

Focus Group Notes: 2010F-06-DADS-01

## **DADS Texas Autism Research and Resource Center (TARRC) Website Focus Group**

### **Focus Group Summary Notes**

**Location: Austin, Texas**

July 12, 2010

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**Acknowledgements**

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# 1 Meeting Details

## 1.1 Source Information

<b>Client</b>	Texas Department of Aging and Disability Services
<b>Group</b>	Texas Autism Research and Resource Center Austin Focus Group
<b>Date of Session</b>	July 12, 2010
<b>Date Notes Completed</b>	July 15, 2010
<b>Facilitator</b>	John R. Litaker
<b>Note-Taker</b>	Martha McGlothlin
<b>Document Number</b>	2010F-06-DADS-01
<b>Participant Representation</b>	<ul style="list-style-type: none"><li>• Caregiver/Adult</li><li>• Parent and Advocate</li><li>• Parent/Older Child</li><li>• Parent/Recently Diagnosed Child</li><li>• Professional</li><li>• Researcher</li><li>• Service Provider Medical</li><li>• Service Provider Non-Medical</li><li>• Teacher/Administrator</li></ul>

## 1.2 Background

Participants were pre-identified based on input from the Texas Department of Aging and Disability Services (DADS). Invitations were issued prior to the event. Participants continued to registered up to and including the day of the event. Twelve participants attended this focus group session. Information in this document is based on the direct feedback of participants.



### 1.3 Questions Posed to Participants

Participants were asked to provide input on the following aspects to support development of the website.

1. Purpose
2. Target audiences
3. Content
4. Design

**Purpose:** Participants were asked 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 2: Purpose of the Website). Participants discussed these example purposes and were asked to identify additional purposes.

**Target audiences:** Participants were asked to identify potential target audiences for the website. A target audience is a group of persons that would potentially use this website. Participants were provided some example target audiences to start the discussion (see Section 3: Target Audiences). Participants discussed these example target audiences and were asked to identify additional target audiences.

**Content:** Participants were asked to identify specific content, or information, desired on the website. Participants were provided some example content to start the discussion (see Section 4: Content of the Website). Participants discussed the example website content and were asked to identify additional content.

**Design:** Participants were asked 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 websites. They were asked to think about the colors, the look and feel, photos, and other aspects of the sites that they liked or disliked.



## 2 Purpose of the Website

### 2.1 Main Themes / Key Points

Five example purposes were identified prior to the 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:**

- Participants suggested that the word “proven” be replaced with “effective and evidence-based.”
- The purpose statement needs to include references to diagnosis.
- Participants indicated that information on the website should not be duplicative of information on other good, reliable websites.
- There is no need to reinvent the wheel if the information is already available on other websites; links to reliable websites should be included.
- The website should be dynamic and constantly evolving as new information is available.
- Participants suggested that “across the lifespan” be added at the end of this purpose statement.
- It was suggested that access to information about a person’s legal rights be added to a purpose statement.
- It was suggested that “autism spectrum disorders” be changed to read “autism and related disorders.”

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

#### **Discussion points:**

- The website should avoid duplication of information if possible.
- This website will represent the State of Texas and should be very reliable.
- There needs to be a certification process that must be met before information is posted to this website.

**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:**

- Participants suggested that caregivers be added to this purpose statement.
- It was noted that the Region XIII Educational Service Center (ESC) has funding for training module development.
- The Region XIII ESC training modules are good and interactive but not all inclusive.
- Participants cautioned that website consumers should not rely on “one-shot” training modules.
- The website should not include any “pet” projects.
- Any businesses or vendors listed on the website need to be very reliable and credible; there needs to be some criteria developed for determining when a business source is added.
- Participants suggested that there should be advocacy for law enforcement officials and first responders to receive training on ASD.

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

**Discussion points:**

- Participants suggested that the website be brought online in phases with the research efforts in a later phase.
- The website should allow researchers to share information, solicit participants for studies, evidence-based research and evidence-based practice.
- The website needs to include tools for parents to be good consumers of research.
- Have to have a process to assure the validity 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:**

- Participants questioned whether the website could be used for fund raising or to identify grant opportunities.

