

Focus Group Notes: 2010F-06-DADS-05

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

Focus Group Summary Notes

Location: Harlingen, Texas

July 20, 2010

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Acknowledgements

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1 Meeting Details

1.1 Source Information

Client	Texas Department of Aging and Disability Services
Group	Texas Autism Research and Resource Center Harlingen Focus Group
Date of Session	July 20, 2010
Date Notes Completed	July 20, 2010
Facilitator	John R. Litaker
Note-Taker	Ethel Garcia
Document Number	2010F-06-DADS-05
Participant Representation	<ul style="list-style-type: none">• Advocate• Caregiver/Adult• Parent/Older Child• Parent/Recently Diagnosed Child• Researcher• Service Provider Medical• Service Provider Non-Medical• Teacher/Administrator

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. Eighteen 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 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:

- This is important as an opening statement, but should not be limited to *information* regarding autism spectrum disorder (ASD), but should also include information on tools to assess for ASD. Participants noted that information on tools for assessment is important because sometimes children receive a diagnosis of ASD, but do not know how this was made. Similarly, some pediatricians are not knowledgeable of diagnostic tools.
- It is important to link to model programs that are currently in existence.
- This statement needs to be worded simply so that all audiences can understand the purpose of the website.
- The word “proven” should be replaced with the term evidence-based research or the term research-based, as this is the standard used in practice. The term evidence-based or research-based should be defined for parents.

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

Discussion points:

- The terms awareness and understanding should be broadly defined to include awareness and understanding of the educational, vocational, and social implications of the disorder. That is, can the website describe some of the issues in providing educational services to someone with autism or the issues involved with successfully hiring and maintaining a person with ASD in the workforce.
- This purpose should include promoting and supporting ASD within the community.
- It should promote awareness and understanding among parents. In particular, the website should provide content on parents helping parents.
- Awareness should include identifying processes to help parents understand what it means to have a newly diagnosed child, the pressures this will bring over time, and available support services.



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:

- A main concern about this statement occurred with the word “professionals” and the definition of this word. Participants noted that while the term professional is probably broad-based to include most professional occupations that may interact with a person with ASD, the term professional might be off-putting. As one participant noted: “If I am a bus driver and I see the word professional, I am not going to think the website is for me and I am not going to the website.”
- Participants were in wide agreement that this purpose – to provide training and development tools – was laudable, but that the target should be broad-based. Therefore, instead of using the word “professionals” that a broader definition to include clinical professionals, classmates, caregivers, coworkers, peers, and persons who may interact with a person with ASD (e.g., bus driver, shop clerk, etc.) will feel like this website is intended for them.
- Professionals could also be broadly expanded to include legislators who may require more information on ASD.
- The term “research” should be expanded to include research or evidence-based training.
- It should be specific concerning what training and to whom, and that this website serves as a portal to training (i.e., that TARRC is not necessarily going to create training modules, but will serve as a conduit to training modules already in place).
- This should include information on grants available.

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

Discussion points:

- Statistics, demographic information, incidence and prevalence information, and quick facts related to the disease should be included. This could serve as a one-stop source for Texas information on the disease.
- Links to the U.S. Centers for Disease Control and Prevention site for state specific (i.e., Texas) data should be provided.
- Information on local research should be made available. Participants noted that research occurs at the local level, but on a smaller scale than at the state level, but that such research has value to the community. They would like to be aware of this research.
- Local research could also be used to identify potential individuals at the local level who could be recruited to participate in a research study.
- Links should be available to publicize research efforts.



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 liked the idea of being able to provide feedback to TARRC. Most of these comments related to specific content feedback that would be useful to the website target audiences.
- Participants were concerned about the “Texas” focus. This sensitivity is due to the strong cultural, historic, and economic ties on both sides of the international border. Participants noted that this situation is not unique to Texas / Mexico border communities, but may also be applicable to north Texas and Oklahoma or east Texas and Louisiana. As such, participants support the idea of an inclusive website that can be used by a large audience. For example, they suggested using the phrase: “Texas and friends.” They also supported cultural diversity.
- Self-advocacy should also be a portion of this site. For example, an individual or family who has learned to self-advocate can provide feedback to others on how to do this.
- Input on support groups for families, for policies, and advisory groups would be welcomed.

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

- No comments provided.



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.

- Legislators
- Caregivers (e.g., pediatricians and obstetricians / gynecologists)¹
- Day-care centers
- Friends / peers / neighbors
- Classmates
- Librarians
- Children (e.g., siblings, friends, or other youth)
- First responders (e.g., law enforcement, fire services, and emergency medical services)
- Criminal justice system (e.g., judges and lawyers)
- State agencies (e.g., within the state health and human services enterprise)
- Support agencies (e.g., Educational Support Centers)
- University students interested in this field
- Faith-based organizations
- Service providers (e.g., home health attendants)
- Youth organizations (e.g., youth groups, boy scouts, summer camp groups, etc.)

¹ This comment was based on a lack of knowledge by these two medical specialties regarding ASD and diagnosis for 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. For each example content section, the consensus of whether to include or not include a section is noted. General comments and agreement from participants included:

- The entire website should be in both English and Spanish with the suggestion that participants are asked to choose their language when they first arrive at the homepage.
- A general disclaimer should be included that the information provided on this website is intended to serve as a resource, but that each person with ASD is different, so information on this site should be considered in that regard.

