} 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.\textsuperscript{184}

\begin{flushright}
\textsuperscript{183} ICF/DD - Intermediate Care Facility for the Developmental Disability
\textsuperscript{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/1838.
\end{flushright}
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 disabled\textsuperscript{185} and meet the ICF/DD\textsuperscript{186} 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\textsuperscript{187}.

\textsuperscript{186} ICF/DD – Intermediate Care Facility for the Developmental Disability.
\textsuperscript{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

<table>
<thead>
<tr>
<th>Age</th>
<th>Children's Choice</th>
<th>NOW</th>
<th>Supports</th>
<th>ROW</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3 to 19th birthday</td>
<td>Age 3 and over*</td>
<td>Age 18 and over</td>
<td>No age restriction</td>
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<tr>
<td><strong>Eligibility Criteria</strong></td>
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<tr>
<td></td>
<td>• Meet LA definition of developmentally disabled</td>
<td>• Meet LA definition of developmentally disabled</td>
<td>• Meet LA definition of developmentally disabled</td>
<td>• Moving from an intermediate care facility for the developmentally disabled (ICF/DD) or nursing facility to the community</td>
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<tr>
<td></td>
<td>• Meet the ICF/DD level of care for medical and/or psychological criteria</td>
<td>• Meet the ICF/DD level of care for medical and/or psychological criteria</td>
<td>• Meet the ICF/DD level of care for medical and/or psychological criteria</td>
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<tr>
<td><strong>Select Covered Services</strong></td>
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<tr>
<td></td>
<td>• Support coordination</td>
<td>• Support coordination</td>
<td>• Support coordination</td>
<td>• Support Coordination</td>
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<tr>
<td></td>
<td>• Family support services</td>
<td>• Center-based respite</td>
<td>• Day habilitation</td>
<td>• Host home services</td>
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<tr>
<td></td>
<td>• Center-based respite</td>
<td>• Employment-related training</td>
<td>• Habilitation</td>
<td>• Respite services</td>
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<td></td>
<td>• Family training</td>
<td>• Supported employment</td>
<td>• Prevocational services</td>
<td>• Day habilitation</td>
</tr>
<tr>
<td></td>
<td>• Specialized therapies, including aquatic, art, therapeutic horseback, music, and sensory integration therapy</td>
<td>• Supported living</td>
<td>• Supported employment</td>
<td>• Supported employment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Adult companion care</td>
<td>• Personal emergency response system</td>
<td>• Shared living services</td>
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<td></td>
<td></td>
<td>• Community integration and development</td>
<td></td>
<td>• Companion care</td>
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<td></td>
<td></td>
<td>• Individual and family support</td>
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<td>• Community living supports</td>
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<td>• One-time transitional services</td>
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<td>• One-time transitional services</td>
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<td></td>
<td></td>
<td>• Personal emergency response systems</td>
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<td>• Transportation - community access</td>
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<td></td>
<td></td>
<td>• Professional services</td>
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<td></td>
<td></td>
<td>• Remote assistance</td>
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<td></td>
<td></td>
<td>• Substitute family care</td>
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<tr>
<td><strong>Protected Date Serving</strong></td>
<td>6-20-2006 (10 year waiting list)</td>
<td>8-18-2004 (12 year waiting list)</td>
<td>12-31-2014 (1.5 year waiting list)</td>
<td>Current</td>
</tr>
<tr>
<td><strong>Average Annual Benefit or Cap</strong></td>
<td>$16,410 (cap) $10,588 (average)</td>
<td>$52,718 (average) $7,945 (average)</td>
<td>$27,886 (average)</td>
<td></td>
</tr>
<tr>
<td><strong>Total # Slots Allocated</strong></td>
<td>1,475</td>
<td>9,032</td>
<td>2,050</td>
<td>210</td>
</tr>
<tr>
<td><strong>Total # Vacant Slots</strong></td>
<td>179</td>
<td>257</td>
<td>121</td>
<td>184</td>
</tr>
</tbody>
</table>

* 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.

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. 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 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.
RECOMMENDATIONS

07

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.
ASD Research Opportunities

POTENTIAL ADDITIONAL RESEARCH OPPORTUNITY
Research around the country on ASD has focused on identifying autism genes, such as the genome sequencing effort spearheaded by Autism Speaks; understanding the initial causes of autism and ways to prevent its manifestation; and in some cases, the effectiveness of treatment interventions, including nutritional and therapeutic.

Research related to clinical interventions for autism is extremely limited in the Capital Region. Several national funding opportunities exist but none of these programs have been pursued by any institution in Louisiana.
A trio of organizations in the Capital Region appear well-positioned to consider pursuit of research opportunities.

**Pennington Biomedical Research Center (PBRC)**

The Pennington Biomedical Research Center (PBRC) is located in Baton Rouge and is nationally recognized for its research in diabetes, obesity, and nutrition. The mission of PBRC is “to discover the triggers of chronic diseases through innovative research that improves human health and the lifespan.”

In 2005, Pennington Biomedical received a National Institutes of Health (NIH) grant to establish a Center of Excellence in Botanicals and Metabolic Syndrome. This center studies how plant extracts can treat Metabolic Syndrome and Type 2 Diabetes. Pennington Biomedical also received an NIH grant to establish an NIH-NIDDK Clinical Nutrition Research Unit to identify prenatal causes of obesity.

In 2006, the Pennington Biomedical Research Center’s Center of Biomedical Research Excellence (COBRE) was established with an award through the NIH to provide support for outstanding junior faculty as they transition from training to establishing their own research programs.

Throughout its history, Pennington has partnered with the U.S. Army, NASA, the Department of Defense, the State of Louisiana, the NIH, the NIDDK, and others to study the effects of diet, nutrition, and exercise on diabetes, obesity, and metabolic conditions. Although not directly related to autism spectrum disorders, the interaction between the brain and the gut are critical to understanding autism. PBRC has much of the infrastructure and scientists in place to phase the study of ASD into its work.

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Irene W. and C.B. Pennington Foundation
The Irene W. and C.B. Pennington Foundation has pursued relationships with Sheppard Pratt and the Lieber Institute for Brain Development to “generate preliminary data about the biological associations of [the] variable outcomes” possible with an ASD diagnosis. This research is intended to serve as a “proof of concept for larger studies that can drive the development of effective intervention strategies.”\(^1\)

The Lieber Institute will be taking a holistic approach to their research, looking at medical, dietary, environmental, educational, and other factors that impact differing outcomes for adults on the autism spectrum.

Our Lady of the Lake Regional Medical Center
Our Lady of the Lake Regional Medical Center broke ground on its free-standing Children’s Hospital in Baton Rouge in February of 2016. This new hospital will function as a regional pediatric services complex capable of attracting medical specialists and services not currently available or in critically short supply in the Capital Region. The new hospital could also catalyze a new level of collaboration among pediatric care providers and serve as a strategic partner that facilitates the establishment of ASD clinical research in the Capital Region.

Our Lady of the Lake Pediatric Development and Therapy Center
As discussed in the Medical Comorbidities section of this report, the services administered by this proposed Center will include neurology, genetics, developmental pediatrics, social services, speech pathology, occupational therapy, physical therapy, and psychological services. This facility will also integrate medical subspecialty services for related comorbid health conditions related to gastrointestinal function, pulmonary function, and sleep disorders in its treatment to provide a holistic approach to therapy. This center envisions becoming a hub of treatment and research related to ASD and other co-occurring medical conditions.

Many local providers and universities work closely together to conduct research studies. Fostering the relationships between providers, universities, hospitals, and research facilities will provide for more robust research initiatives leading to quicker application and impact on the population.

Specific funding opportunities currently exist for research focused on ASD, including Autism Treatment Networks, Autism Centers of Excellence, Autism Intervention Research, Department of Defense Congressionally Directed Medical Research programs, and Autism and Developmental Disabilities Monitoring Networks. A summary description of each follows.

**Autism Treatment Network**

The Autism Treatment Network (ATN) is a national network of hospitals and physicians focused on improving the treatment of individuals with autism. Seventeen ATN sites have been approved by Autism Speaks with Houston and Little Rock being geographically the closest to Baton Rouge. ATNs are self-sufficient facilities that generate their own funding streams through treatment and research grants from the NIH primarily, but ATNs also are supported through Autism Speaks.

Funding as an ATN: approximately $165,000 per year for three years


**Autism Centers of Excellence**

Autism Centers of Excellence (ACE), funded by the NIH, bring together expertise, infrastructure, and resources focused on major questions about autism. ACEs are collaborations of basic and clinical scientists. The research objectives of these centers can include intervention projects, service projects, or other identified priority research objectives, for example: identification of biological signatures for autism and their relevance to prediction of treatment response and outcomes.

Funding as an ACE: $1.5 million (annual)

Approximately ten to 15 ACE awards anticipated in each round.

For more information on ACE, visit [https://www.nichd.nih.gov/research/supported/Pages/ace.aspx](https://www.nichd.nih.gov/research/supported/Pages/ace.aspx).
Autism Intervention Research

The Autism Intervention Research (AIR) network works in conjunction with ATNs but secures funding through the Health Resources and Services Administration (HRSA) and the federal Autism Cares Act – recently renewed for $260 million annually over the next five years. This funding is designed to support clinical research on children with autism to develop a standard protocol for treatment. There are three programs funded through this grant: Autism Intervention Research Program (AIR-P), Secondary Data Analysis Studies (SDAS), and Autism Longitudinal Data Project (ALDP).

