

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

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

### **Focus Group Summary Notes**

**Location: Tyler, Texas**

July 20, 2010

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**Acknowledgements**

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# Table of Contents

<b>1</b>	<b>MEETING DETAILS.....</b>	<b>1</b>
1.1	SOURCE INFORMATION .....	1
1.2	BACKGROUND.....	1
1.3	QUESTIONS POSED TO PARTICIPANTS .....	1
<b>2</b>	<b>PURPOSE OF THE WEBSITE .....</b>	<b>2</b>
2.1	MAIN THEMES / KEY POINTS.....	2
<b>3</b>	<b>TARGET AUDIENCE(S) OF THE WEBSITE .....</b>	<b>4</b>
3.1	MAIN THEMES / KEY POINTS.....	4
<b>4</b>	<b>CONTENT OF THE WEBSITE .....</b>	<b>5</b>
4.1	MAIN THEMES / KEY POINTS.....	5
<b>5</b>	<b>DESIGN OF THE WEBSITE.....</b>	<b>9</b>
5.1	MAIN THEMES / KEY POINTS.....	9
<b>6</b>	<b>ADDITIONAL COMMENTS .....</b>	<b>11</b>
<b>7</b>	<b>ABBREVIATIONS.....</b>	<b>12</b>



# 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 Tyler Focus Group
<b>Date of Session</b>	July 20, 2010
<b>Date Notes Completed</b>	July 24, 2010
<b>Facilitator</b>	Martha McGlothlin
<b>Note-Taker</b>	Debra C. Stabeno
<b>Document Number</b>	2010F-06-DADS-06
<b>Participant Representation</b>	<ul style="list-style-type: none"><li>• Advocate</li><li>• Caregiver/Adult</li><li>• Parent/Older Child</li><li>• Parent/Recently Diagnosed Child</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 register up to and including the day of the event. Nineteen 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 indicated that this purpose statement does the most to reach out to families.
- Experienced service providers for treatments and interventions should be listed on the website.
- The website should have a local focus and that should be the primary purpose.
- There was general support for this purpose statement.

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

#### **Discussion points:**

- This purpose statement is supported 100% as most people do not understand ASD.
- The website should convey to professionals and the public how to interact with people with ASD.
- The website should promote individual and family advocacy.
- The site should include links to other resources such as Autism Speaks – The First 100 Days.
- There was general support for this purpose statement.

**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:**

- Pediatricians should be added and emphasized as a professional group.
- There are several good autism websites available now but many professionals do not access them currently.



- The website should include information / resources about treating ASD across the lifespan.
- There should be links to existing training resources.
- The website should include resources for day-care centers, for young children and day programs for individuals beyond school age.
- There should be online and print resources and links to organizations that provide services / support for people with ASD.
- The site should include blogs for families.
- There was general support for this purpose statement.

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

**Discussion points:**

- Participants have concerns about who will screen and approve research efforts and findings to be posted on the website; the research has to be credible.
- There should be categories of research efforts with links to other organizations that provide services including early childhood intervention, sensory and behavioral, etc.

**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 if the website is the right forum for input.
- Participants support the opportunity for political advocacy for needed change.

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

- No comments were made.



### **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.

- General public
- Faith-based community
- Law enforcement
- Professionals should be categorized, e.g. pediatricians, therapists, support groups, law enforcement



## 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:

- There needs to be an editor for the website and postings need to be written professionally.
- The 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.
- The website needs to have a local focus and include local providers / programs / services.
- It is critical that the website information be kept up to date particularly for local provider / services information.
- The website name should be Texas specific not government specific or many people will not access the site. TARRC sounds like a government program.
- There needs to be a formal process to validate the information that gets posted on the website and the information needs to be updated regularly.
- The website should include a glossary of terms, definitions and acronyms.

**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>• Participants suggest that the website include pictures, background and contact information including phone numbers for staff. Participants indicated that the Tyler newspaper website could be used as a good example.</li> <li>• Participants indicated that staff listed should answer their own calls / emails and should be available to take calls when website consumers need help without being passed through multiple people. It was questioned whether the “Our Mission” category was really needed on the website.</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>• The website should include information / resources about treating ASD across the lifespan.</li> <li>• The website should include resources for day-care centers, for young children and day programs for individuals beyond public school age.</li> <li>• There should be online and print resources and links to organizations that provide services / support for people with ASD.</li> <li>• The site should include blogs for families.</li> <li>• Participants expressed concern about having fill-in-the-blank screening tools and quizzes available on the site; there was general support for</li> </ul>



- not posting these tools on the website.
- It was suggested that the website could include examples of early signs and symptoms with an indication that they are not intended to diagnose but should include links to local professionals.
- It was recommended that links to other good websites should be included; e.g., Autism Speaks- The First 100 Days.
- The website should include developmental milestones and links to Early Childhood Intervention (ECI) programs.
- Participants were concerned about how treatments / interventions will be screened and approved for posting on the website.
- It was suggested that theater interventions should be included.
- Participants noted that pediatricians in this area of the state usually refer patients to speech / language services first.
- It was noted that there are overlaps between treatments and interventions and services and resources.
- Participants suggested that the website should contain information on the Admission, Review and Dismissal (ARD) process
- Some participants had concerns regarding whether alternative treatments and interventions should be included and strongly noted that the website should not “tempt” parents to use alternative treatments.
- Some participants indicated that a description of all treatments and interventions, both evidence-based and alternative should be included but should not be endorsed or recommended.
- Some participants felt that the website should not limit any credible information but consumers should be encouraged to consult with a professional.
- Respite services should be included.
- The website should not promise a cure.

