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## **Texas Department of Aging and Disability Services**

### **Texas Autism Research and Resource Center Website Focus Group Final Report**

July 29, 2010

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# 1 Executive Summary

## 1.1 Introduction

The 81st Texas Legislature, through House Bill 1574, directed the development of a statewide resource center for autism spectrum disorders (ASD). The Texas Department of Aging and Disability Services (DADS) was assigned responsibility for implementing the center, now named the Texas Autism Research and Resource Center (TARRC). Once operational, TARRC will provide information and resources on ASD, including the availability of state and local services to individuals with ASD, their families, and to professionals who interact with individuals with ASD.

An initial activity of the TARRC is to create a website, or “virtual center,” to provide ASD information and resources to the aforementioned stakeholders. As such, the DADS TARRC project team commissioned The Litaker Group to conduct focus groups in Austin, Dallas, El Paso, Harlingen, Houston, Lubbock, and Tyler to obtain stakeholder input on the website. A total of 96 persons participated in these focus groups. Participants represented various stakeholder groups, including parents, family members, and other caregivers, individuals with ASD, teachers/school administrators, researchers, advocates, service providers, and professionals who may interact with individuals with ASD in the course of their job duties.

Data were gathered on the following topics:

1. Purposes of the website
2. Target audiences
3. Content
4. Design

## 1.2 Findings

### 1.2.1 Purpose of the Website

Five example purposes were proposed to the participants. Participants generally supported the five purposes listed below, and suggested modifications which are noted in Section 5.1.1 of this report.

1. To communicate reliable and helpful information regarding autism spectrum disorders, including proven treatments and interventions
2. To promote awareness and understanding of autism spectrum disorders among the Texas population
3. To provide professionals with effective training and development tools to encourage supportive, understanding relationships when working with individuals on the spectrum and their families
4. To publicize significant research efforts and communicate important findings to better inform Texans, including the research community



5. To solicit input from citizens to enhance programs and policies in Texas for the benefit of individuals with ASD and their families

### 1.2.2 Target Audiences

Participants agreed that the website should serve multiple audiences – from individuals with ASD and their caregivers to professionals who may occasionally interact with ASD individuals (e.g., police) to potential employers. Other suggested target audiences included:

- General public
- Criminal justice system
- Daycare Providers
- Educators
- Legislators
- Employers and prospective employers
- Extended family members of persons with ASD
- First Responders
- Government / state agency staff
- Professionals of all types (e.g., medical service providers, teachers, restaurant staff, etc.)
- Researchers
- Youth organizations

### 1.2.3 Content

Participants provided information on the types of content they feel would be useful to the target audiences previously identified. Themes from the sessions were:

- A primary focus for website content should be families.
- The website should be available in both English and Spanish.
- Content should be presented in simple terminology so that users can understand it.
- The website should provide links to other websites that have valuable information on ASD; participants advised DADS not to “recreate the wheel.”
- Stakeholders must be able to access information regarding services and providers, both at the state and local level, via the website.
- Information on the website should cover the lifespan of individuals affected by ASD, not just children.
- Participants expressed an interest in connecting with other people and sharing information via the website (e.g., blog).
- The website should highlight evidence-based treatments and interventions, but other treatments/interventions, such as emerging practices, should be referenced as well but not endorsed by DADS.
- Comprehensive training for professionals is not likely via the website, but short videos that create awareness could be very helpful to professional audiences.



- Participants defined “professionals” very broadly and felt information applicable to all types, from daycare providers to pediatricians, should be made available.
- Participants suggested a Wiki-based calendar that would provide information regarding ASD events statewide and in local communities.
- Information on individuals’ legal rights, ranging from special education law to guardianship matters, and on self-advocacy should be addressed.
- Criteria and processes should be developed to govern what information (e.g., research studies to publicize, organizations to mention) should go on the website.
- Website users should be provided contact information, including phone numbers, mailing addresses, and email addresses, for TARRC staff.

#### 1.2.4 Design

Participants identified several common website design themes. These included: (1) information being organized by key target audiences; (2) search capabilities to identify service providers, especially locally; (3) search capability to locate desired information within the website; (4) ease of navigation and user-friendliness; and (5) use of pleasing soft colors, simple page design, ample pictures, and video streaming capability.

### 1.3 Next Steps

Based on input provided by stakeholders at these seven focus groups, the TARRC project team will work with DADS website developers to create content and structure for the website. If time allows, focus group participants may be asked to help test the developed website prior to its release. The project team anticipates that the website will be developed in phases, with the first phase ready to go live in December 2010 or January 2011.



## **2 Introduction**

In 2009, the 81st Texas Legislature passed House Bill 1574 directing the development of a statewide resource center for autism spectrum disorders (ASD). The legislature charged the Texas Department of Aging and Disability Services (DADS) to develop this new resource center known as Texas Autism Research and Resource Center (TARRC). This resource center is designed to provide information and resources on ASD, including availability of state and local services to individuals with ASD, their families, and to professionals who interact with individuals with ASD throughout the state.

An initial activity of the TARRC is to create a website to provide ASD information and resources to the aforementioned ASD stakeholders. As such, the DADS TARRC project team commissioned The Litaker Group under a Health and Human Services Commission master contract to conduct seven focus groups to obtain input for the website. DADS sought input to meet the following objectives for the website:

- Determine the primary objectives for offering a TARRC website;
- Assess information needs of the primary audiences;
- Determine what specific information and resources to include on the website to meet the needs of target audiences; and
- Obtain design ideas for the website.