**Autism Intervention Research Network on Physical Health**
This program supports applied empirical research studies to advance the evidence base on the effectiveness of interventions to improve the health and well-being of children and adolescents with ASD and other developmental disabilities and to advance best practices for the diagnosis of ASD and other developmental disabilities at an earlier age.

Funding: approximately $300,000 over three years per grantee

For more information on AIR-P, visit [http://www.airpnetwork.org/](http://www.airpnetwork.org/).

**Secondary Data Analysis Studies**
This program supports secondary data analysis to advance the evidence base on the effectiveness of interventions and to advance best practices for the diagnosis of ASD and other developmental disabilities at an earlier age.

Funding: approximately $100,000 for one year

**Autism Longitudinal Data Project**
This program supports the implementation and completion of research studies that examine longitudinal data on ASDs and other developmental disabilities to study risk factors of these conditions, the effects of various interventions, and trajectories of child development over the life course.

Funding: approximately $500,000 per year for three years

Department of Defense (DoD) Congressionally Directed Medical Research Programs: Autism

This grant award program supports research with the potential to have a major impact on the treatment and management of ASD. Funding must support a clinical trial and may not be used for preclinical research studies. The FY2015 appropriation was $6 million (total for both the clinical and idea development award). These awards are determined by a panel of consumers (people who both treat autism and are affected with a diagnosis).

Funding: approximately $1 million over five years


Autism and Developmental Disabilities Monitoring (ADDM) Network

This funding opportunity is intended to enhance the capacity of surveillance programs to implement or enhance a population-based, multiple-source surveillance program for ASD and other developmental disabilities that co-occur with ASD. The project will fund sites to participate in the network and will enhance surveillance activities through two components: (A) surveillance of eight-year-olds and (B) surveillance of four-year-olds. The eight-year-olds’ surveillance is required and the four-year-olds’ surveillance is optional.

Funding:
Component A: approximately $450,000 for one year; Component B: approximately $125,000 for one year.

ADDM works on a four-year grant cycle with the current cycle having begun in January 2015.

For more information on ADDM, visit [http://www.cdc.gov/ncbddd/autism/addm.html](http://www.cdc.gov/ncbddd/autism/addm.html).
POTENTIAL ADDITIONAL RESEARCH OPPORTUNITY

The 21st Century Cures Act passed by the United States House of Representatives would extend $8.75 billion to the National Institutes of Health. Additionally, NIH would host a new Cures Innovation Fund specifically dedicated to breakthrough biomedical research. While not directly geared toward autism, this bill would impact funding and clinical trials through the NIH. This bill would “streamline various regulations and requirements to make sure researchers are able to comply with them, and it would eliminate duplication in the review process by fostering broader utilization of central institutional review boards (IRBs) for trials being conducted at multiple institutions.”193 Earlier this year, the Senate signaled it would not take up the bill, although some Senate committees have passed bills that support the 21st Century Cures Act and provide additional funding for NIH.194

As other recommendations from this report are implemented, the infrastructure and capacity for research will be greatly expanded. Provider organizations with an appropriate patient base for research could serve as research partners – especially research focused on best practices for treatment intervention.

193 http://energycommerce.house.gov/fact-sheet/hr-6-21st-century-cures-act-frequently-asked-questions
ASD RESEARCH OPPORTUNITIES | Recommendation

08 RECOMMENDATION

ASD RESEARCH OPPORTUNITIES
The substantial health care delivery, education, and research infrastructure in the Capital Region offers great potential for participating in national ASD care and research initiatives.

1. Our Lady of the Lake Children’s Hospital and the Pennington Biomedical Research Center should lead a sustained effort to establish the Capital Region as a Nationally Recognized ASD Research and Care Network Hub with a specific emphasis on biomedical treatments and therapies for those with ASD.

Through this effort, the Capital Region could create an Autism Treatment Network (ATN) facility as well as an Autism Center of Excellence that is eligible for federal funding. Achieving this status helps in the pursuit of additional federal dollars for research related to autism. Further, Baton Rouge should work to develop the necessary capacity and resources to become an Autism and Developmental Disabilities Monitoring Network site.

The Our Lady of the Lake Pediatric Development and Therapy Center, a neurodevelopmental therapy and autism treatment center, wants to become an Autism Treatment Network facility when fully implemented and should be a natural site for implementation.
Conclusion
As the reality of Autism Spectrum Disorder (ASD) grows in the Capital Area Region so must the resolve to identify and pursue development of the resources needed to meet the many challenges ASD presents to our citizens on the spectrum and their families. This assessment project, designed to identify significant gaps in our region’s ASD resources infrastructure, benefitted greatly from the experience-based knowledge, keen insights, and honest opinions offered across a period of approximately two years by dozens of ASD stakeholders.

The result of this assessment is a formidable list of 25 recommendations that touch all the key chapters of a normal lifespan from early diagnosis and intervention through the Pre-K-12 education years and transitions into post-secondary education, employment, and independent living. Some of the recommendations require near term tactical efforts, others are more midterm strategic projects, and a few are visionary, aspirational goals. Each recommendation would make an important contribution to the building of an ever stronger ASD resource infrastructure in the Greater Baton Rouge region.
Acknowledgments
This project would not have been possible without the input and wisdom of a vast number of committed parents, stakeholders, and advocates who generously contributed their knowledge, personal stories, insights, and ideas. The Baton Rouge Area Foundation, the Huey and Angelina Wilson Foundation, and SSA Consultants extend our sincere appreciation to all who graciously spent time with our project team and provided access to the information vital to the execution of this assessment project.

We are grateful to Louisiana state and local government officials who have made services and improved programs for citizens with disabilities a priority. In particular, we would like to thank the following who contributed to the creation of this report.

Representative Steve Carter  
Louisiana House of Representatives

Senator Dan Claitor  
Louisiana Senate

Warren Drake  
Superintendent,  
East Baton Rouge Parish Public School System

Jim Donelon  
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John White  
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Louisiana Department of Education
Additionally, we thank the following individuals who informed this work and inspired our team.

**ABILITIES PEDIATRIC THERAPY SERVICES**
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Greg and Jennifer Price

Louis Quinn

Jennifer and Sean Reilly

Victor Sachse

Linda Spain

Dennis Stevens

Gary Solomon

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Appendices
# Autism Working Group Discussion

**July 31, 2014, Baton Rouge Area Foundation Offices**

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EXECUTIVE SUMMARY

At a summit held at the Baton Rouge Area Foundation on July 31, 2014, 36 concerned community members and BRAF staff members shared their thoughts and experiences on autism services in the Baton Rouge area. Several themes repeated themselves throughout the day: consolidation of information and coordination of services is deficient and important to providing appropriate care. Funding for existing and future resources is limited, clinical providers are stretched thin and will only be strained further in the future. Transitional programs for adults with autism are limited, and families lack effective resources to provide opportunities and support for their children. Additional interviews with individuals and service providers need to be done and a robust community assessment will be compiled by SSA consultants.

MINUTES

A meeting to discuss autism was convened on July 31, 2014 in the Falk Conference Room at the Baton Rouge Area Foundation’s office. Community members in attendance were Rabbi Barry Weinstein, Bill Silva, Bobby Welch, Cheryl Knight, Chris Meyer, Christel Slaughter, Elissa McKenzie, Errin Flynn, Frank Simoneaux, Gwen Hamilton, Jamie Tindle, Jan Ross, Dr. Scott Meche, Jennifer Winstead, John Paul Funes, Lauren Perry, Linda Spain, Mark Thomas, Mary Terrell Joseph, Melissa Juneau, Raymond Jetson, Robert and Conway Pettit, Sara Elizabeth Monsour, Shelley Hendrix, Steve Whitlow, Teresa Wilson, Victor Sachse, and Walter and Mary Ann Monsour. Foundation staff members in attendance were John Spain, Amber Cefalu, Beverly Moore, Lauren Crapanzano, Lois Smyth, and Mukul Verma.

I. WELCOME

John Spain welcomed everyone to the meeting and thanked them for their participation in the discussion. He thanked the Pennington Family Foundation and Lori Bertman who have provided both leadership and funding for various autism projects in the community and explained that Lori could not be at today’s meeting because she was conducting a staff strategic planning session out of town. John also acknowledged the leadership of Matt and Sherri McKay, Walter and Mary Ann Monsour, Jennifer Eplett Reilly, Stephen and Colleen Waguespack, Melissa Juneau, Shelley Hendrix and Linda Spain for their support and encouragement in starting this project.

John shared with the group details of the early research and more than two dozen interviews done by the foundation in preparing for this workshop. He introduced Dr. Christel Slaughter with SSA Consultants who would lead the discussion. All participants introduced themselves and shared why they were in attendance at the meeting.

II. AUTISM SERVICES STRENGTHS

Participants were asked to discuss existing strengths in the services provided to individuals with autism in the Capital region.

Several participants noted the increased awareness of autism. This awareness has led to increased diagnosis and earlier intervention, greater willingness from families to discuss their diagnosis and seek help, better services, and a better quality of life for those affected.
Participants noted that local Baton Rouge therapists are well trained and qualified to provide care. Most occupational therapists, physical therapists, and speech providers are knowledgeable and work to keep the family as part of the team. Participants stated that maintaining professional training and early intervention is key to continuing to provide adequate provider support to families.

