

Focus Group Notes: 2010F-06-DADS-02

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

**Focus Group Summary Notes**

**Location: El Paso, Texas**

July 14, 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 El Paso Focus Group
<b>Date of Session</b>	July 14, 2010
<b>Date Notes Completed</b>	July 23, 2010
<b>Facilitator</b>	John R. Litaker
<b>Note-Taker</b>	Debra C. Stabeno
<b>Document Number</b>	2010F-06-DADS-02
<b>Participant Representation</b>	<ul style="list-style-type: none"><li>• Teacher/Administrator</li><li>• Parent/Older Child</li><li>• Service Provider Medical</li><li>• Parent/Recently Diagnosed Child</li><li>• Teacher/Administrator</li><li>• Service Provider Non-Medical</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 register up to and including the day of the event. Six 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 who 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 noted that some “non-proven” interventions have validity and work in some children and that the website should be willing to provide information on non-proven interventions.
- The website should provide information on all options so individuals can assess what works best, however, the website should outline which ones are scientifically proven.
- Becoming an evidence-based intervention takes years and some new interventions are very promising
- Educators (i.e., school officials who provide services) can only use evidence-based or scientifically based interventions / treatments, so knowing which ones are evidence-based is useful.

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

#### **Discussion points:**

- There were no discussion points on Example 2.

**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 links be provided to training resources that are good and already available.



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

**Discussion points:**

- There were no discussion points on Example 4.

**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 noted that this example purpose has political implications for advocacy at the state and federal level.

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

**Discussion points:**

- Parents should be a priority for this website.
- The website should be as comprehensive as possible for parents and families with newly diagnosed relatives and serve as a portal for others needing the latest information.
- However, participants warned that the site could have too much information.
- It would be nice if the site could provide baseline data for parents with a newly diagnosed child or for parents seeking information on diagnosis.



### 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.

- Community at large
- Employers
- Families of persons with ASD should include siblings and other Children with Special Health Care Needs (CSHCN)
- First responders
- Higher education (e.g., colleges and researchers)
- Independent school districts and private schools
- Insurance companies and third party payers
- Law enforcement
- Medical community
- Military (with a particular emphasis on availability of local resources)
- Siblings
- Teachers



## 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 include the following.

- Include services available from government agencies
- Provide information on rights, especially those from schools
- Identify diagnoses that would fall under the umbrella of ASD
- Make available entire site in English and in Spanish with other languages to be considered that would be appropriate to Texas
- Include links to Texas resources, but endorsed by DADS<sup>1</sup>
- Make sure state institutions and resources have credibility
- Offer search function by zip code
- Provide information for services that are available locally
- Make available ability to print content in PDF
- Provide videos
- Present content that is optimistic and point out the positive aspects to ASD as well as the challenging aspects

**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>• Opportunity to ask questions to TARRC</li> <li>• Blog for parents to share experiences</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>• Information on ASD and other disorders / disabilities</li> </ul>	
<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>• Option for asking a professional a question</li> <li>• Information specific to Texas</li> <li>• Link to resources; there are currently a lot resources out there to link to</li> <li>• Online social stories (e.g., Channing publications)</li> <li>• Screening tool (e.g., the nine indicators of a diagnosis of ASD; if you have six of them you should seek a professional evaluation)</li> <li>• Checklists</li> <li>• Questions to ask</li> <li>• Education resources (what services are available and where)</li> <li>• Information on legal definitions and framework</li> <li>• Services and resources for older persons with ASD</li> <li>• Services and resources across age ranges (e.g., ECI, schools, and colleges)</li> </ul>	

<sup>1</sup> Participants were in agreement that DADS / TARRC may be unable to make endorsements



	<ul style="list-style-type: none"> <li>• Services and resources on transitional issues</li> <li>• Information on workforce and vocational issues and opportunities</li> <li>• Service qualifications (i.e., the qualifications a person should possess if they are offering a particular type of service or intervention)</li> <li>• Services located in areas with high numbers of military personnel or dependents (i.e., benefits are available to assist military dependents with obtaining / paying for ASD services, but identifying these services in the community is difficult for individuals not familiar with local and state resources).</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>• 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>• Success stories for children and parents</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>• Research changes so much that content must be updated so parents can continue their education</li> <li>• Parents would like to know all information available</li> <li>• Each child is different and responds differently to interventions</li> <li>• Treatment modalities (e.g., ABA and using pictures)</li> <li>• Medical and nutritional treatments</li> <li>• Children often need a variety of treatments</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</li> </ul>
<b>Get Involved</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• Parent-to-parent contact opportunities</li> <li>• How to reach a parent to talk with others</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>• Calendars that provide links to <u>local events</u></li> <li>• Promotion and highlighting of local, state, and national events (e.g., April is national autism awareness month)</li> <li>• Content management system function of the website to give ownership of specific pages to local providers or jurisdictions. This would provide limited permission for select persons to update calendar information in 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> </ul>
<b>Contact Us</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• 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>• Other local points of contact (e.g., Workforce Solutions that can assist a</li> </ul>



<b>Other: General Considerations</b>	<ul style="list-style-type: none"><li>• person with ASD to get a job or remain in the workforce)</li><li>• Use of social networking</li></ul>
	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section
	<ul style="list-style-type: none"><li>• Information on guardianship issues</li><li>• Information specific to adults with ASD (e.g., transition issues, diagnosis as an adult, services available to adults, guardianship)</li><li>• Information to assist individuals who are high functioning</li><li>• Information should be made available to the community at large to support positive interactions with persons with ASD, including providing support to children and parents in a public setting</li><li>• Request a section that highlights people with ASD (i.e., a “Who am I” 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 site needs to be friendly to both parents and professionals
- Use of bold colors is preferred (e.g., as in the second website)
- Prefer limited text (except in areas as appropriate)
- Prefer use of icons and pictures
- Provide clear buttons
- The use of video clips provided a mixed response
- The site needs to be dynamic and have information on current events, news, and a section highlighting people with ASD (i.e., the “Who am I” section)
- There needs to be a map on the front page for a user to be able to click on a location to get local service information
- Some like being able to choose local service information by zip code better. This is due partly to the fact that El Paso has multiple independent school districts so simply choosing El Paso as a location may not differentiate between different services offered at the ISD level
- Have videos that show success stories

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

Website Example	Focus Group Participant Feedback
<b>Website 1</b>	<ul style="list-style-type: none"><li>• Generally, participants did not like this website</li><li>• Did not like the color scheme</li><li>• Felt it was not user-friendly</li></ul>
<b>Website 2</b>	<ul style="list-style-type: none"><li>• Participants preferred this site</li><li>• Liked the layout</li><li>• Liked the color scheme</li><li>• Felt you could find the information you needed</li></ul>
<b>Website 3</b>	<ul style="list-style-type: none"><li>• Liked the use of video clips, but prefer not on the homepage as in this site</li><li>• Liked the rotating stories on the front of the website highlighting current activities</li></ul>



## 6 Additional Comments

Participants noted the following additional comments:

- 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.

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