## **3 Purpose of This Report**

This report provides a summary of feedback obtained from all focus group participants. It is intended to identify themes to assist DADS in creating the framework and structure of the new TARRC website. Specific reports for each of the seven focus groups have also been provided to DADS. To promote an open dialogue in the focus group sessions, information in this report is not attributed to a particular person.



## 4 Methods

### 4.1 Participants and Locations

The DADS TARRC project team had predetermined that focus groups are the optimal method for soliciting input from ASD stakeholders throughout Texas. The DADS project team identified individual stakeholder groups to participate in the focus groups. These groups included: (1) parent of recently diagnosed child; (2) parent of an older child with ASD; (3) caregiver to an adult with ASD; (4) researcher; (5) professional; (6) non-parent family member; (7) adult with ASD; (8) medical service provider; (9) non-medical service provider; (10) teacher/administrator; and (11) advocate.

An invitation to participate in a focus group was drafted by the Litaker Group and approved by the TARRC project team. The invitation letter and registration information were sent to proposed participants via email. Individuals who could not attend made recommendations for alternates.

A total of seven focus groups were conducted across Texas. They were held during the month of July in the following cities: (1) Austin; (2) El Paso; (3) Lubbock; (4) Dallas; (5) Tyler; (6) Harlingen; and (7) Houston. These locations were chosen to make sure that all DADS-designated service regions across the state are represented in the discussions.

### 4.2 Focus Group Format and Process

A standardized framework was used to collect information at each focus group. This process was used to reduce potential bias in the data collection process and to minimize variation among facilitators in leading the discussions. Discussions for each focus group were led by a facilitator and a scribe who recorded participant comments on large flip chart note pads for individuals to see.

Participants were asked to provide input based on the following topics: (1) purpose for the website; (2) target audiences for the website; (3) content of the website; and (4) design of the website.

**Purpose:** To think about the purpose of the website. Specifically, they were asked: Why would you want to visit this website one day? Participants were provided some example purposes to start the discussion (see Section 4.1: Purpose). Participants discussed these example purposes and were asked to identify additional purposes.

**Target Audiences:** To identify potential target audiences for the website. A target audience is a group of persons who would potentially use this website. Participants were provided some example target audiences to start the discussion (see Section 4.2: Target Audiences). Participants



discussed these example target audiences and were asked to identify additional target audiences.

**Content:** To identify specific content, or information, desired on the website. Participants were provided some example content to start the discussion (see Section 4.3: Content). Participants discussed the example website content and were asked to identify additional content.

**Design:** To identify a potential design, including features of the website. Specifically, they were asked: What should the website look like? Participants viewed a series of slides showing some examples of non-autism web sites (see Section 4.4: Design). They were asked to think about the colors, the look and feel, photos, and other aspects of the sites that they liked or disliked.



## 5 Findings

In the following sections, input and feedback from focus group participants are organized by topic and main themes and key points for each topic. The responses and comments have been collated and summarized from all focus groups so they are not identifiable by participant or location. Generally speaking, focus group participants indicated that it is critical for the website to have the following characteristics in order to be successful:

- All pages should be available in English and in Spanish
- The site should be up to date
- Information on the website should include all age spans from infants to adults
- There should be information on the transition from young adult to adulthood and the services and resources available across this transition
- The website should be easy to navigate and have a nice look and feel

### 5.1 Purpose

#### 5.1.1 *Main Themes and Key Points*

Five example purposes were presented to each focus group. These example purposes were used to start a discussion with the participants. Each example purpose was reviewed individually and participants were asked to identify what they liked or disliked about each example and if each example should be considered as a potential purpose. Additional purposes were also identified.

**Example 1:** To communicate reliable and helpful information regarding autism spectrum disorders, including proven treatments and interventions.

#### **Discussion Points**

- Overall, focus group participants were supportive of this purpose but noted the following concerns.
  - o A number of participants expressed concern about the word “proven” and suggested replacing it with “evidence-based”, “research-based” or with “evidence-based and emerging practices.”
  - o The suggestion was made to modify the wording to include the word “diagnosis” so that information on diagnosis would be included on the website. Additionally, the suggestion was made to include the word “resources.” Possible wording would be “... diagnosis, treatments and interventions, and resources.”
  - o Simplicity of wording and non-judgmental wording for this purpose was suggested.
  - o Information provided should cover the life span and not be limited to children and should include transition. In one location participants reported that there is a need to identify resources for adults and considerations for parents of children



- with ASD regarding transitions that occur across the life span.
- o The website should be comprehensive but not be overwhelming in the presentation of information.

**Example 2: To promote awareness and understanding of autism spectrum disorders among the Texas population**

**Discussion Points**

- Overall, focus group participants were supportive of this purpose.
- Focus group participants noted that awareness and understanding are dependent on the educational level of the website users.
- Focus group participants supported the website promoting awareness and understanding to a wide variety of audiences, including the parents of a newly diagnosed child/adolescent or an individual recently diagnosed.
- In one focus group a participant suggested that the website promote individual and family advocacy.

**Example 3: To provide professionals with effective training and development tools to encourage supportive, understanding relationships when working with individuals on the spectrum and their families**

**Discussion Points**

- Overall, focus group participants were supportive of this purpose but noting concerns identified below.
  - o Some focus group participants expressed concern about whether the website could provide effective training and suggested changing the word “training” to “education opportunities” or to “effective information.” Some participants questioned whether the website would be able to provide the continuing education on ASD needed by professionals. The question was asked as to whether professional development includes continuing education.
  - o In one focus group participants suggested expanding this purpose statement to include key strategies/implementation tools in addition to development tools.
  - o One focus group suggested that the word “professionals” be broadly defined.
  - o The type of training / education opportunities could include links to other websites.
  - o Participants in one focus group cautioned that website consumers should not rely on “one-shot” training modules.



