

Focus Group Notes: 2010F-06-DADS-03

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

### **Focus Group Summary Notes**

**Location: Lubbock, Texas**

July 16, 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 Lubbock Focus Group
<b>Date of Session</b>	July 16, 2010
<b>Date Notes Completed</b>	July 24, 2010
<b>Facilitator</b>	John R. Litaker
<b>Note-Taker</b>	Martha McGlothlin
<b>Document Number</b>	2010F-06-DADS-03
<b>Participant Representation</b>	<ul style="list-style-type: none"><li>• Adult with ASD</li><li>• Assistant Professor Special Education</li><li>• Caregiver/Adult</li><li>• Parent/Older Child</li><li>• Parent/Recently Diagnosed Child</li><li>• Researcher</li><li>• Service Provider Medical</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. Thirteen participants attended this focus group session. Information in this document is based on the direct feedback of participants. Feedback from two attendees who could not attend was submitted by email and included where appropriate in the report.



### 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:**

- Add the following after proven treatments and interventions: and resources
- Having a site with resources is the number one reason someone will come to the website.
- Participants discussed the term “proven” and asked who would decide what is proven. They asked if this would be verified by studies or hard science.
- Whatever information is provided should be non-judgmental.

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

#### **Discussion points:**

- The “Texas population” should include employers to help employers have an understanding of how to work with staff who may have ASD.
- Other “populations” include schools, police, and the medical profession.
- Awareness and understanding will be dependent on the education level of the users.
- This website should serve a variety of persons.

**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 suggest changing the wording of effective training to effective information.



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

**Discussion points:**

- Publicized information should be evidence-based.
- Links should be provided to nationwide groups like Quackwatch.
- TARRC should not recreate the wheel in providing this information.
- It should serve as a community center and provide basic research results.
- Links should be provided.

**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 like the idea of persons being able to provide input to TARRC and to others, but do not see this as a place for venting.
- This would include proposed legislation and rules that would impact Texans with ASD.

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

- The website should be focused on Texas as rules vary across the state.
- It should provide information on local resources.
- Resources should be a primary challenge.
- Trying to find resources and help is a challenge. If the TARRC website could help individuals with ASD or others who need this information find it, that would be ideal.



### 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.

- The term ***professionals*** should be broken out into specific groups
- General public
- Pediatricians
- Volunteers who may interact with persons with ASD
- Age-specific peers (e.g., students who may attend high school with someone with ASD)
- Co-workers
- Friends of persons with ASD
- Families of persons with ASD
- Faith-based organizations
- Retail establishments (e.g., stores, restaurants, and movie theaters)
- Travel industry (e.g., airlines)
- Day-care establishments
- Community groups (e.g., boy scouts, youth camps, summer camps)

In addition, 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).



## 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:

- 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)).
- The website should not be too basic, but it should also not overwhelm visitors.
- The website should start out general and focus people to more specific information (e.g., Overview of Topic X and after they select Topic X then it would provide additional specific information on that topic).
- The website should encourage and provide an opportunity for users to seek out local resources.
- The entire site must be completely bilingual in English and Spanish.

**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>• This section is a given and must be a part of the website</li> <li>• Provide contact information from administrative standpoint</li> <li>• Provide information on legislation that created TARRC</li> <li>• Discuss next steps and the future of TARRC and of the TARRC website</li> <li>• Provide contact information for TARRC and contact information for the webmaster</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>• Quizzes are helpful, but caution is urged because parents give background information in order to use the quiz properly</li> <li>• A link to Texas Education Agency website on Autism (<a href="http://www.txautism.net">www.txautism.net</a>) (e.g., to training provided online) should be provided</li> <li>• Myths about ASD should be addressed</li> <li>• The spectrum should be differentiated between different disorders (e.g., Autism and Asperger's) with regard to behaviors</li> <li>• The spectrum should be discussed, not just with definitions, but with examples and descriptions (e.g., a person with Autism exhibits these types of characteristics)</li> <li>• Information should be provided concerning what to do when your child receives a diagnosis of ASD</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>• Services and resources should be searchable by region, county, and zip code</li> <li>• Information on resources and services to employers               <ul style="list-style-type: none"> <li>○ Helping prepare someone for employment</li> </ul> </li> </ul>