Legislation in Louisiana has expanded insurance coverage for certain therapies like Applied Behavioral Analysis (ABA). Through legislation sponsored by Representative Franklin Foil, Louisiana is expanding the opportunity for families to get impactful therapy early on. This legislation went into effect last year.

Several state, local, and private programs were discussed.

- DHH’s EarlySteps program has begun screening all children for autism who are enrolled in the program and who are 18 months or older. Increased resources and parental interest have improved this service.
- The Pediatric Residency program at Our Lady of the Lake has partnered with The Emerge Center to send residents to the center. This opportunity allows medical residents to observe and learn about kids with autism so they are exposed to a multi-disciplinary approach to treatment during their training. Participants echoed the importance of this practice since a family’s first conversation is often with a pediatrician. Partnerships with the medical community, universities, and service providers are critical for appropriate care.
- Then Center for Autism and Related Disorders (CARD) provides ABA therapy for children who have aged out of The Emerge Center. CARD offers many programs depending on a student’s needs such as shadowing at school, play groups, group therapy, and visiting the home to help with homework. The center works with children six days per week, and insurance covers the care.
- Participants noted the state has created various scholarship and school choice programs that allow funding to follow the students. These programs may provide additional educational and treatment options for children with autism.

Given the limited number of clinical providers, participants discussed the potential to use Allied Health professional training programs that already exist at LSU, McNeese, and Nicholls to continue to train qualified care providers.

Participants noted the strong, family-oriented culture in Baton Rouge which encourages a team-based, family-centered approach and improves care. Additionally, the group noted the generous community we live in which enables organizations to operate because of donor funding. Finally, participants noted that multiple organizations have made autism a priority, as evidenced by the number of organizations represented at the meeting.

III. EXISTING AUTISM SERVICES

Participants were asked to discuss existing autism services in our area and what each organization offers.

Abilities Pediatric Therapy Services offers speech and language support from early childhood through early adulthood. They practice a multidisciplinary mode of operations.

EarlySteps provides care from three months of age until the child is three years old, unless the child has limitations in two or more areas. Therapists with EarlySteps come to the home or daycare to work with the child. DHH recently increased the eligibility requirements and switched to a cost participation model. Participants noted that some pediatricians refer to outpatient clinics first rather than EarlySteps. Medicaid
funding now covers intervention for kids with an autism diagnosis, even if the child does not meet all the requirements for EarlySteps.

The McKay Center at the Dunham School provides academic support for over 200 of their 800 students. The center was created to serve siblings of students already enrolled at Dunham. Now, the McKay center has grown to serve any families who need their services. The Center has 23 students on the autism spectrum receiving direct care. Inclusion is intrinsic to the Dunham program and opportunities for mainstreaming with other Dunham students are frequent. The center is fee based for pre-K through 12th grade and has been in operation for six years.

Access to Better Communication (ABC) is an organization with speech language pathologists geared towards enhancing social skills development. The group works with upper elementary and high school students and is a private provider.

St. Lillian's Academy is a private, Christian school focused on helping children with developmental disabilities. Each student has a multidisciplinary team: speech therapist, physical therapist, occupational therapist, and special education teacher. The school has a strong connection with St. Luke’s Episcopal School including a buddy program and weekly chapel. St. Lillian’s is primarily for children ages 5-13, but has an early intervention program for children ages 3-5. Their oldest class will not age out of the program; instead, the school will expand as their children age. There are about 20 students enrolled full time. Additionally, an outpatient occupational and physical therapy clinic runs on site.

Behavioral Intervention Group (BIG) offers ABA and neurotherapy for children up to 8 years of age. They are privately funded and do not accept Medicaid.

The Chesney Center is a private speech and occupational therapy clinic that works with children of any age, but does not accept Medicaid.

The Emerge Center offers services beginning with early intervention through age eight. The center offers services that include: feeding interventions, language, speech, ABA therapy, and social workers who work with families. Emerge is starting a transitional kindergarten class this year and recently piloted Bloom – a multidisciplinary program with 11 kids. The center does accept Medicaid and Bayou Health plans. Last year Emerge touched 584 kids in services, provided 25,000 hours of therapy, assisted 48 kids under the age of 5, performed 15,000 hours of ABA therapy, and assessed 141 Early Steps clients. The center is a privately funded 501c3.

The East Baton Rouge Parish School system provides special education programs to children in the parish, many of whose parents cannot afford, do not know about, or cannot get to the private schools. The school system serves children ages 3-21 in 35 different classes. Each class has 4-5 children. The program is very integrated and attempts to mainstream the children into regular classrooms.

The McMains Center is a multidisciplinary assessment and treatment center.

The state’s School Choice Program provides families with additional financial resources to select the best school for special needs students. The funding can be applied to qualifying schools in any one of the 7 largest parishes in Louisiana. To date more than 400 students have been enrolled in the program. The state’s Student Tuition Organization Program also allows private donors to fund scholarships.

Hope Academy accepts children with all disabilities pre-K through 12th grade. The school serves approximately 170 students and tries to mainstream their students. While they receive state scholarships,
their funding is not sufficient. The goal is to create a comprehensive program serving all the needs of their students.

IV. AUTISM SERVICES GAPS AND FUTURE OPPORTUNITIES

John Spain suggested several potential avenues for future research including training for care providers, educational opportunities for students with autism, coordination of services, independent living as an adult, the financial burden on families, and best practices around the country.

Participants were then asked to discuss where they see gaps in services in our area. The educational barrier of getting money to schools and becoming a focused charter school was discussed. Participants noted the expense of ABA therapy and limited access to qualified therapists, regardless of socio-economic status. The shortage of professional therapy and service providers was noted. Participants suggested supplementing ABA therapists with Allied Health professionals and trained parents to allow resources to go further. Additionally, participants discussed the challenge in getting an accurate diagnosis due to a patchwork of providers.

Autism is a long-term issue with gaps in services from infancy to adulthood. The complicated nature of the issue was discussed in the context of each child needing a unique approach to care. Autism is challenging on families, and the strain was qualified by noting that over 80% of marriages end in divorce after a diagnosis.

Capital Area Human Services District was asked to elaborate on its “single point of entry” services. CAHSD is a regional entity of DHH that operates independently. Individuals with developmental disability get an eligibility determination from CAHSD to allow children to obtain a New Opportunities Waiver. There is a nine year waiting list for the waiver. In the interim, families can receive funding from the Flexible Family Fund ($258 a month) after a 2-3 year waiting list. Personal caretakers can come to the home to help with hygiene and communication skills for children on the waiting lists. EarlySteps refers children to CAHSD just before the child turns three years old. CAHSD can provide funding and referrals to non-governmental programs.

Participants discussed the lack of a single leader for the effort in autism stating that no one entity owns the problem.

The gap in services and access between those in poverty and those who can afford private services was discussed. Access and funding is a challenge for those living in poverty. Additionally, those who are self-employed experience their own issues in getting appropriate insurance coverage for ABA therapy.

Participants discussed the lack of transition programs for children leaving high school. Programs such as 3L Place in Boston were discussed as potential best practices programs.

The Emerge Center participates in managed care and Bayou Health insurance coverage. Reimbursement is capped by visit and they experience challenges keeping the continuity of treatment within the managed care system.

The “No Wrong Door” legislation by Willie Mount was discussed as a model to coordinate services at the government level without turning people away. The program has not been instituted and revenues need to be maximized at the state level to see results.
Participants discussed the confusion and difficulties frequently experienced getting care through existing entities. One parent was told by CAHSD they require an IEP to get a child on the waiting list. However, since the child was enrolled in a private education institution, the EBR school system took two years to issue the IAP. The parent was required to resubmit an IEP every year to remain on the waiting list with CAHSD.

Personal care attendants were discussed as an underfunded resource for families. Long-term savings could be realized with effective use of this resource to prevent a child needing more serious care as they aged. Early Periodic Screening Diagnosis and Treatment (EPSDT) was discussed as a non-Waiver Medicaid option for personal care attendants.

Families Helping Families reaches 7,000 people via email and provides support, information, resources, workshops, and seminars. The organization is funded by the state through the Office of Public Health and fundraisers.

Participants discussed a lack of extracurricular and summer programs for children with autism that are comparable to activities their siblings participate in. A few entities remarked that these opportunities do exist but are not well publicized.

Several participants noted the need for a one-stop website, phone line, and/or center where participants can receive information about all services and programs offered in the area. The United Way Initiative “Help me Grow” was brought up and preliminary discussion suggested that the endeavor is still in the planning stages.

Bill Silva and Jennifer Winstead discussed future research opportunities through the Pennington Biomedical Research Center. Dr. Redmond at the Center is researching prenatal nutrition and the effect on the development of diseases. It was also suggested that the impact of ABA training and research studies might become a part of Pennington’s clinical trials program. Through population science efforts and partnerships with DHH, Pennington has the ability to effectively evaluate the implementation of any autism efforts pursued. John Spain remarked that BRAF will is currently conducting a master plan for the health district and said we would explore how these issues might be included in that work.