**Example 4:** To publicize significant research efforts and communicate important findings to better inform Texans, including the research community

**Discussion Points**

- Overall, focus group participants were supportive of this purpose but noted the following concerns.
  - o Many of the comments from focus group participants related to the specific content on the website regarding research.
  - o Concern was expressed in several of the focus groups about the process that would be used to determine which research would be included on the website. In some instances participants were not in agreement on whether only evidence-based research should be included. For example, some participants believed all research was relevant since each child was different. Although there did appear to be consensus that research should be noted as being evidence-based or non-evidence based.
  - o One participant suggested a possible rewording of this purpose: “To promote the research involvement of professionals and those affected by ASD, provide links to research-based sites, and communicate relevant findings in an easily understood way.”
  - o Support of inclusion of links to other research sites was voiced in the focus groups.
  - o Participants at one location suggested that the website be brought online in phases with the research efforts in a later phase and that the website needs to include tools for parents to be good consumers of research.

**Example 5:** To solicit input from citizens to enhance programs and policies in Texas for the benefit of individuals with ASD and their families

**Discussion Points**

- Overall, focus group participants were supportive of this purpose.
- In one focus group participants noted that this purpose has political implications for advocacy at the state and federal levels.
- Focus group participants expressed multiple opinions on whether the website should focus on Texas or should be broader. Some participants suggested that a broader focus would promote inclusion while others noted that because rules and regulations vary by state, the website should only focus on Texas-specific programs and policies.
- Focus group participants at one location expressed concern about the Texas focus because of the international border and supported an inclusive website that can be used by a variety of audiences. However
- In one location participants questioned whether the website is the appropriate forum for soliciting input, while participants in another location indicated that the opportunity for input on support groups for families, policies, and advisory groups would be welcomed.

**Additional Examples:** Focus group participants provided the following additional input on potential purposes for the website

#### **Discussion Points**

- The website should provide support, including social, emotional, and mental, to the entire family.
- The website should empower parents to learn how to help their children.
- A primary focus of the website should be on persons with ASD but with equal focus on individuals on the spectrum, families, and professionals.
- The website should be dynamic and constantly evolving as new information becomes available.
- A possible purpose is to provide links to existing information and not to duplicate information on other credible websites.
- A suggested purpose is to identify resources for families of persons with autism-related disorders across the lifespan and across the domains of health, education, recreation, legal services and emergency preparedness.



## 5.2 Target Audiences

### 5.2.1 *Main Themes and Key Points*

Focus group participants were asked to identify potential target audiences for the website. In this context, a target audience is defined as a group of persons who would potentially use this website. Four example target audiences were presented to each focus group to begin a discussion on this topic. Focus group participants were asked if they supported the four examples and also were given the opportunity to identify other potential target audiences. Focus group participants agreed that all four examples for target audiences should be included but provided some additional input for consideration (Table 1). Focus group participants also suggested additional target audiences for consideration (Table 1). In addition, focus group participants suggested that the target audiences, when appropriate, be age specific (e.g., information on working with adults with ASD or information on grade school students with ASD).



**Table 1:** Target audiences and examples

Target Audience	Specific Individuals
<b>Example target audiences</b>	
1. Families of person with autism spectrum disorder	<ul style="list-style-type: none"> <li>• Siblings</li> <li>• Spouses</li> <li>• Extended families, (e.g., grandparents, aunts, uncles, and cousins)</li> </ul>
2. Persons with autism spectrum disorder	<ul style="list-style-type: none"> <li>• Self advocates</li> <li>• Friends of persons with ASD</li> </ul>
3. Researchers	<ul style="list-style-type: none"> <li>• University students interested in this field</li> </ul>
4. Professionals providing services to / interacting with persons with ASD	<ul style="list-style-type: none"> <li>• Professional categories</li> <li>• Direct delivery and support services professionals</li> <li>• Ancillary and incidental service professionals</li> <li>• Medical community</li> <li>• Medical personnel who are not specialists in ASD</li> <li>• Pediatricians</li> <li>• Home health providers</li> <li>• Volunteers interacting with persons with ASD</li> </ul>
<b>Additional target audiences proposed by participants</b>	
<ul style="list-style-type: none"> <li>• Criminal justice system</li> </ul>	<ul style="list-style-type: none"> <li>• Judges</li> <li>• Juries</li> <li>• Lawyers</li> </ul>
<ul style="list-style-type: none"> <li>• First responders</li> </ul>	<ul style="list-style-type: none"> <li>• Fire, police, and emergency medical services</li> </ul>
<ul style="list-style-type: none"> <li>• Employers and prospective employers</li> </ul>	<ul style="list-style-type: none"> <li>• Job coaches</li> <li>• Fellow employees / coworkers</li> </ul>
<ul style="list-style-type: none"> <li>• Educators</li> </ul>	<ul style="list-style-type: none"> <li>• University / college faculty and staff</li> <li>• Independent school district teachers and staff</li> <li>• Private school teachers and staff</li> <li>• Fellow students</li> <li>• Counselors</li> </ul>
<ul style="list-style-type: none"> <li>• Youth organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Youth groups</li> <li>• Boy scouts</li> <li>• Girl scouts</li> <li>• Summer camp groups</li> </ul>
<ul style="list-style-type: none"> <li>• Government / State Agency staff</li> </ul>	<ul style="list-style-type: none"> <li>• Child Protective Services</li> <li>• Adult Protective Services</li> <li>• Health and Human Services Commission</li> <li>Enterprise</li> </ul>
<b>Other proposed target audiences</b>	
<ul style="list-style-type: none"> <li>• Foster Families</li> <li>• Insurers and third party payers</li> <li>• Emergency room social workers</li> <li>• Daycare providers and parents</li> <li>• Day program providers</li> <li>• Respite providers</li> <li>• Local elected officials</li> <li>• State and Federal law / policy makers</li> <li>• Military – particularly regarding availability of local</li> </ul>	<ul style="list-style-type: none"> <li>• Librarians</li> <li>• Retail industry, (e.g. stores, restaurants, movie theaters)</li> <li>• Travel industry, (e.g., airlines)</li> <li>• Individuals and families with a possibility of an autism and related disorders diagnosis</li> <li>• Newly diagnosed patients / parents</li> <li>• General Public</li> <li>• Faith-based community</li> </ul>



