Executive Summary

COMMUNITY
MEDICAL AND RESEARCH COMMUNITY
THERAPEUTIC SERVICE PROVIDERS
PRE-K THROUGH 12 EDUCATORS
POST-SECONDARY EDUCATIONAL INSTITUTIONS
STATE AGENCIES AND LEGISLATURE
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 2006.2 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.3 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&id=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.
Communuity

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 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.

4 Find more information on Exceptional Lives on page 81 of this report.
2. A comprehensive, robust ASD stakeholder organization\(^5\) based in the Capital Region should design and execute a community education campaign focused on *Learn the Signs of Autism*,\(^6\) 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

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\(^5\) See Community Recommendation 1 on page 16.

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. 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.
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.
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.
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

    7 Center for Disease Control and Prevention, “Autism Spectrum Disorder (ASD), Screening and Diagnosis.” http://www.cdc.gov/ncbddd/autism/screening.html
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 171.19) 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.