V. NEXT STEPS

Participants agreed that minutes from the meeting should be distributed and an additional meeting held at the appropriate time. Additionally, if anyone knew someone or an organization had been left out of the conversation to please let us know so they can be included in the future. All participants were encouraged to contact the Foundation or Christel Slaughter with any additional thoughts resulting from the meeting. She indicated that a follow-up survey would be sent for additional feedback.

One participant described what the next steps could look like:

- Complete an exhaustive defined demographic survey to determine the breakdown by age of all developmentally disabled individuals and their needs by age group, and scope of problem;
- Open a Spectrum Center via a public-private partnership that serves as a 24/7 one stop shop;
- Establish a development component to the center that raises private dollars and targets public dollars
One consistency noted among all services gaps in autism care is the current lack of funding. Participants urged finding a way to compel the state to fund autism in a comparable way to other states. Additionally, it was noted that not including other developmental disabilities could fragment funding.

BRAF agreed to complete an analysis of autism in the Baton Rouge area and follow up with all participants and interested parties.
VI. DREAMING BIG

Participants in the discussion were asked to describe what would be a miracle solution for our children with autism. Below are the results of these ideas. Central themes included coordinating services and organizations, centralizing information for families, improving access and quantity of education and support services, increasing mainstream opportunities for children, and developing a roadmap for transitioning autistic children to adulthood.

Activities for our Children
1. Provide summer programs and camps for children with special needs over the age of 12
2. Include individuals with and without disabilities in our schools, churches, workplaces, universities, retail merchants, and all communities

Best Practices
1. Research how other states handle the financial component of education and caring for children with special needs
   a. Many pour funding into education no matter public or private school (see Oklahoma)
2. Research best practice guidelines for interventions

Coordination of Services
1. Create a 24/7, 365 phone number for parents of children with autism to receive support and counsel (similar to “t-phone” for suicide prevention)
2. Create a resource center for families with special needs to plan a program to follow including support for families
3. Coordinate all assets (and needed assets) into an integrated network that establishes a pathway from childhood to adult life
4. Provide better information on how to navigate through the system to maximize services
5. Coordinate benefits for both private and public services
6. Create a portal that serves as a single point of entry for a wide range of families impacted by a loved one with a diagnoses
7. Host semi-annual regional summit for service providers to encourage coordination and awareness of emerging practices
8. Create a resource center with advisors to help navigate how to get appropriate services
9. Follow up with this core group to encourage collaboration
10. Establish “Spectrum Center” – public/private clearing house and referral center to direct to services (assessment and then referral)
11. Centralize information services – all referrals from doctor, parents, friends, teachers, etc.. should be funneled to this program
12. Integrate an assessment center
   a. Pediatrics, neurologists, child psychologists, child psychiatrists, speech/language pathologists, occupational therapists, social workers, physical therapists
   b. Provide accurate assessment/diagnosis for a constellation of conditions and prescribe multi-faceted plan of therapies across ages and wide ranges of severity of functioning
13. Connect healthcare and education in public school programs
   a. Public education should direct all families to critical healthcare resources with any kind of disabilities and refer to Families Helping Families
14. Locate providers centrally in one physical location to decrease the “scramble for services”
15. Establish an umbrella organization to coordinate services
16. Refer children early or at parents’ concern  
17. Support Families Helping Families to be able to intake all families

**Education**
1. Address education needs and gaps either privately or publicly  
2. Address the gap for higher functioning children’s educational needs  
3. Establish a network of independent schools to provide special education  
4. Consolidate educational and therapeutic resources: too many small for-profit schools drawing from same source of private funding  
5. Economize funding of independent schools rather than small batches of funding for individual efforts at small private schools  
6. Provide educational opportunities that have high expectations of the child and necessary resources for the child to succeed  
7. Integrate a school for teenage children that provides social and extracurricular activities and offers a well-rounded experience which mimics a typical child’s experience  
8. Create a real solution - no band-aids on public education

**Family Support**
1. Connect parents of children with autism to each other via one point of contact  
2. Provide a resource for parents to get education on available services and how to navigate “the system”  
3. Address the gap that exists for families with resources. Those that do not qualify for Medicaid spend every last dollar on services  
4. Provide accessible programs to help understand insurance options for people who need private insurance  
5. Create a list of concerned clergy and social workers available gratis to offer “ecumenical” interracial support to families in need

**Funding**
1. Advocate for services and dollars to state  
2. Establish a development branch of single point of entry service center that raises money from both public and private sources  
3. Increase funding for New Opportunities Waiver slots  
4. Coordinate funding for services, both public and private, that will enable “middle class” families that have needs but do not qualify for need-based services

**Independent Living as an Adult**
1. Create a program for post-high school individuals to transition into the community and allow people to live as independently as possible  
2. Create adult transitional services:  
   a. Employment/volunteer options for adults with developmental disabilities  
   b. Entrepreneurial opportunities for adults  
   c. Successful vocational and life skills training programs  
3. Provide educational training for older children/young adults that could provide job training and employment opportunities to promote independence  
4. Create a continuity plan from birth to adulthood for parents  
5. Develop a stabilization unit for this population → clogging up local ERs/EDs and lengthy stays at local hospitals
Proper Planning
1. Identify all available assets and needed assets
2. Support BRAF to lead funding the efforts to identify all assets, needed assets, and coordination of assets
3. Conduct a broad-based survey to determine
   a. Number of kids through adults with current needs
   b. Level of need at each age level
   c. Corresponding available resources
4. Conduct research on employing technology services that could be delivered at the home
5. Support one entity in identifying
   a. Community needs
   b. National (local) models as best practices
   c. Money to follow the child to services available
6. Address diversity of income, cultural/ethnic heritage, metropolitan/rural, family literacy

Services and Service Providers
1. Provide services for individuals on the low end of the autism spectrum
2. Expand programs for children over six
3. Develop quality provider capacity for all areas
4. Provide best practice diagnostic evaluations for lifespan
5. Provide high quality therapy services especially in public sector for low income children
6. Provide education or training for specialized service provider on job training not just classroom – “train the trainee”
7. Increase provider acceptance of Medicaid
8. Provide unconditional care (regardless of child’s behavior or abilities)

State Services
1. Offer more help with the provision of Personal Care Assistance, both for people waiting for a Children’s Choice waiver and those with Children’s Choice until they obtain a New Opportunities Waiver
2. Provide quality services once a waiver is received so that funding is not wasted
3. Provide autism services for families that qualify for Medicaid
VII. APPENDIX

Best Practices Places to Visit/Research

Throughout the discussion, several sites around the country were mentioned as potential site visits or resources for information moving forward in the Baton Rouge autism discussion. These entities are listed below.

Denver Continuation Program

3L Place in Chicago

California Mind Institute at UC Davis

Center of Excellence for Education in Texas
Appendix B

AUTISM PARENT GROUP DISCUSSION - SEPTEMBER 9, 2014
# Autism Parent Group Discussion

**September 9, 2014, The Emerge Center**

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EXECUTIVE SUMMARY
At a summit held at the Emerge Center on September 9, 2014, concerned parents, community members, and Baton Rouge Area Foundation staff members shared their thoughts and experiences on autism services in the Baton Rouge area. Several themes repeated themselves throughout the day: families are strained financially and emotionally when they receive an autism diagnosis. The consolidation of information and coordination of services is deficient and important to providing appropriate care. Educational opportunities are limited and often inadequate and transitional, vocational programs for adults with autism are non-existent. Additional interviews with individuals and service providers need to be done and a robust community assessment will be underwritten by the Baton Rouge Area Foundation, Pennington Family Foundation, and Huey and Angelina Wilson Foundation.

MINUTES
A meeting to discuss autism with parents and grandparents of children with autism was convened on September 9, 2014 in the conference room at the Emerge Center. Community members in attendance were Kathleen Bachman, Janet Beckwith, Karen Di Benedetto, Marci and Charles Blaize, Tiffany Brumfield, Allison Cascio, Allison Citron, Penni Cedotal, Bambi Guilbeau, Chantelle Harris, Ashley Havard, Tirany Howard, Melissa Juneau, Lorien Kuo, Cyd LaPour, Cherell Lewis, Kate McLean, Rachel Ayn Pickens, Jan Ross, Linda Spain, Linda Stone, Theresa Tekkal, Ruth Thornhill, Jamie Tindle, Lisa Washington, Teresa Wilson, Alaina Wright. Foundation staff members in attendance were John Spain, Beverly Moore, and Lauren Crapanzano.

I. WELCOME
Melissa Juneau welcomed everyone to the meeting and particularly thanked the parents in attendance for taking time out of their day to share their stories. She thanked the following community leaders for their help in organizing this event and commitment to improving autism care in Baton Rouge: Linda Stone from Hope Academy, Jan Wilson from the Wilson Foundation, Jamie Tindle and Teresa Wilson from Families Helping Families, and Rachel Ayn Pickens from the Pennington Family Foundation. She introduced John Spain with the Baton Rouge Area Foundation who would lead the discussion. John seconded Melissa’s appreciation of the parent’s time and thanked all of the organizations that made the meeting possible. John introduced the two BRAF staff members who will be working on this project with him: Beverly Moore, Director of Civic Leadership Initiatives and Lauren Crapanzano, Project Manager. John spoke of the partnership between BRAF, the Pennington Family Foundation and the Huey and Angelina Wilson Foundation on this project and the importance of having a unified front in this movement. He noted that both The Pennington Foundation and the Wilson Foundation have done tremendous work in the autism space before BRAF took the project on.