resources	<ul style="list-style-type: none"> <li>• Law enforcement</li> <li>• Support groups</li> </ul>
<ul style="list-style-type: none"> <li>• Friends / peers / neighbors / classmates</li> </ul>	

## 5.3 Content

### 5.3.1 Main Themes and Key Points

Participants were asked to comment on the example content documents. Comments specific to an example content section are noted in Table 2. General comments and agreement from participants include the following:

- The entire website should be bilingual in English and Spanish
- Information should be non-judgmental
- Information should be accurate and unbiased
- The site should reflect the different populations in Texas
- There should be a process and criteria developed regarding how decisions are made on what information to post and what links are included on the website.
- Link to currently available resources whenever possible
- Website should be compliant with the American with Disabilities Act
- Make all information available in print and in PDF
- Information in this website should be consistent with information in other state of Texas websites (e.g., information posted on the Texas Education Agency website at [www.txautism.net](http://www.txautism.net))
- Information on the website needs to be written to consumer demographics from new mothers to professionals
- Website consumers should be able to sign up for email alerts when new local information is posted

### 5.3.2 Types of Content Discussed

In this section, the following main types of content were discussed.

- About TARRC
- About Autism Spectrum Disorders (ASD)
- Services and Resources
- Training and Development
- Research
- ASD in the News
- Get Involved
- Calendar
- Contact Us



**Table 2:** Focus group feedback on specific content to be included in the About TARRC section

About TARRC	
General Comments	
<ul style="list-style-type: none"> <li>• Some participants questioned the name of the website and asked if it should be called the Texas Autism Website or something other than TARRC</li> <li>• Participants noted that TARRC is a statewide initiative and not necessarily the website name</li> <li>• This section should provide consumers an opportunity to ask questions and seek feedback from TARRC</li> </ul>	
Section Name	Comment
TARRC and Its Collaborative	<ul style="list-style-type: none"> <li>• Include history of TARRC, information on legislation that created TARRC (i.e., H.B. 1574) and how the center came about</li> <li>• Provide information on the collaborative, their role, and whether they will contribute to the website</li> <li>• Provide information on next steps of TARRC and the TARRC website</li> <li>• Note that the website was created with input from stakeholders statewide</li> </ul>
Our mission	<ul style="list-style-type: none"> <li>• Include a vision and mission statement</li> </ul>
TARRC in the News	<ul style="list-style-type: none"> <li>• Keep this section up to date</li> </ul>
Press Releases	<ul style="list-style-type: none"> <li>• Keep this section up to date</li> </ul>
Publications / Reports	<ul style="list-style-type: none"> <li>• Keep this section up to date</li> </ul>
Staff	<ul style="list-style-type: none"> <li>• Provide contact information from administrative standpoint (e.g., who is the TARRC contact person)</li> <li>• Provide contact information to include phone number, fax number, email, and mailing address</li> <li>• Provide local DADS / TARRC contact information for cities statewide</li> <li>• Provide contact information under the Contact Us section</li> </ul>
Locations / Directions	<ul style="list-style-type: none"> <li>• Provide administrative contact information for TARRC</li> </ul>



**Table 3:** Focus group feedback on specific content to be included in the About ASD section

About ASD	
General Comments	
<ul style="list-style-type: none"> <li>Provide links to already existing resources whenever possible</li> </ul>	
Section Name	Comment
Overview of the Disorder	<ul style="list-style-type: none"> <li>Include a description of the disorders across the spectrum and how they present</li> <li>Include frequent co-morbid disorders and how they present</li> <li>Differentiate between different disorders in the spectrum (e.g., Autism and Asperger's)</li> <li>Include information on other syndromes related to ASD (e.g., Fragile X)</li> </ul>
Early Signs of Autism	<ul style="list-style-type: none"> <li>Include examples of early signs and symptoms with an indication that they are not intended to diagnose but should include links to local professionals</li> </ul>
Evaluation and Diagnosis	<ul style="list-style-type: none"> <li>Provide information what to do when your child receives a diagnosis of ASD</li> </ul>
Treatment and Interventions	<ul style="list-style-type: none"> <li>Include link to MH/MR</li> <li>Provide information for newly diagnosed</li> </ul>
Autism FAQs	<ul style="list-style-type: none"> <li>Discuss facts and myths related to ASD (e.g., facts and myths related to the causes, treatments, and living with ASD)</li> <li>Frequently asked questions (FAQs) on issues related to parental guilt and how to overcome, and other similar issues</li> <li>Address specific cultural issues (e.g., how the Hispanic community deals with ASD relatives and the need to overcome denial by a father who believes in the machismo aspect of Hispanic culture)</li> <li>Include a glossary of terms and have imbedded links that would take consumers directly to a definition / description of the term</li> </ul>
Screening Tool or Quiz	<ul style="list-style-type: none"> <li>Provide quizzes. Quizzes are helpful, but caution is urged because parents may require more information in order to use the quiz properly</li> <li>Provide family screening tools</li> <li>Include link to the Modified Checklist for Autism in Toddlers (M-CHAT)</li> <li>Include link to the Autism Speaks First 100 Days Kit</li> <li>Include link to the Autism Speaks video examples</li> <li>Include a screening tool or guide for what services are available and guidance on how to access those services</li> </ul>
Proposed New Section: Success Stories	<ul style="list-style-type: none"> <li>Add a section on success stories (i.e., individuals who have exceptional skills because of ASD or who have excelled notwithstanding a diagnosis of ASD)</li> <li>Consider having links to people willing to share their stories</li> </ul>
Proposed New Section: Prognosis	<ul style="list-style-type: none"> <li>Add a section on prognosis to include information on: what to expect from this diagnosis, what is the life expectancy,</li> </ul>



