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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.

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.

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>.



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

I Have Autism:

I have been medically diagnosed with autism spectrum disorder. My medical condition impairs my ability to communicate with others. As a result I may have difficulty understanding your directions, and I may not be able to respond to your questions. I may also become physically agitated if you touch me or move too close to me.

Please do not interpret my behavior as refusal to cooperate. I am not intentionally defying your instructions.

(Please see reverse side for additional information) →



If I exhibit any of these behaviors, I request that you contact the person noted below on my behalf; s/he will confirm my diagnosis and provide information you may need about my identity. Sincerely,

My Printed Name

Contact Printed Name

Contact Printed Number

This certification has been issued by the Alabama Department of Public Health in accordance with

Code of Ala. 1975, § 32-6-6.2.

For more information, visit adph.org



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 provides 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/>.



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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.