John shared with the group details of the early research and more than two dozen interviews done by the Foundation in preparing for this project. He opened up the floor to the parents to share their experiences in Baton Rouge with a child with autism.

II. DISCUSSION
The first person to speak was a grandmother to an 8 year old grandson. She stated that John Spain had aptly summarized her family’s experience with gaps in services and the community’s needs. She felt that Louisiana deserves better and should not be at the bottom of every list.
Another mother with a 15 year old son stated that there are not gaps in services, there are wide chasms and gorges. Her son has been mainstreamed into public school in a gifted art and academics program, but tried several different schooling options before finding this program that has for the most part been great for her son. She stated that no one in the East Baton Rouge parish school system is certified to teach children with autism. She described the extensive waiting lists, financial burden, and family stress she has experienced. Throughout her family’s experience, information on programs and support was hard to come by.

A mother of a nine year old son described her experience with programming. She has been at Emerge since her son was three after a developmental psychologist referred her. While Emerge has been a great resource for her family, she does not know what they will do when he ages out this year. She is aware of Hope Academy and the McKay Center at Dunham, but cannot afford the tuition. Her visits to public schools have left her disappointed in the inability of the schools to adapt to her child’s needs. She described an ideal model where a charter school specific to autism was available for her child.

One mother described the immense need for educational training programs in the field of autism. In encouraging such programs, more therapy providers, physicians, and support personnel would be available to parents. In her experience, pediatricians were not able to give her a diagnosis and she continued pushing until she was able to find the right doctor. She moved from Lafayette to Baton Rouge because of the stronger network of providers and more numerous qualified, individual therapists.

A woman with a 10 year old with Asperger’s lauded Families Helping Families for their support navigating the system. Her son has been to several schools and struggled with the change that happens when he is mainstreamed. Now he is at Hope Academy and seems to like it and be doing well. She and her daughter struggle to find normalcy and she reminded the group of the strain on every member of the family.

Next, several participants shared the struggles of finding a qualified baby sitter. Such a person must be adequately trained to work with a child with autism and demonstrate the ability to work with each parent’s child. Respite Care workers received through NOW Waivers have demonstrated varying levels of commitment and are overworked themselves which makes it difficult for families to work with them. Parents want the ability to do simple things together like grocery shop or go to dinner without worrying about their child at home. Siblings are often called upon to act as a second or third set of hands for their brothers and sisters on the autism spectrum.

Another mother described the challenge of finding appropriate care in Baton Rouge which forced her to move to Houston with her son with Pervasive Developmental Disorder. While she lived with him there he received therapy and education from Including Kids. Her husband commuted back and forth from Slidell to spend weekends with them in Houston. Seeing little improvement, they moved back to Louisiana. Now, after her husband passed away she is a single parent navigating the system. Her son is at Hope Academy and has been pleased with care. She sees a void in BCBA therapists who are reimbursable through insurance. She would love her son have the ability to attend after school programs with BCBA therapists or summer programs like other children. After waiting over 8 years for a NOW Waiver, she was told she did not qualify because of her income.

One mother struggles to fund her children’s care. She had 3 children diagnosed with autism, and one passed away from a stroke at a young age. Now, she is struggling to provide proper care for her other children and must choose which child has the greatest needs. Families Helping Families has helped her find appropriate schools, but the costs to finance appropriate care and education is too much.

A mother of a young girl who has autism and is deaf said that she wants her child to be able to receive public education for free and in an appropriate, accommodated manner. Children with autism should be
mainstreamed as much as possible, not just for the children’s benefit but also the teachers. She participated in the Developmental Disabilities Council’s Partners in Policy Making and encouraged other parents to apply to participate in the next class. The next application deadline is September 30.

Another mother of a 20 year old boy with autism described the roller coaster they experienced. They received a proper diagnosis at age 3 and she hired a consultant from the New Jersey Institute to provide him with 3 years of 40 hours/week of ABA therapy. She taught herself how to provide proper care and stopped working to support her son. They hired shadows in schools and switched schools 5 times before finding Hope Academy. Now, after hard work from the family and better educational opportunities, her son is a social butterfly who plays sports and has blossomed, but she doesn’t know what the next steps for her child will be after Hope Academy.

A mother of a young child with autism discussed the difficulties in getting initial services. Her child was put on a 6 month waiting list for an official diagnosis, 1.5 year waiting list following the diagnosis to get an evaluation, and then more waiting lists to actually get services. To bypass this system, she took her child to a physician in Mississippi to get the necessary diagnosis. Her dedication to her child has helped him learn and grow academically, but his temper often impedes social interactions. Her daily struggles include balancing a successful career and caring for her child, ensuring that he does not run away from home, and dealing with judgmental people assuming she is a bad parent.

One mother discussed her fear that her child will get in trouble with law enforcement who are not trained to recognize autism versus a drug or alcohol problem. A child with autism will respond differently than an officer expects which could trigger law enforcement to assume the child is guilty of a crime.

Several mothers discussed the lack of opportunities in vocational and transitional training for their children. While many acknowledged that their children are not destined for Harvard, they are capable of a vocation and some level of independence. With a proper transitional program that begins when the child is a young teenager, more productive futures for children with autism can be attained.

Related, parents discussed that children with autism need to be taught academic skills differently than children without autism. The Hope School, for example, has a Kid’s Café that reinforces life skills by replicating a real restaurant. Another mother described her child learning to read in school and the importance of distinguishing between a child’s ability to memorize versus read for a teacher. Because children with autism learn and respond differently, their education must be tailored to their needs.

A mother of a 12 year old with autism described her successes in navigating the public school system with help from Families Helping Families. She traveled back and forth to New Orleans for doctor’s visits initially. Now, he is in an East Feliciana Parish public school where he has a shadow all day and receives ABA therapy at school. After getting help from Families Helping Families in navigating the IEP system, she now helps other families do the same.

Several families reiterated the importance of early intervention and the sharing of information. If a family gets in with the right provider, they are appropriately referred to additional services as needed. However, if not, families get stuck bouncing around the system until they find what works for them. Parents of other children with autism are often the resource in the area.

A mother of a 21 year old daughter described the struggles once your child reaches adulthood. Until she aged out of child support, the daughter could not qualify to get disability support because of this income. Now, her daughter is on her own with little support and resources.
One mother of a 17 year old who can be aggressive struggled with what was appropriate care for him. She brought him to Pinecrest Developmental Center at 15 where his providers did not know how to properly care for him which resulted in a near fatal incident. She wants to see biomedical research focused on medications, aggression, and comorbidities. No one in Baton Rouge is equipped to deal with children who have severe autism nor are aggressive toward themselves or others.

Finally, one mother ended the discussion saying that she was grateful for everything that had been shared. Her child is young and she appreciated hearing all of the challenges and even opportunities these other families had experienced.

III. NEXT STEPS

Participants agreed that minutes from the meeting should be distributed. John Spain told participants that in coordination with the Pennington Family Foundation and the Huey and Angelina Wilson Foundation, BRAF would put together a scope of work and begin looking into the successes and gaps in autism services in Baton Rouge. He acknowledged that this project would not result in an overnight fix, but that providing a real solution would take years of work and dedication.
IV. APPENDIX

**Best Practices Places to Visit/Research**

Throughout the discussion, several sites around the country were mentioned as potential site visits or resources for information moving forward in the Baton Rouge autism discussion. These entities are listed below.

- Rafael Academy
- The May Institute
- Palm Springs Charter School
Appendix C

ASCENSION PARISH SCHOOL BOARD PROFESSIONAL LEARNING COMMUNITY PROBLEM-SOLVING FLOW CHART
**APSB PLC Problem-Solving Flow Chart**

**Step 1:** 80% of Students are proficient in core instruction

**Provide Core/Tier 1 Instruction:**
- Common Core Standards
- Whole class instruction
- Differentiated instruction
- Research-based core curriculum
- Best practices for instruction
- District Benchmark assessments
- Curriculum-based assessments
- Formative assessments
- Analyze data to form flex grouping
- DIBELS, DRA, Math Universal Screening tools
- PLC’s collaborate regularly to monitor mastery of Essential Standards

**Step 2:** Determine if student concern is related to core curriculum or is a learner-based issue.

a.) If it is a situational difficulty (with one or a few essential standards) problem solve within the PLC and provide instruction within flexible groups.

b.) If the student shows a pattern of difficulties and it is not due to core instruction:
   - Request Cum Review/Student History Report from counselor
   - Document Parent Contact (see sample script) and begin parent

**Step 3:** Teacher presents to PLC relevant data collected in Step 2
- Peer group and grade level comparisons
- Problem solve student concerns in PLC’s
- Determine and Document Intervention Plan:
  - Target area of deficit
  - Focus and setting of research-based intervention
  - Progress monitor weekly or bi-weekly
  - Schedule follow-up date to determine student progress in relation to the Intervention

Refer Major Behavior Issues to the PBIS Team
Document Parent Contact

**Step 4:** Implement and monitor interventions with ongoing problem solving at PLC meetings
- Is the student closing the gap?
- Are the interventions positively impacting performance in core curriculum?