Section Name	Comment
	what are the social, educational, and vocational expectations of someone with autism, and information on how to transition to independent living
Proposed New Section: Other	<ul style="list-style-type: none"> <li>• Provide information on emergency preparedness activities (e.g., hurricane preparedness) as it relates to ASD (e.g., care during evacuation or sheltering, obtaining medication during evacuation, etc.)</li> </ul>

**Table 4:** Focus group feedback on specific content to be included in the Services and Resources section

Services and Resources	
General Comments	
<ul style="list-style-type: none"> <li>• Consider separating services from resources.</li> <li>• Provide links to already existing resources whenever possible</li> <li>• Include general information on how to access resources, especially for caregivers of the newly diagnosed</li> <li>• Provide local information</li> <li>• Make available the ability to search for information by county, region, or zip-code</li> <li>• Use a Texas map that can be highlighted by region to request services</li> <li>• Provide information on services to all potential users</li> </ul>	
Section Name	Comment
State Services and Programs	<ul style="list-style-type: none"> <li>• Add information on legal resources and rights for Texans</li> <li>• Include links to legal service providers including those who specialize in guardianship issues</li> <li>• Add information on rights of parents and children, including applicable information from the Americans with Disabilities Act</li> <li>• Provide information on guardian and trust issues for those caring for or responsible for adults with ASD</li> <li>• Include where families can obtain information on funding support for treatment (e.g., Medicaid and Medicare)</li> <li>• Include a category for financial resources including Supplemental Security Income (SSI)</li> <li>• This category should include insurance information and provide information across all socio-economic levels</li> <li>• Identify Medicaid waiver programs</li> </ul>
Special Education through Public Schools	<ul style="list-style-type: none"> <li>• Include links to the education system including special education and Parent Teacher Associations (PTA)</li> <li>• Add service and resource information to high school students</li> <li>• Communicate information concerning awareness of educational services available for the child / family with ASD <ul style="list-style-type: none"> <li>○ Early childhood intervention (ECI)</li> <li>○ Special education resources</li> <li>○ Post-secondary options</li> <li>○ Guardianship information</li> </ul> </li> <li>• Include information on class waivers</li> </ul>



Section Name	Comment
University-Based Services and Programs	<ul style="list-style-type: none"> <li>• Include education programs from academia</li> <li>• Include credible academic resources</li> </ul>
Regional and Local Service Providers	<ul style="list-style-type: none"> <li>• Include information about how to locate a “trusted” provider</li> <li>• Include transition services from pediatric to adult including both community based and medical services</li> <li>• Include private and vocational services in addition to those offered in the public sector</li> <li>• Include a category for faith-based services and links to those services</li> <li>• Include information regarding community participation opportunities, e.g., fitness programs, mother’s day out programs, etc.</li> <li>• Include “how to” guides by age group</li> <li>• Include information for transitional services and planning</li> <li>• Include services and resources for older persons with ASD</li> <li>• Include resources and information on daily living (e.g., time management guidelines), acceptance, nutritional needs, lifestyle, and resources for parents</li> <li>• Provide local resource information on respite care resources for parents</li> <li>• Add transition service information</li> </ul>
Proposed New Section: Other	<ul style="list-style-type: none"> <li>• Provide a blog or podcast to allow the website to become interactive and alive</li> <li>• Include information about group homes and adult training resources</li> <li>• Provide information for siblings</li> <li>• Provide information regarding available local and state support groups</li> <li>• Provide employment opportunities for persons with ASD</li> </ul>
Texas Council on Autism and Pervasive Development Disorders	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Autism Organizations	<ul style="list-style-type: none"> <li>• Provide links to the following both in this section and as appropriate in other sections <ul style="list-style-type: none"> <li>○ <a href="http://www.autismnj.org/doc/blueprint.org">www.autismnj.org/doc/blueprint.org</a></li> <li>○ Center for Autism and Related Disorders</li> <li>○ Autism Society of America</li> <li>○ Autism Society of Greater Austin</li> <li>○ Centers for Disease Control and Prevention website</li> <li>○ AutismSpeaks.org</li> <li>○ Texas statewide leadership for Autism (e.g., online courses and available continuing education units)</li> <li>○ Texas Education Agency website at <a href="http://www.txautism.net">www.txautism.net</a></li> </ul> </li> </ul>
TARRC Library / Recommended Readings	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>