**Services and Resources**

Include this section  Do not include this section

- There should be a category for financial resources including Supplemental Security Income (SSI). This category should include insurance information and provide information across all socio-economic levels.
- Participants questioned why Applied Behavior Analysis (ABA) was included under Services and Resources as it seemed more appropriate under the Treatment and Intervention category.
- A link to the Center for Autism and Related Disorders (CARD) should be included.
- Services and Resources should include public, private and not-for-profit providers. It was reported that 50% of businesses in East Texas were not-for-profit.
- The website should include easy-to-understand information about governmental services and programs, e.g. CLASS waiver, including information about getting on the waiting list as early as possible.
- Services and Resources should include information about group homes and adult training resources.
- Information should be provided regarding legal rights of parents.
- Participants indicated that there should be links to special education staff at educational service centers and independent school districts (ISD).
- Participants indicated that communications with a local special education professional at the individual school campus are very important
- The website should include the names and contact information for local



diagnosticians.

**Training and Development**

Include this section  Do not include this section

- Participants suggested that the word “training” should be changed to “education” in this section.
- Day program providers need access to current information and resources.
- Schools serve as a safe haven to many parents; parents and young adults with ASD need a lot of resources about transition planning and adult resources after transitioning from the school safety net.
- Group homes are a booming business in this part of the state and need access to education and developmental resources.
- There needs to be significant resources for both newly diagnosed parents and young adults making transitions.
- Professionals, even in schools, need resources to support education / training. Access to blogs where other teachers can provide testimonials would be helpful and provide a good support system.
- Young adults should have access to theater resources.
- It would be helpful if the website could include a “bag of tricks” including resources and activities for schools and day-care settings.
- Education programs from academia are very important.
- Education tools for legal issues particularly guardianship information need to be added.

**Research**

Include this section  Do not include this section

- Participants suggested that research could possibly be categorized as peer-reviewed, published or non-published.
- It was indicated that the website should have blog capability.
- Credible academic resources should be included on the website.
- 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.

**ASD in the News**

Include this section  Do not include this section

- There was general support for this section.

**Get Involved**

Include this section  Do not include this section

- This section should include contact information for local, state and federal elected officials.
- There should be links to applicable legislation, both proposed and passed.
- Participants indicated that it would be helpful to have information regarding local and state support groups available.
- Under the sponsor event category, participants indicated that local sponsors could be identified.
- Information on state and local support groups should be included.

**Calendar**

Include this section  Do not include this section

- Participants indicated that local events should be included. Participants are concerned about who and how this section will be kept up to date.



**Contact Us**

Include this section

Do not include this section

- This section should include contact information for area state legislators and members of Congress.



## 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 should be easy to upload for rural areas with access issues
- Easy to navigate
- Keep it local
- Need to be able to learn something new
- Useful information for everyone looking
- Needs to include a robust local link
- User-friendly; easy to navigate
- Written at a level for all
- Verbiage is understandable for all
- Average reading level is considered – should be written at newspaper level
- Newly diagnosed parents / families don't feel alone – access to local resources
- Local, current, credible
- Current information
- Useful to parents
- Current / local
- Contacts have to be contactable
- Program availability / connectivity; information about how to apply for services
- Parents can get specific contact information
- Keep local information updated and include links to local websites
- Hispanic population – it is critical that they get the information needed
- The website should be in both English and Spanish
- Readability – with easy links
- Need a reliable place to send people with clear contacts / addresses
- Someone needs to confirm contactability for all contacts listed
- Needs to include information about which doctors / professionals are still providing services and taking new patients
- Local providers and stakeholders should be notified when the website is up and running

Note: Participants asked to be notified when the website is up and running.



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

<b>Website Example</b>	<b>Focus Group Participant Feedback</b>
<b>Website 1</b>	<ul style="list-style-type: none"><li>• The puzzle piece graphic should be included.</li><li>• It is difficult to know where to start on this website.</li><li>• The print is small.</li></ul>
<b>Website 2</b>	<ul style="list-style-type: none"><li>• Like the words across the top and down the left side</li><li>• Like having the site map at the bottom</li><li>• Like the links to social media at the bottom</li><li>• Like having the "Contact Us"</li><li>• Like having the table in the middle</li><li>• Like the pictures and icons</li></ul>
<b>Website 3</b>	<ul style="list-style-type: none"><li>• Like having the option to play the video</li><li>• Would like the option of downloading a video to Facebook</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