**Step 5:** (Decision Point)

In PLC’s, discuss intervention data and decide one of the following: Continue, Stop, Select New, or Intensify

- If Team selects “Continue, Select New, or Intensify” repeat steps 3, 4, & 5
- If student reaches success at grade level, stop intervention and return to Step 1
- If there is a poor response to the first intervention (for comprehension concerns only), invite the Speech/Language Pathologist to the PLC to join the problem-solving discussion

Document Parent Contact
Solicit the help of the SBLC Facilitator or Pupil Appraisal if you need assistance in interpreting the data in the decision making process.

**Step 6:** (Decision Point)

- A student should not be referred to SBLC if the below criteria are present:
  - The problem is instructional or curricular in nature
  - The problem is environmental (including V/H or attendance) in nature

If any of these criteria are met, continue with the PLC Problem-Solving cycle and work with parents to address concerns, if applicable.

- A student should be referred to SBLC for further problem solving if:
  - the above criteria are not present
  - Student does not show success after adjusting interventions

To begin the SBLC referral process, schedule an SBLC Intake Meeting with the SBLC Facilitator.

**SBLC Intake Meeting:**
Teacher(s), SBLC, Pupil Appraisal and administrator meet to review all student information, student work and data to analyze the case.
- If it is determined that the PLC problem-solving cycle was not implemented adequately or complete data was not gathered, the problem-solving returns to the PLC.
- If it is determined that a disability is suspected, the case is officially opened as an SBLC referral and parent contact is made by the SBLC facilitator to schedule an initial SBLC meeting.
Appendix D

EAST BATON ROUGE PARISH PUBLIC SCHOOL SYSTEM
KEY PRE-APPRAISAL INTERVENTION DOCUMENTS
Response To Intervention: Academic/Elementary

**Tier 1:** General education and enrichment. Provide high-quality instruction for all students with a research-based comprehensive reading and math program. Obtain Benchmark data at least 3 times a year. Monitor for approximately one grading period. Look for failing grades and low benchmark scores.

- **Yes**
  - Did at least 80% of students master the curriculum/new skill?
    - Identify bottom 20% of class (Universal Screening/Peer Comparison) and document on Tier One Documentation of Student Interventions/Strategies form and the Data Profile Sheet.
    - Confirm hearing and vision check is 2 years current.
    - Other screenings as needed (e.g., speech and language, motor, health, social emotional, Dyslexia, etc.)
    - Begin an orange RTI folder on the student containing all documentation and screening results.
  - Did the parent meeting alleviate the problem?
    - Complete the necessary forms to request an SBLC meeting. Parent contact within 10 days. Bring the student's Cumulative and orange RTI folders to the SBLC Committee and consider for Tier 2.

- **No**
  - Did at least 80% of students master the curriculum/new skill?
    - Re-teach skill to class and retest.
    - A parent conference should be held and the data and screening results reviewed. Document the conference on a Parent Conference Form. Document attempts to contact. Monitor progress for 1 to 2 weeks.
  - Did the parent meeting alleviate the problem?
    - Continue communication with the home to alert of student’s progress.

**Tier 2:** Provide an additional 30 minutes daily in reading or 30 minutes 3 times a week in math, strategic instruction, at the student’s instructional level while student is in a small group (2-3 students).* This should take place outside of the general education classroom with a certified teacher,* highly qualified staff, *other knowledgeable staff. Progress monitor weekly on instructional level to obtain 6 to 12 data points through the 6 (minimum) to 12 (maximum) weeks of implementation. No more than 12 weeks should pass without a decision about the interventions effectiveness. Review progress at least 3 times in the SBLC to monitor data.

- **Yes**
  - Did this alleviate the problem? Refer to data points.
    - Continue to provide support at the Tier 2 level or move back to Tier 1. Continue progress monitoring. If there is a change, the teacher should alert the SBLC.

- **No**
  - Did this alleviate the problem? Refer to data points.
    - Continue to provide support at the Tier 3 level, move to Tier 2, or solely to Tier 1. Continue progress monitoring. If there is a change, the teacher should alert the SBLC.

**Tier 3:** Most intensive and explicit instruction. SBLC creates this plan on the Tier 3 form as a committee. PAS person should be included. Continue Tier 1. Provide an additional 60 minutes daily (reading) or 30 minutes daily (math) at the student’s instructional level in a small group (2-3 students).* This should take place outside of the general education classroom with a certified teacher,* highly qualified staff, *other knowledgeable staff. Progress monitor weekly on instructional level to obtain 6 to 12 data points through the 6 (minimum) to 12 (maximum) weeks of implementation. No more than 12 weeks should pass without a decision about the interventions effectiveness. Review progress at least 3 times in the SBLC to monitor data.

- **Yes**
  - Student is considered by the SBLC team for a multidisciplinary evaluation. Pupil Appraisal must be involved at this level to review data. Continue Tier support during PAS evaluation.
**Response to Intervention: Behavior**

**Tier 1:** School-Wide PBIS. PBIS committee to establish school-wide expectations for all students with reinforcers and consequences. The PBIS committee reviews the school-wide discipline report to determine effectiveness of the Tier 1 level supports.

- **No**
  - Did at least 80% of students succeed on the school’s PBIS plan?
  - Re-teach or re-examine the PBIS expectations to the class/school and rescreen.
  - Did meeting with the parent alleviate the problem?
  - Continue communication with home to alert of student’s progress.

- **Yes**
  - 20% of students need more support. If a student has 5 behavior write ups on the Classroom Minor Behavior Tracking Form (= 1 ODR), complete the Data Profile Sheets, meet with guardian, and document on the Parent Conference Form.
  - Begin an orange RTI folder containing all student documentation and screening results. Keep the orange RTI folder in the cumulative folder/ yellow ESS folder if available.

**Tier 2:** 20% of students may need more specific behavior supports. Your school’s PBIS committee should outline Tier 2 interventions available at your school. Also, continue Tier 1 support.

- The Universal Behavior Screener can be used as a baseline. Other measures to obtain baselines such as other rating scales, and observational data are welcome.
- Complete a Tier 2 BSP within 10 days. Select a Tier 2 intervention that targets your hypothesis (i.e., what is the function of the behavior?). Implement the Behavior Support Plan (BSP). Examples: small-group/school-based counseling, parent training, classroom management (specific classroom expectations), check-in/checkout, mentoring, self-monitoring, community resources, etc.
- Progress monitor every two weeks for 4 to 6 data points (= 8 to 12 weeks of intervention) via the Universal Behavior Screener and the other selected measure (used to obtain other baselines) if available.
- Continue using the Classroom Minor Behavior Tracking Form.

**Tier 3:** 5% of students may need intensive and systematic behavior support. Continue Tier 1.

- Complete a Tier 3 Comprehensive FBA/BSP with the SBLC (make sure to invite your Pupil Appraisal Staff and/or Behavior Interventionist, and parent). Define the behavior and make sure you have a baseline.
- Implement the BSP (i.e., individual counseling, social-skills training, teach the behavior, teaming, etc.).
- PAS may conduct observations of student.
- Progress monitoring should be based on the frequency of the behavior (daily vs. weekly). The Universal Behavior Scale may be used to progress monitor weekly. SBLC should meet at least 3 times to track data. Continue to use the Classroom Minor Behavior Tracking Form. At least 6 to 12 data points should be obtained through the 6 (minimum) to 12 (maximum) weeks of implementation. No more than 12 weeks should pass without a decision about the BSP’s effectiveness.

- **No**
  - Did this alleviate the problem? Refer to progress monitoring data.
  - Continue to provide support at the Tier 2 level or fade the behavior plan and return the student solely to Tier 1. Progress monitor. If there is a change in behavior, the teacher should alert the SBLC.

- **Yes**
  - Did this alleviate the problem? Refer to progress monitoring data.
  - Continue to provide support at the Tier 3 level or fade the behavior plan and return the student to Tiers 2 and/or 1. Progress monitor. Teacher alerts SBLC to change.

**Student is considered by the SBLC team for a multidisciplinary evaluation. Pupil Appraisal must be involved at this level to review data. Continue Tier support during PAS evaluation.**
Response to Intervention: Academic/Middle and High Schools

**Tier 1:** General education and enrichment. Provide high-quality instruction for all students with a research-based comprehensive reading and math program. Obtain Benchmark data at least 3 times a year. Monitor for approximately one grading period. Look for failing grades and low benchmark scores.

- Did at least 80% of students master the curriculum/new skill?
  - No: Re-teach skill to class and retest.
  - Yes: Identify bottom 20% of class (Universal Screening/Peer Comparison) and document on Tier One Documentation of Student Interventions/Strategies form and the Data Profile Sheet.
    - Confirm hearing and vision check is 2 years current.
    - Other screenings as needed (e.g., speech and language, motor, health, social emotional, Dyslexia, etc.)
    - Begin an orange RtI folder on the student containing all documentation and screening results.

- Did the parent meeting alleviate the problem?
  - Yes: Continue communication with the home to alert of student's progress.
  - No: Complete the necessary forms to request an SBLC meeting. Parent contact within 10 days. Bring the student's Cumulative and orange RtI folders to the SBLC Committee and consider for Tier 2.