**Table 5:** Focus group feedback on specific content to be included in the Training and Development section

<b>Training and Development</b>	
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• TARRC should link to already available content and not seek to recreate content</li> <li>• The word “training” may have different interpretations to different people</li> <li>• Change the word “training” to “education”</li> <li>• Stress that training is generalized and that all persons with ASD are different and may respond differently in different situations</li> <li>• Training should be provided online</li> <li>• Information on where you can go for training</li> <li>• Links to persons / organizations that provide training services (e.g., an organization that provided DVD training to police)</li> </ul>	
Section Name	Comment
For Parents	<ul style="list-style-type: none"> <li>• Provide information concerning                             <ul style="list-style-type: none"> <li>○ What to expect on a daily basis</li> <li>○ How to modify a home (e.g., color schemes, light, sounds) and how to successfully integrate a home that is an extension of the classroom</li> <li>○ How to interact with siblings</li> <li>○ How to successfully parent a child with ASD, including strategies for creating a successful home structure (e.g., creating calendars, schedules, visual pictures to get ready in the morning)</li> <li>○ A research-based or evidence-based visual calendar for daily living</li> </ul> </li> <li>• Communicate information concerning awareness of educational services available for the child / family with ASD                             <ul style="list-style-type: none"> <li>○ Early childhood intervention (ECI)</li> <li>○ Special education resources</li> <li>○ Post-secondary options</li> <li>○ Guardianship information</li> </ul> </li> </ul>
For Professionals	<ul style="list-style-type: none"> <li>• Define the term “professional” as many parents of children with ASD consider themselves as professionals</li> </ul>
Conferences / Seminars / Lectures	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Video and Other Presentations	<ul style="list-style-type: none"> <li>• Training videos are helpful, but should be from 3 – 5 minutes in length</li> <li>• Short “awareness” videos may be a good substitute for in-depth training</li> </ul>
Proposed New Section: First Responders	<ul style="list-style-type: none"> <li>• Include training resources for law enforcement and first responders</li> <li>• Include reliable / credible video training resources to first responders</li> </ul>
Proposed New Section: Other	<ul style="list-style-type: none"> <li>• Add training resources for people with ASD regarding topics such as job training</li> <li>• Include a category for employers and potential employers</li> <li>• Include a category for caregivers including daycare</li> <li>• Include training on social skills</li> </ul>

Section Name	Comment
	<ul style="list-style-type: none"> <li>• Include job coaching skills</li> <li>• Training for child care staff</li> <li>• Training for head start staff</li> <li>• Training for schools (to help them recognize ASD diagnosis)</li> <li>• Training for parents (e.g., self education on the disease itself and how to build a support system for themselves)</li> <li>• Child advocacy training</li> <li>• Training to support family unity and the role of the caregiver</li> <li>• Include educational opportunities for adults on the spectrum on topics to include dating and bullying</li> </ul>

**Table 6:** Focus group feedback on specific content to be included in the Research section

Research	
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• The ability to solicit participants for research studies and opportunities to participate in research should be included</li> <li>• Information presented in this section will be controversial</li> <li>• Research findings are constantly changing, thus requiring constant updates to the website</li> <li>• Participants expressed concern about the process to approve what research gets posted on the website. It was suggested that posting criteria be developed and that a screening committee be appointed, including external experts, to develop a credible way to approve what information gets posted on the website.</li> <li>• Participants suggested calling this section “sponsored research”</li> </ul>	
Section Name	Comment
Evidence-Based and Emerging Practices	<ul style="list-style-type: none"> <li>• Participants suggested that research could possibly be categorized as peer-reviewed, published or non-published.</li> <li>• Emerging practices and the current state of the practice should be included</li> </ul>
Current Research in Texas	<ul style="list-style-type: none"> <li>• Participants would like to know who will synthesize the research to put it on the website and suggest making this process known to website users</li> </ul>
Past Research Studies	<ul style="list-style-type: none"> <li>• Participants would like to know how past research will be defined and in what time period. This is particularly important since research findings are provided very rapidly, therefore something only a few years old could be “past research” and may be outdated.</li> </ul>
TARRC Research Publications	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Research FAQs	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
TARRC Symposium Information	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Current Studies Soliciting Participants	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Proposed New Section: Other	<ul style="list-style-type: none"> <li>• Provide a link to PubMed and other search engines for research</li> <li>• Provide information on translating research to practice</li> <li>• Include a link to the National Institutes of Health</li> </ul>

**Table 7:** Focus group feedback on specific content to be included in the ASD in the News section

ASD in the News	
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• Include “cool facts” and stories</li> </ul>	
Section Name	Comment
Recent Articles	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Archived Articles	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>

**Table 8:** Focus group feedback on specific content to be included in the Get Involved section

Get Involved	
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• None</li> </ul>	
Section Name	Comment
Participate in Research	<ul style="list-style-type: none"> <li>• See comments in “Research” section</li> <li>• This section should also include links to research efforts underway and include opportunities to participate in ongoing research</li> </ul>
Take a TARRC Survey	<ul style="list-style-type: none"> <li>• A question was also asked about what kind of surveys would be included on the website</li> </ul>
Volunteer for TARRC	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Sponsor an Event	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>
Make a Donation	<ul style="list-style-type: none"> <li>• The question was asked about to whom/what would donations be made</li> </ul>
Submit a Suggestion to TARRC	<ul style="list-style-type: none"> <li>• Consumers should be able to submit suggestions regarding the website design and content</li> </ul>