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

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.



### 3 Target Audience(s) of the Website

#### 3.1 Main themes / key points

Four example target audiences were identified prior to the focus group. These example target audiences were used to start a discussion with participants. The target audiences were read to participants and they were asked if these were appropriate target audiences for the website. They were further asked to identify additional target audiences for the website. The four example target audiences discussed were:

- Families of person with autism spectrum disorder
- Persons with autism spectrum disorder
- Researchers
- Professional providing services to / interacting with persons with ASD

Focus group participants agreed that the target audiences listed above should be included and suggested the following additional target audiences for consideration.

- Individuals with the possibility of an autism and related disorders diagnosis
- Individuals on the spectrum with higher needs
- Both direct delivery and support services professionals
- General public
- Government social services, e.g., Child Protective Services, Adult Protective Services, emergency room social workers, counselors, law enforcement
- Childcare providers
- Respite providers
- Care givers
- Educators
- One participant questioned the distinction between audience and user.



## 4 Content of the Website

### 4.1 Main themes / key points

Participants were asked to comment on the example content documents. Comments specific to an example content section are noted in Table 1. General comments and agreement from participants included:

- It was suggested that the DADS website would be a great, inexpensive and central location to host this website.
- Participants suggested that when a consumer does a web search for “Texas Autism” that this be the first site to come up from the search.
- The website should not be promoted as all things to all people.
- Web designers should “fight” for clear cut words.
- The website should be relevant to Texas and link to reliable Texas sites.
- 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.
- Participants suggested that the criteria should be “evidence-based”.
- Information on the website should be available in English and Spanish and the TARRC should have translation contracts in place for consumers who speak other languages.
- It was suggested that translations be considered for Vietnamese, African, Chinese and Indian populations as well as links to a support person who is knowledgeable about the specific culture and autism. Website information should be culturally appropriate for these populations.
- It was noted that medical institutions have language translators available by phone and that Google has a translation service.
- Participants suggest that materials posted on the website be reflective of the public’s literacy skills and be written at a 3<sup>rd</sup> to 5<sup>th</sup> grade reading level.

**Table 1:** Focus group feedback on example content for the TARRC website

Example Content Section	Specific Feedback
<b>About TARRC</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• No specific comments were made regarding this section.</li> </ul>
<b>About ASD</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• Should include a link to the Autism Society of America.</li> <li>• Should include a link to Autism Society of Greater Austin, a parent-run organization with a great resource list.</li> <li>• Any Baby Can in San Antonio also has a good resource list.</li> <li>• The site should include a disclaimer and a prominent statement that any treatments / interventions included on the site are not endorsed by the state.</li> <li>• Support the inclusion of Autism FAQs.</li> <li>• The certification process for determining what can be posted on the website should include a category on ethics so that parents will be</li> </ul>