**Tier 2:** Provide an additional 30 minutes 3 times a week, 90 minutes total (reading or math), strategic instruction, at the student's instructional level while student is in a small group (5-6 students).* This should take place outside of the general education classroom with a certified teacher,* highly qualified staff,* other knowledgeable staff. Progress monitor weekly on instructional level to obtain 6 to 12 data points through the 6 (minimum) to 12 (maximum) weeks of implementation. No more than 12 weeks should pass without a decision about the interventions effectiveness. Review progress at least 3 times in the SBLC to monitor data.

- Did this alleviate the problem? Refer to data points.
  - No: Continue to provide support at the Tier 2 level or move back to Tier 1. Continue progress monitoring. If there is a change, the teacher should alert the SBLC.
  - Yes: Student is considered by the SBLC team for a multidisciplinary evaluation. Pupil Appraisal must be involved at this level to review data. Continue Tier support during PAS evaluation.

- Did this alleviate the problem? Refer to data points.
  - Yes: Continue to provide support at the Tier 3 level, move to Tier 2, or solely to Tier 1. Continue progress monitoring. If there is a change, the teacher should alert the SBLC.

- Student is considered by the SBLC team for a multidisciplinary evaluation. Pupil Appraisal must be involved at this level to review data. Continue Tier support during PAS evaluation.
Tier One Documentation of Student Interventions/Strategies

Alternative strategies and interventions for improvement of the student's academic skill have been implemented and the student has not made progress. Documentation of student performance must be provided.

<table>
<thead>
<tr>
<th>Strategies/Interventions</th>
<th>Results</th>
<th>Dates (To/From)</th>
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Interventions for Tier One may include:
- Explicit and systematic small group instruction within the regular classroom
- Instruction has been provided using a different teaching strategy.
- Instruction has been provided using a different response mechanism.
- Student has been provided with additional practice activities.
- Student has been provided with immediate and specific feedback.

Student:  _Noah I. Cue_  Subject Area: _Reading/ Lang. Arts_  Grade: _2nd_  Date: _August 11th, 2010_

Tier One Documentation of Student Interventions/Strategies

Alternative strategies and interventions for improvement of the student's academic skill have been implemented and the student has not made progress. Documentation of student performance must be provided.

<table>
<thead>
<tr>
<th>Strategies/Interventions</th>
<th>Results</th>
<th>Dates (To/From)</th>
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</thead>
<tbody>
<tr>
<td>Utilize the Treasures Reading Series to deliver instruction on the LA Language Arts Curriculum.</td>
<td>Series Placement Test administered August 11th yielded beginning first grade levels in all areas of reading.</td>
<td>August 11th, 2010 – ongoing.</td>
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<tr>
<td>Some of the research-based strategies used include: Guided Reading, Skills Review and Practice, Paired Reading, Error Word Drill and flexible grouping.</td>
<td>DIBELS Oral Reading Fluency (9-10-10) Fall Benchmark Score of 25 cwpm falls below the expected beginning of the year score of 55 cwpm for a 2nd grader. The class average on DIBELS was 50 cwpm.</td>
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<tr>
<td>Use the Computer Literacy Lessons from beginning 1st grade.</td>
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</table>
**Tier Two Documentation of Student Interventions/Strategies**

Alternative strategies and interventions for improvement of the student’s academic skill have been implemented and the student has not made progress. Documentation of student performance must be provided.

<table>
<thead>
<tr>
<th>Strategies/Interventions</th>
<th>Results</th>
<th>Dates (To/From)</th>
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Interventions for Tier Two may include:
- Explicit and systematic small group instruction in our outside of the regular classroom.
- Supplemental instruction has been provided using a different teaching strategy.
- Student has been provided with additional practice activities.
- Instruction has been provided targeting specific areas of weakness.

**Additional Student Information**

Student: Noah J. Cuag  | Subject Area: Reading / Lang. Arts  | Grade: 2nd | Date: 10-15-10 11-09-10

**Tier Two Documentation of Student Interventions/Strategies**

Alternative strategies and interventions for improvement of the student’s academic skill have been implemented and the student has not made progress. Documentation of student performance must be provided.

<table>
<thead>
<tr>
<th>Strategies/Interventions</th>
<th>Results</th>
<th>Dates (To/From)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teacher provided small group (1-5) instruction using Triumphs supplemental curriculum 2-3 times a week for 30 minutes each time.</td>
<td>DIBELS Oral Reading Fluency Scores measured every other week: (25 cwpm is baseline, target is 50).</td>
<td>10-15-10 - Present</td>
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<td>A peer tutor worked with Noah via flash cards containing 10 unknown words 2 times a week for 15 minutes to target words in this week’s story.</td>
<td>10-15-10 – 25 cwpm (new baseline)</td>
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<td>10-26-10 – 24 cwpm</td>
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<td>11-12-10 – 26 cwpm</td>
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<td>11-26-10 – 27 cwpm</td>
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<td></td>
<td>12-03-10 – 26 cwpm</td>
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<tr>
<td>Teacher provided small-group instruction using Language! 3 times a week for 30 minutes per time outside the regular classroom setting.</td>
<td>Added on 11-9-10 SBLC meeting.</td>
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14
**Tier 2 Data Chart: Progress Monitor Every 2 Weeks**

Student Name: ________________________________

School: ___________________ Grade: ______________

What is the intervention? ____________________________

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<th>DAY#</th>
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Baseline  • Intervention

Dependent Variable: ____________________________

Put numbers in the blanks on the left of the graph to indicate if it is percentage 10, 20, 30, or words correct per minute (WCPM): 10, 20, 30, 40, etc. Baselines can include scores from the beginning of Tier one and end of it (which would be the new baseline for Tier 2).
### INSTRUCTIONAL INTERVENTION DOCUMENTATION SHEET FOR TIER THREE

**INSTRUCTIONS:** Refer to the LDOE Reading, Writing and Math Instructional Intervention Supplements for appropriate informal assessment and strategies.

<table>
<thead>
<tr>
<th>Student:</th>
<th>Teacher:</th>
<th>School Year:</th>
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<table>
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<tr>
<th><strong>GENERAL INFORMATION:</strong></th>
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<tbody>
<tr>
<td>School: USA Elem.</td>
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<tr>
<td>Grade: 2nd</td>
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<tr>
<td>Subject: Reading/Language</td>
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</table>

<table>
<thead>
<tr>
<th>Tier Three Referral Date:</th>
<th>Intervention Start Date:</th>
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<tbody>
<tr>
<td>12-10-10</td>
<td>12-10-10</td>
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<thead>
<tr>
<th>First Intervention Review Date:</th>
<th>Sufficient Progress?</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>12-21-10</td>
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<tr>
<th>Second Intervention Review Date:</th>
<th>Sufficient Progress?</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>1-14-11</td>
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<tr>
<th>Final Determination Date:</th>
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<tr>
<td>1-28-11</td>
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</table>

*An instructional intervention is a series of planned activities that are different from those activities normally occurring in the child’s regular education program.

**What is the referring problem? (To be stated in specific and measurable terms.)**

Noah is unable to read fluently at a rate commensurate with his peers. The average student in his class reads 68 cwpm while he reads at 26 cwpm. Despite Tier II interventions and support, he has earned failing grades in reading class (1st 6 weeks – 68).

**What data supports the existence of the problem? (Baseline data)**

Most recent reading probe of 26 cwpm on 12-03-10.

**What is the goal to resolve this problem? (To be stated in specific and measurable terms.)**

Noah will gain 2 words per minute each week which is the typical growth rate for a second grader. This should improve his reading fluency to 50 cwpm in 12 weeks. If successful, can take additional weeks to reach an overall goal of 60 correct words per minute.

**Describe the intervention to be attempted (Please complete all information as noted.)**

Noah will increase his fluency rate by at least 2 cwpm per week. By the end of the Tier III intervention period, he will read at least 50 cwpm.

Noah will be placed in Headsprout Early Reading Intervention program (computer directed). 5 times per week for 60 minutes per session under the direction of Ms. Imp Lenten. Headsprout includes 40 lessons which provide instruction in phonemic awareness, letter-sound decoding, irregular words, vocabulary, connected text, and comprehension. This program generates multiple reports to monitor progress to be reviewed weekly.

Noah will earn a DIBELS ORF score of at least 50 cwpm at the end of the intervention process.
12-21-10 – first review meeting. *Headsprout Early Reading* intervention program will be increased to 30 minute sessions 5 times a week in order to improve Noah’s reading skills as measured by ORF probes.

1-14-11 – second review meeting. Teacher will begin Paired Reading 3 times a week for 10 minutes each session in addition to the Headsprout Early Reading intervention program.

1-28-11 – third review meeting. Noah achieved a growth of 1.3 cwpm each week rather than the targeted 2.0 cwpm growth.

Noah’s rate of improvement is slower than his peer classmates who achieved an average growth rate of 2.0 cwpm yielding an average of 82 cwpm.

12-21-10 – DIBELS ORF probe = 30 cwpm. (ORF probes indicate an increase of 6 cwpm compared to goal of 8 cwpm.)

12-28-2010 – Off for winter break.

1-7-2011 – DIBELS ORF probe = 33 cwpm

1-12-10 – DIBELS ORF = 42 cwpm. (ORF probes indicated an increase of 10 cwpm compared to goal of 12 cwpm.)

1-21-11 – DIBELS ORF probe = 42 cwpm.