**Table 9:** Focus group feedback on specific content to be included in the Calendar section

<b>Calendar</b>	
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• Include calendars that provide links to local events</li> <li>• Promote and highlight local, state, and national events (e.g., April is national autism awareness month)</li> <li>• Have a content management system function on the website to give ownership of specific pages to local providers or jurisdictions. This would allow limited permission for select persons to update calendar information on their community. For example, a person in El Paso would be responsible for updating the El Paso calendar. To focus group participants this is a better proposition than having someone in Austin trying to update calendar sections with local information.</li> <li>• Participants are concerned about who and how this section will be kept up to date</li> </ul>	
Section Name	Comment
Calendars with Major Events and Dates	<ul style="list-style-type: none"> <li>• See under general comments</li> </ul>

**Table 10:** Focus group feedback on specific content to be included in the Calendar section

<b>Contact Us</b>	
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• Include local contact information for someone from DADS (i.e., all people are not computer literate and may need to contact DADS) to include phone number and postal mail address</li> <li>• Include local points of contact (e.g., Workforce Solutions that can assist a person with ASD to get a job or remain in the workforce)</li> </ul>	
Section Name	Comment
Not applicable	<ul style="list-style-type: none"> <li>• No feedback provided</li> </ul>



## 5.4 Design

### 5.4.1 Main Themes and Key Points

At the beginning of each focus group discussion about website design, participants were shown examples of three different, non-Autism-related websites.<sup>1</sup> Two slides exhibiting essential features for each of the three websites were also presented to participants. Participants were asked to provide feedback on each of the three websites and slides.

Based on discussions in all focus groups, several common website design themes emerged (Table 3). These included: (1) information being organized by key target audiences; (2) availability of search function for local services and providers; (3) ease of navigation and user-friendliness; (4) and use of colors, pictures, and videos. In addition, participants commented on positive and negative qualities of each of the three example websites (Table 4). In addition, participants discussed what features or elements a website should and should not have (Table 5).

**Table 11:** Website design themes

Themes	Description
1. Organized by key target audiences	Focus group participants recommend that the website categorize information by specific target audiences, (e.g., persons with ASD, families of persons with ASD, professionals, etc.). At least two focus groups indicate there should be “Who am I” buttons / links for the key target audiences.
2. Search feature for local services / providers	Focus group participants support a search feature for local resources, services and providers. There were many suggestions regarding how this search function should be designed, (e.g., by county, by zip code, by independent school district, by educational services center, etc.). If possible, participants support multiple search options.
3. Easy to navigate; user-friendly	Focus group participants recommend that the website be user-friendly for all audiences, be easy to navigate and text should be limited. The website should be welcoming and use a variety of visuals, icons, pictures and graphics.
4. Colors	Focus group participants prefer the use of bold yet soothing colors such as blue, tan, and ecru. Participants suggested that the design avoid using dark backgrounds with white lettering, as it is difficult to read and avoid using too much red and yellow.

<sup>1</sup> This process was used in six of the seven focus groups. The first focus group in Austin had four website examples. Based on feedback received at this meeting, one website was eliminated from the set of examples due to negative feedback.



Themes	Description
5. Use of pictures	Focus group participants recommend the use of pictures on the website including pictures of children and adults with ASD performing daily activities and pictures and icons to serve as links to other information.
6. Use of videos	Most focus group participants recommend the availability of videos on the website but most prefer the videos not be on the website homepage. Some participants would like the capability to download videos to social networking sites. Most participants also liked the video streaming or rolling banners including current or newly released information.
7. Links to social media	Many participants liked the idea of linking the website to social media outlets like Facebook and Twitter.



**Table 12:** Focus group feedback on example websites

Website	Positive Qualities	Negative Qualities
<b>Website 1</b>	<ul style="list-style-type: none"> <li>• None identified</li> </ul>	<ul style="list-style-type: none"> <li>• Generally, participants did not like this website</li> <li>• Color scheme not visually appealing</li> <li>• Do not like the yellow</li> <li>• Not user-friendly</li> <li>• Not professional</li> <li>• Cluttered</li> <li>• Difficult to know where to start</li> <li>• Print is too small</li> <li>• Big graph takes up too much space</li> </ul>
<b>Website 2</b>	<ul style="list-style-type: none"> <li>• Most focus group participants preferred this website</li> <li>• Format of words across the top and down the left side</li> <li>• Links to social media sites</li> <li>• Search function</li> <li>• Layout</li> <li>• Color scheme</li> <li>• Colors are soothing</li> <li>• Believe you could find the information needed</li> <li>• Appears easy to navigate</li> <li>• Scrolling banners, although they may not be ADA compliant</li> <li>• Website well organized</li> <li>• Not too busy</li> <li>• Site map at the bottom</li> <li>• "Contact us" area</li> <li>• Table in the middle</li> <li>• Pictures and icons</li> <li>• Icons used for links</li> </ul>	<ul style="list-style-type: none"> <li>• None identified</li> </ul>
<b>Website 3</b>	<ul style="list-style-type: none"> <li>• Generally, most participants did not prefer this website although it contains features they like</li> <li>• Use of video clips but not on homepage</li> <li>• Rotating stories on homepage highlighting current activities</li> <li>• Streaming video as it brings a human component to the website</li> <li>• Option to play videos</li> <li>• Option of downloading a video to Facebook</li> </ul>	<ul style="list-style-type: none"> <li>• Too busy</li> <li>• Too cluttered</li> <li>• Too red</li> </ul>