	informed.
<b>Services and Resources</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• Should be able to link to the most detailed information possible</li> <li>• Should be able to link to where to access services, e.g., Early Childhood Intervention (ECI)</li> <li>• Families need to know how to access services.</li> <li>• The website should include resources for all domains, e.g., treatment, social, recreational, etc.</li> <li>• Add tools, legal resources and access to services information.</li> <li>• Should include information about how to locate a “trusted” provider.</li> <li>• Include a “how to” guide for consumers trying to locate a service provider.</li> <li>• Should include transition services from pediatric to adult including both community based and medical services.</li> <li>• There needs to be a screening tool or guide for what services are available and guidance on how to access those services.</li> <li>• AutismRiskManagement.com was suggested as a reliable link.</li> <li>• Parents want black and white information but most information is not definitive; parents need good information on which they can make informed decisions.</li> <li>• The website should include a tool that includes sample questions to ask providers to determine if they are qualified.</li> <li>• This section should be categorized by professionals, physicians, psychologists, psychiatrists, different therapy providers, and education support.</li> <li>• Information should be included on the Admission, Review and Dismissal (ARD) process and the Individualized Education Program (IEP).</li> <li>• The site should also include private and vocational services in addition to those offered in the public sector.</li> <li>• Recommended products and books should be included on the website; it was acknowledged that a state agency may not be able to “recommend” a product.</li> <li>• Include a Texas Map and search capability by county and zip code for local services. The search function for services should be in categories such as early childhood intervention, education, etc.</li> <li>• There should be information available regarding emergency preparedness, e.g., hurricane preparedness and how to deal with controlled substances prescriptions.</li> <li>• The site should include information for migrant populations.</li> <li>• Participants suggested that a link with the Heart of Texas Autism Network be considered including blog capability.</li> <li>• There was a liability concern expressed regarding information shared on a blog.</li> <li>• Services and resource information for siblings should be included.</li> </ul>
<b>Training and Development</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• This section should include training resources for law enforcement and first responders.</li> <li>• Reliable / credible video training resources should be available to first responders.</li> <li>• Training resources for law enforcement and first responders should cover the basics.</li> <li>• The State of Florida has some good training materials on autism safety and risk management.</li> </ul>



	<ul style="list-style-type: none"> <li>• Illinois was also mentioned as a state with good training and development resources.</li> <li>• It was suggested that the term “professional” should be defined as many parents of children with ASD consider themselves as professionals.</li> <li>• Add training resources for people with ASD regarding topics such as job training.</li> <li>• Add training resources for potential employers, law enforcement, and first responders regarding interactions with first responders and what to do in certain circumstances.</li> </ul>
<b>Research</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• Include research findings</li> <li>• Should be able to solicit participants for research studies</li> </ul>
<b>ASD in the News</b>	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• No specific comments were made regarding this section.</li> </ul>
<b>Get Involved</b>	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• No specific comments were made regarding this section.</li> </ul>
<b>Calendar</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• It will be important to update this information frequently.</li> </ul>
<b>Contact Us</b>	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• No specific comments were made regarding this section.</li> </ul>
<b>Other: General Considerations</b>	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• No specific comments were made regarding this section.</li> </ul>



## 5 Design of the Website

### 5.1 Main themes / key points

Participants were shown examples of three websites unrelated to autism. Two slides were shown for each of the three websites. Website features were noted and participants were asked to comment about which sites they liked and which sites they did not like. General comments are provided below while specific comments on each of the three example websites are noted in Table 2:

- The website design should be connected to specific target audiences and include information that each audience needs.
- The website design should include search and share functions.
- The website should include blog capability to allow consumers to share information. The blog might be organized by topic, e.g. sensory integration.
- Easy to use - not too much to look at.
- Should not be as busy as the DADS website.
- Not too many words.
- Include a search for services capability by zip code.
- Include visuals, pictures, and graphics.
- Avoid a dark background with white lettering as it is difficult to read.
- Break up text where possible.
- Like having menu across top.
- Include rotating “hot topics.”
- Should be limited to only 4-6 main areas.

**Table 2:** Focus group feedback on example websites

Website Example	Focus Group Participant Feedback
Website 1	<ul style="list-style-type: none"><li>• No specific comments were captured regarding this website.</li></ul>
Website 2	<ul style="list-style-type: none"><li>• No specific comments were captured regarding this website.</li></ul>
Website 3	<ul style="list-style-type: none"><li>• No specific comments were captured regarding this website.</li></ul>
Website 4	<ul style="list-style-type: none"><li>• No specific comments were captured regarding this website.</li></ul>



## 6 Additional Comments

Participants noted the following additional comments:

- It was suggested that an additional focus group be held for persons with autism.
- 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.

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.



## 7 Abbreviations

**Table 3:** List of abbreviations used in focus group summaries

Abbreviation	Description
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
IEP	Individualized 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
PDF	Portable Document Format
PTA	Parent Teacher Associations
SSI	Supplemental Security Income
TARRC	Texas Autism Research and Resource Center