	<ul style="list-style-type: none"> <li>○ Link to employers friendly to persons with ASD (although permission would need to be obtained first)</li> <li>○ Job coaching for persons with Autism</li> <li>○ Information on workplace awareness</li> <li>• Transportation resources at the local level <ul style="list-style-type: none"> <li>○ Home-to-home services</li> </ul> </li> <li>• Information on Applied Behavior Analysis and access (if it is a state services)</li> <li>• Services that the state is required to provide</li> <li>• Information on how a family can put together a treatment team</li> <li>• Service and resource information to high school students</li> <li>• Local numbers or resource centers, including 211</li> <li>• Transition service information</li> <li>• Legal information (e.g., rights under state law for persons with ASD by age grouping)</li> <li>• Information on rights of parents and children, including applicable information from the Americans with Disabilities Act (ADA)</li> <li>• Link to the Texas Education Agency (<a href="http://www.txautism.net">www.txautism.net</a>) website</li> <li>• Information on guardian and trust issues for those caring for or responsible for adults with ASD</li> <li>• Link to local advocacy groups or support groups</li> <li>• Information for vocational counselors</li> <li>• Data driven information <ul style="list-style-type: none"> <li>○ For example, a recent data-driven research study conducted in New Jersey available at: <a href="http://www.autismnj.org/doc/blueprint.org">www.autismnj.org/doc/blueprint.org</a></li> </ul> </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 and development would be very helpful</li> <li>• Videos would be particular useful, but the shorter the better (3 – 5 minutes)</li> <li>• Training implies an examination, maybe consider calling it something other than training (e.g., information)</li> <li>• The word training may have different interpretations to different people</li> <li>• Do not use the term “specialized training”</li> <li>• Stress that training is “general” and that persons with Autism vary</li> <li>• Training should be provided for law enforcement, especially street officers, through outside resources, not necessarily by TARRC</li> <li>• Training should be provided online</li> <li>• Short “awareness” videos may be a good substitute for in-depth training</li> <li>• Information on where you can go for training should be included</li> <li>• Links to persons / organizations that provide training services (e.g., an organization that provided DVD training to police) should be provided</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>• Participants suggest calling this sponsored research</li> <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> <li>• They recommend not listing all research</li> <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> <li>• If the website is dynamic there could be a top 20 topics section. Participants suggested these topics would need to be decided by a</li> </ul>



	<p>committee</p> <ul style="list-style-type: none"> <li>• Link to other researchers, what grants are available, current workshops, and who is doing what should be included</li> <li>• There is a need for a committee of high-quality researchers to evaluate research information provided on the site</li> <li>• Links to autism-related grants should be provided</li> <li>• Information about study recruitment would be helpful</li> <li>• Participants recommend having links to volunteering</li> <li>• They would like information on translating research to practice</li> <li>• Basic research results should be provided</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>• Did not discuss this section due to time limitations</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>• Did not discuss this section due to time limitations</li> </ul>
<b>Calendar</b>	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• Did not discuss this section due to time limitations</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>• Did not discuss this section due to time limitations</li> </ul>
<b>Other: General Considerations</b>	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> <li>• A Twitter feed for updates on research and new information posted to the website should be provided. This could be a short blurb and would not require major resources for TARRC</li> <li>• For other languages, accommodation must be available for translation</li> <li>• Information in other languages could be provided in hard copy</li> <li>• State information provided on the website should be evidence-based</li> <li>• Information should be non-judgmental</li> <li>• Information should be accurate and not biased</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:

- Website must be ADA compliant
- Do not like videos on the homepage
- Layout should categorize information
- Participants like sub categories
- Site must be user-friendly
- Must have search functionality for resources and services (e.g., by zip code) and a general search feature for topics on the website

**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 did not like this website</li><li>• Color scheme not visually appealing</li><li>• Not professional</li></ul>
<b>Website 2</b>	<ul style="list-style-type: none"><li>• Prefer this website</li><li>• Appears easy to navigate</li><li>• Like scrolling banners, although they are not ADA compliant</li><li>• The colors are soothing</li></ul>
<b>Website 3</b>	<ul style="list-style-type: none"><li>• Did not prefer this site</li><li>• Did not like videos on the homepage</li></ul>

## **6 Additional Comments**

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