**Table 13:** General website design comments

The website should	The website should not
<ul style="list-style-type: none"> <li>• Be connected to specific target audiences and include information that each audience needs</li> <li>• Include search and share functions</li> <li>• Include blog capability to allow consumers to share information. The blog might be organized by topic (e.g., sensory integration)</li> <li>• Be easy to use and not too much to look at</li> <li>• Include a search for services capability by zip code</li> <li>• Include visuals, pictures, and graphics</li> <li>• Break up text where possible</li> <li>• Have the menu across the top of the screen</li> <li>• Include rotating “hot topics”</li> <li>• Be limited to only 4-6 main areas</li> <li>• Be easy to navigate and user friendly</li> <li>• Be welcoming</li> <li>• Be friendly to persons with ASD, parents and professionals</li> <li>• Use icons and pictures</li> <li>• Provide clear buttons</li> <li>• Use bold colors</li> <li>• Have video capability</li> <li>• Be dynamic and have information on current events, news, etc</li> <li>• Have a “Who Am I” section</li> <li>• Include a map where consumers can do a search for local services / providers</li> <li>• Focus on the positive aspects of ASD.</li> <li>• Include “success stories.”</li> <li>• Be ADA compliant</li> <li>• Include pictures of children and adults with ASD doing everyday things</li> <li>• Include new, up-to-date information</li> <li>• Be written at a level all can understand (e.g., third to fifth grade reading level)</li> <li>• Have a map link to the resource / service / provider (e.g., via MapQuest or Google maps)</li> <li>• Include a visitor count</li> <li>• Have a local focus</li> <li>• Be easy to upload in rural areas that have limited Internet access</li> <li>• Be kept current</li> <li>• Be in both English and Spanish</li> <li>• Be useful for parents</li> <li>• Confirm that any contacts listed or linked can be contacted</li> <li>• Include information about how to apply for services</li> <li>• Include information on which doctors / professionals are still providing services and accepting new patients</li> </ul>	<ul style="list-style-type: none"> <li>• Be as busy as the DADS website</li> <li>• Have too many words; text should be limited where possible</li> <li>• Include a dark background with white lettering as it is difficult to read</li> <li>• Be busy / cluttered</li> </ul>





## 5.5 Additional Comments

Focus group participants were asked to provide additional comments not made in the four main topic areas. These comments are listed as follows:

- It was suggested that an additional focus group be held for persons with autism.
- DADS will need to allow ownership at the local level if the agency wants local partners or service providers to provide calendar update information.
- Participants asked if DADS is developing the website or if they are contracting with a private developer. Participants suggested DADS contract with a private developer.

Participants were also asked to share what was most important to them about the website. The responses are as follows:

- Focus on Family
- Include resources for individuals and families
- Good for families and professionals
- Navigation easy – quick ways to get to the information you like
- Get the website up and running soon
- Useful information
- Professionals needing resources know where to come
- Becomes widely known – includes options for sponsorship
- Comes up when you Google ASD – may have to pay to have it listed
- Include support for siblings
- Link to other good resources
- Helpful, accurate and good for individuals
- DADS affiliation needs to be dropped – TARRC should be the prominent domain
- Easy to use; good web resources
- Need a knowledgeable web designer for key words and linking capability
- The website needs to be user-friendly, provide clear and quick access, and have a search function.
- The colors should have eye appeal, be softer, such as blues and tans.
- The headings should have drop-down menus.
- The design should include a search window.
- The top of the home page needs to catch the attention of a visitor to the site.
- The first thing a visitor to the site should see is: “I am a person with ASD”; “I am the parent of someone with ASD”; “I am a family member of someone with ASD”; “I am a professional interacting with someone with ASD.” Each could be in a different colored box for the user to click on or each could be in a big bubble on the home page.
- The website has to be purposeful and user-friendly for people with ASD.
- Consider identifying the 10 key questions that are most important.



- The website needs to have the capability for a user to type in a question and receive a response.
- The website should be simple, not cluttered.
- The website should be current, not outdated.
- The MHMRA of Houston website is very good when looking for a professional.
- When there is bulleted information, consider having the words change color if the user has already reviewed/touch that information.
- It should have a site map.
- The site should provide easy access to local services.
- Having the capability of counting how many times a particular question is submitted should be considered.
- Being able to sign up for email notification of updates on the site should be considered.

None of the focus group participants opted out of receiving further communication from DADS on this project and all would be interested in being contacted to participate in testing of the new site.



## 6 Appendix

### 6.1 Appendix 1 – Abbreviations

**Table 14:** List of abbreviations used in this report

<b>Abbreviation</b>	<b>Description</b>
ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADRC	Aging and Disability Resource Centers
ARD	Admission, Review and Dismissal (process)
ASD	Autism Spectrum Disorders
CARD	Center for Autism and Related Disorders
CPS	Child Protective Services
CSHCN	Children with Special Care Needs
DADS	The Texas Department of Aging and Disability Services
DFPS	Department of Family Protective Services
ECI	Early Childhood Intervention
ESC	Educational Service Center
FAQ	Frequently Asked Questions
HHSC	Health and Human Services Commission
IEP	Individual Education Program
ISD	Independent School District
M-CHAT	Modified Checklist for Autism in Toddlers
MH/MR	Mental Health and Mental Retardation
NARPA	National Association for Rights Protection and Advocacy
NIH	National Institutes of Health
PDF	Portable Document Format
PTA	Parent Teacher Associations
SSI	Supplemental Security Income
TARRC	Texas Autism Research and Resource Center
TEA	Texas Education Agency