1-27-10 – DIBELS ORF = 48 cwpm.

The evaluation criteria for the intervention: Noah was to achieve DIBELS ORF score of about 50 cwpm by the end of the intervention process.

• Attach a copy of the DIBELS’ booklet to show chart and scores.
## Tier 3 Data Chart: Progress Monitor Every Week

### Student Name: ________________________________

School: ___________________ Grade: ___________________

What is the intervention? ____________________________________________

### Data Table

<table>
<thead>
<tr>
<th>DAY#</th>
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<th>DATA</th>
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### Baseline vs. Intervention

- Baseline
- Intervention

### Dependent Variable:

Put numbers in the blanks on the left of the graph to indicate if it is percentage 10, 20, 30, or words correct per minute (WCPM): 10, 20, 30, 40, etc. Baselines can include scores from the beginning of Tier one, Tier 2 (beginning), and Tier 2 (ending, which would be the new baseline for Tier 3) if measuring the same thing.
Appendix E

ABA ENROLLMENT FORM FOR LEAs
The following checklist shows all documents that must be submitted to the Molina Medicaid Solutions Provider Enrollment Unit in order to enroll in the Louisiana Medicaid Program as an EPSDT Health Services provider:

<table>
<thead>
<tr>
<th>Completed</th>
<th>Document Name</th>
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<tbody>
<tr>
<td>*</td>
<td>2. Completed PE-50 Addendum – Provider Agreement Form (two pages).</td>
</tr>
</tbody>
</table>
| *         | 4. Louisiana Medicaid Ownership Disclosure Information Forms for Entity/Business. *(Only the disclosure of ownership portion of this enrollment packet can be done by choosing Option 1.)*
> **Option 1 (preferred):** Provider Ownership Enrollment Web Application. Go to [www.lamedicaid.com](http://www.lamedicaid.com) and click on the Provider Enrollment link on the left sidebar. After entering ownership information online, the user is prompted to print the Summary Report; the authorized agent must sign page 3 of the Summary Report and include both pages 2 and 3 with the other documents in this checklist.
> -or-
> **Option 2 (not recommended):** If you choose not to use the Provider Ownership Enrollment web application, then submit the hardcopy Louisiana Medicaid Ownership Disclosure Information Forms for Entity/Business.
| *         | 5. *(If submitting claims electronically)* Completed Provider's Election to Employ Electronic Data Interchange of Claims for Processing in the Louisiana Medical Assistance Program (EDI Contract) Form and Power of Attorney Form (if applicable). |
|           | 6. Copy of voided check or letter from the bank on bank letterhead verifying the account and routing number for the account to which you wish to have your funds electronically deposited *(deposits slips are not accepted).* |
|           | 7. Copy of a pre-printed document received from the IRS showing both the employer identification number (EIN) and the official name as recorded on IRS records *(W-9 forms are not accepted).* |
|           | 8. To report “Specialty” for this provider type on Section A of the PE-50 in the Basic Enrollment Packet, please use Code 44 *(Public Health).* |
| **        | 9. **Only For Charter Schools:** Completed Declaration of Charter School Status Form. |
| **        | 10. Completed PE-50 EPSDT Health Services For Children With Disabilities Provider Enrollment Supplement Agreement |
| **        | 11. Completed PE-50 EPSDT Provider Supplement Agreement B. |
| **        | 12. Completed PE-50 EPSDT Provider Supplement Agreement C - School Board/Charter School Certification of Understanding *(If applicable)* |
|           | 13. Printout of online medical license verification from the governing license board for each therapist identified in the list specified in item 13 above. This verification must contain the license number, the effective date of issuance, and the current status of the license. |
|           | 15. Copy of the Early Intervention license from the Department of Social Services for providers serving the 0 to 3 year old population |
|           | 16. **Only For Parish School Board/Charter Schools:** Completed Amendment to the Provider Agreement Between DHHS-BHSF and the appropriate Parish School Board/Charter School *(4 pages).* |

* Forms are included in the Basic Enrollment Packet

** Forms are included here

PLEASE USE THIS CHECKLIST TO ENSURE THAT ALL REQUIRED ITEMS ARE SUBMITTED WITH YOUR APPLICATION FOR ENROLLMENT. FORMS MUST BE SUBMITTED AS ORIGINALS WITH ORIGINAL SIGNATURES *(NO STAMPED SIGNATURES OR INITIALS)* – DO NOT SUBMIT COPIES OF THE ATTACHED FORMS.

Please submit all required documentation to:
Molina Medicaid Solutions Provider Enrollment Unit
PO Box 80159
Baton Rouge, LA 70898-0159
In order to facilitate your enrollment as an EPSDT Health Services provider in Medicaid of Louisiana, you must provide the information that is requested below.

Name of Provider:__________________________________________________________

Medicaid Provider Number:________________________________________________________________

Address (Mailing and Street):_______________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

Telephone Number:_______________________________________________________________________

Address and Telephone Number if Other Sites (if applicable):________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

Check the EPSDT health service(s) you wish to provide, list any restrictions related to the age or the number of children, geographical areas, or other factors, or enter “none.” Attach documentation of applicable licensing and certification for staff providing these services.

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>RESTRICTIONS</th>
</tr>
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<tbody>
<tr>
<td>Audiologic Evaluation</td>
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<tr>
<td>Speech and Language Evaluation</td>
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<tr>
<td>Speech, Language or Hearing Therapy</td>
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<td>Occupational Therapy Evaluation</td>
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<td>Occupational Therapy</td>
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<tr>
<td>Physical Therapy Evaluation</td>
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<td>Physical Therapy</td>
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<tr>
<td>Behavioral Health Services</td>
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<td>Applied Behavior Analyst</td>
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* All services must be provided as part of or in the interest of establishing an Individual Service Plan (ISP) or an individual Family Service Plan (IFSP).
The Agreement, made by and between Medicaid of Louisiana and ______________
(Provider), sets forth the terms of participation in Early Periodic Screening and Diagnostic
Treatment (EPSDT) health services to children with disabilities. The parties, intending to be legally bound,
agree as follows.

1. The provider agrees to adhere to all general enrollment conditions of Medicaid of Louisiana.

2. The provider agrees to comply with all applicable program requirements for services, timeliness
standards, and reasonable standards of medical and other health professional practices set forth in the
EPSDT Health Services Provider Manual.

3. The provider agrees to maintain sufficient staff, facilities, equipment, and supplies to provide
the agreed upon services and notify Medicaid of Louisiana promptly, in writing, whenever
he/she is not longer able to provide the services.

4. The provider agrees to ensure that recipients are allowed to choose providers freely.

5. The provider agrees to establish procedures through which eligible recipients and families may
present grievances which may arise from EPSDT services provided under this agreement.

6. The provider agrees that the submission by or on behalf of the provider of any claim shall be
certification that the specific services for which the payment is claimed were provided to the person
identified as the recipient.

7. The provider agrees to keep records necessary to disclose the extent of EPSDT services
provided to recipient for five years from the date of payment, to provide this information, as
requested, to Medicaid of Louisiana or its authorized representative, and to cooperate with on-
site reviews, and other monitoring and training activities.

8. The provider agrees to use Medicaid funds received for these services solely for the provision
and/or enhancement of health services to children. These Medicaid funds may be used for the
direct provision of these services and to defray the administrative cost of providing these
services.

9. The provider agrees to submit claims within 1 year of the date of service and to submit these
claims electronically.

10. The provider agrees to participate in KIDMED recipient outreach activities, including identifying
and informing recipients of the benefits of preventive care, and how to access KIDMED
screening services.

11. The provider agrees to provide age appropriate KIDMED medical, vision, and hearing screening
services to Medicaid recipients under the age of 21 who are receiving EPSDT health services
reimbursed by Medicaid or to contact KIDMED immediately to arrange for these screening services.
12. The provider agrees to refer any suspected child abuse, neglect, and/or sexual abuse of recipients under the age of 21 promptly to the Office of Community Services in the parish where the recipient resides.

13. Medicaid of Louisiana agrees to reimburse the provider for EPSDT health services covered by Medicaid in accordance with applicable regulations and the schedule of maximum Medicaid fees for these services.

14. The effective date of this agreement shall be the date on which it is signed by Medicaid of Louisiana unless otherwise stated.

15. This agreement may be terminated by either party upon 30 days after the receipt of a written notice by the other party.

I certify that the information provided on this form is true to the best of my knowledge.

_________________________________________________          _______________________
Provider- Authorized Signature
Date

__________________________________          _______________________
Medicaid Director or Designee
Date
Individual Therapist Form (Applied Behavior Analyst)

Please Print Name of EPSDT Health Services:

List all individuals that are providing the therapy services identified on the PE-50 EPSDT Health Services for Children with Disabilities Provider Enrollment Supplement Agreement form (i.e., Audiology, Speech and Language, Occupational Therapy, Physical Therapy, Behavioral Health Services and/or Applied Behavior Analyst. Attach a copy of a current license for each.

<table>
<thead>
<tr>
<th>Therapist Name</th>
<th>Therapist Specialty</th>
<th>Therapist License Number</th>
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Signature ____________________________________________ Date  _______________

Signature of Authorized Representative _____________________________ Date of Signature _______________

Print Name of Authorized Representative ________________________________

Revised 10/2014