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

Example Content Section	Specific Feedback
About TARRC	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • Add a vision statement for TARRC (to accompany the mission statement) • Provide the history of TARRC, including background on House Bill 1574, the need for a center, and how the center came about • Mention that the website was designed based on input from participants who attended seven focus groups in Texas
About ASD	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • Section on prognosis to include information on: what to expect from this diagnosis, what is the life expectancy, what are the social, educational, and vocational expectations of someone with autism, and information on how to transition to independent living • Section on success stories (i.e., individuals who have exceptional skills because of ASD or who have excelled notwithstanding a diagnosis of ASD) • Information on other syndromes related to ASD (e.g., Fragile X) • Information on expected comorbid conditions (e.g., someone with ASD is often depressed or anxious or that blindness occurs at a higher rate in individuals with ASD) • Causes of ASD • Facts and myths related to ASD (e.g., facts and myths related to the causes, treatments, and living with ASD) • Frequently asked questions (FAQs) on issues related to parental guilt and how to overcome, and other similar issues • 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) • Information on self-advocacy to help students, children, and adults reach a high quality of life, how to develop talents, and how to have full integration to society



	<ul style="list-style-type: none"> • General information on ASD <ul style="list-style-type: none"> ○ How to evaluate ○ Prognosis ○ Life expectancy ○ Independent living and transition information ○ Talents and success stories ○ Exceptional skills ○ Independent living information ○ Related syndromes ○ Differential diagnoses ○ Likely comorbid conditions ○ Social syndrome information
Services and Resources	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • Resources and information on daily living (e.g., time management guidelines), acceptance, nutritional needs, lifestyle, and resources for parents • Information on what to expect on a daily basis • Information on 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 • Information on how to interact with siblings • Information on 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) • Local resource information on respite care resources for parents • Information on a research-based or evidence-based visual calendar for daily living • Section entitled: proven methods of providers • Links to early childhood intervention • Information on transportation resources • Information to employers and how to employ persons with ASD • Information on working with pets / pet therapy • Ability to identify resources by county level • Transitional information <ul style="list-style-type: none"> ○ Children with ASD will become adults with ASD and then older adults with ASD ○ Aging with autism ○ Living with ASD over the lifetime ○ Working with ASD • Information targeted toward schools on early intervention <ul style="list-style-type: none"> ○ Information on early intervention is essential ○ Information on how listening to the child or parents can help teachers identify a need for interventions • Links to proven methods such as applied behavioral therapy providers and Son-Rise Program • Information for families on daily living • Blog or podcast to allow the website to become interactive and alive • Training for professionals <ul style="list-style-type: none"> ○ For example, available training modules and manuals developed by the University of Texas at Brownsville • Links to private and agency-based practitioners (e.g., doctors, social workers, educational specialists) • Instructions where families can obtain information on funding support for treatment (e.g., Medicaid and Medicare)



	<ul style="list-style-type: none"> • Communicate information concerning awareness of educational services available for the child / family with ASD <ul style="list-style-type: none"> ○ Early childhood intervention (ECI) ○ Special education resources ○ Post-secondary options ○ Guardianship information
Training and Development	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • No comments were made.
Research	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • Include grants available and active or pending legislation • Funding for grants for services and research • Research should not be limited to Texas research, but should provide information internationally.
ASD in the News	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • No comments were made.
Get Involved	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • No comments were made.
Calendar	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • No comments were made.
Contact Us	<input type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • No comments were made.
Other: General Considerations	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section <ul style="list-style-type: none"> • Provide a child site / child section on the website • Site should be multi-cultural • Provide a glossary of educational terms • Spanish vocabulary and terms should be translated, but not in a literal translation, but rather in terms that explain the symptoms and support • Links to the following <ul style="list-style-type: none"> ○ AutismSpeaks.org ○ Autism Society of America ○ Texas Statewide Leadership for Autism (e.g., online courses and available continuing education units) ○ Centers for Disease Control and Prevention website



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:

- There is a need to focus on positive aspects of ASD and not just the negative aspects. Participants specifically noted that it is important for parents and caregivers to realize that ASD, while challenging, is manageable.
- Participants would like to see pictures of children with autism doing everyday things, socializing, etc.
- They would like to see online video streaming or short broadcasts of information as on the home page of website number three.
- They would like the website to be organized so users can easily find information to one age group.
- When clicking a link, please have a new page popup instead of leaving the previous page.
- A search bar is needed (e.g., to search for information on Asperger's syndrome).
- A method to search for resources is needed. Some suggestions included:
 - County name
 - Distance to locations
 - Include resources in all surrounding areas based on zip code or county
 - Create an online map that would have an area highlighted in a specific color when the mouse moves across it
- Participants also request a map link to the resource (e.g., via MapQuest or Google maps).
- A visitor count on the homepage or some accessible page should be included.
- There needs to be a search bar on the website to find specific topics.
- Participants would like resources stratified by specific regions (e.g., Education Service Center).



Table 2: Focus group feedback on example websites

Website Example	Focus Group Participant Feedback
Website 1	<ul style="list-style-type: none">• Generally, participants did not like this website• Felt this website was cluttered
Website 2	<ul style="list-style-type: none">• Positive feedback about this website• This website is not busy• It is well organized• Like the colors used
Website 3	<ul style="list-style-type: none">• Generally, participants did not prefer this website, although some noted that they liked it• Like the streaming video as it brings a human component to the website



6 Additional Comments

No additional comments were made.

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

