

Focus Group Notes: 2010F-06-DADS-04

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

Focus Group Summary Notes

Location: Dallas, Texas

July 19, 2010

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Acknowledgements

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Table of Contents

1	MEETING DETAILS.....	1
1.1	SOURCE INFORMATION	1
1.2	BACKGROUND.....	1
1.3	QUESTIONS POSED TO PARTICIPANTS	1
2	PURPOSE OF THE WEBSITE	2
2.1	MAIN THEMES / KEY POINTS.....	2
3	TARGET AUDIENCE(S) OF THE WEBSITE	5
3.1	MAIN THEMES / KEY POINTS.....	5
4	CONTENT OF THE WEBSITE	6
4.1	MAIN THEMES / KEY POINTS.....	6
5	DESIGN OF THE WEBSITE.....	9
5.1	MAIN THEMES / KEY POINTS.....	9
6	ADDITIONAL COMMENTS	10
7	ABBREVIATIONS.....	11



1 Meeting Details

1.1 Source Information

Client	Texas Department of Aging and Disability Services
Group	Texas Autism Research and Resource Center Dallas Focus Group
Date of Session	July 19, 2010
Date Notes Completed	July 24, 2010
Facilitator	Martha McGlothlin
Note-Taker	Debra C. Stabeno
Document Number	2010F-06-DADS-04
Participant Representation	<ul style="list-style-type: none">• Advocate• Caregiver/Adult• Non-parent family• Parent/Older Child• Parent/Recently Diagnosed Child• Professional• 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. 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 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 were concerned with the word “proven” and indicated that there are not many “proven” treatments and interventions.
- The word “proven” should be replaced with evidenced-based and emerging practices as all children react differently to different services, treatments and interventions.
- Participants also suggest that controversial treatments and interventions be considered for inclusion in the purpose and on the site because some are helpful with some children on the spectrum but with a disclaimer that the State is not endorsing these treatments or interventions.
- It was noted that even some traditional treatments are controversial for some children.
- Participants were supportive of including this purpose statement modified based on comments above.

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

Discussion points:

- Participants are particularly concerned with promoting awareness and understanding for newly diagnosed individuals and their parents.
- Participants supported 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:

- A main concern about this statement centered on the words “effective training” as participants do not believe the website will provide training in the traditional sense. The purpose and the site, itself, should not imply that all the training needed by professionals is available on this website and that professionals are only able to practice within the bounds of their competency.
- It is suggested that words “effective training” be replaced with “educational opportunities.”
- It is suggested that the purpose statement should be expanded to include key strategies / implementation tools in addition to development tools.
- Participants were supportive of including this purpose statement modified based on comments above.

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

Discussion points:

- Participants were concerned about the process to determine what research is considered “significant” and what research gets posted on the site. It is recommended that the process to post research efforts or findings be juried or peer-reviewed.
- Participants strongly suggested that the site include links and references to the latest research.
- There was a difference of opinion on whether only evidenced-based research findings be posted as some participants want all findings publicized but with disclaimers.
- It was suggested that clarification should be provided that research is different than clinical practice.
- Participants strongly suggested that the purpose for this site include opportunities to promote Texas’ evidenced-based research and identify opportunities for participation in new or ongoing research.
- Participants were supportive of including this purpose statement modified based on comments above.
- A suggested rewording of this purpose is: To promote the research involvement of professionals and those affected by ASD, provide links to research-based sites, and communicate relevant findings in an easily understood way.

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 discussed the opportunity to seek information to influence legislative policy and funding.
- Participants were supportive of including this purpose statement.



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

Discussion points:

- There is a need to identify resources available to individuals with autism across the lifespan (in each area).
- There is a need to identify resources for adults and to provide information on transition planning to parents of children with ASD.



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.

- New diagnosed patients / parents
- Siblings
- Spouses
- Extended families, e.g., grandparents, aunts, uncles, cousins, etc.
- Adults with ASD
- Childcare providers
- Law enforcement officials
- Judges / juries
- Child Protective Services (CPS) – foster families
- Persons interacting with persons with ASD
- First responders
- General public
- Lawmakers / policy makers
- Professions providing direct services, ancillary services and incidental services
- (Prospective) employers
- (Prospective) university/college faculty and staff



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:

- Include a search feature by category and by key words
- Don't reinvent the wheel – there are lots of good resources already developed and the TARRC website should provide links to those resources
- Limit redundancy with other websites to the extent possible
- Write website at a reading level that is easy to understand

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"> • Press releases / publications / reports should be more prominent; assumption is that all press / publications will be up to date and that the site will be dynamic and updated constantly 	
About ASD	<input checked="" type="checkbox"/> Include this section	<input type="checkbox"/> Do not include this section
	<ul style="list-style-type: none"> • Consider some sub-typing of treatments and interventions • Include both evidenced-based and alternative treatments and interventions but include controversies for all as even some evidenced-based treatments are controversial • Include potential side effects of bio-medical treatments / interventions which have side effects • Include a description of the different disorders and how they present • Include frequent co-morbid disorders / associated features • Provide a section for non-professionals but more for families • Include link to the Modified Checklist for Autism in Toddlers (M-CHAT) • Include link to the Autism Speaks First 100 Days Kit • Include link to the Autism Speaks video examples • Include link to MH/MR • Include link to National Association for Rights Protection and Advocacy (NARPA) • Make available legislative links • Provide family screening tools 	
Services and Resources	<input checked="" type="checkbox"/> Include this section	<input type="checkbox"/> Do not include this section
	<ul style="list-style-type: none"> • Provide older patients/individuals information about group homes around the state/county • Include links to local / regional service providers; it is critical to keep this information up to date • Include links to the Aging and Disability Resource Centers (ADRC) • Provide information for newly diagnosed • Include information for transitional services and planning 	



- Include a glossary of terms and have imbedded links that would take consumers directly to a definition / description of the term
- Provide an index and a search feature by category and key words
- Move link to Applied Behavior Analysis (ABA) under regional / local service providers
- Include a category for faith-based services and links to those services
- Include information regarding community participation opportunities, e.g., fitness programs, mother's day out programs, etc.
- Include "how to" guides by age group
- Include a "know your rights" and self advocacy category
- Include links to other services, e.g., Early Childhood Intervention (ECI)
- Include a financial resources section including information about navigating insurance (including self-funded insurance plans) and payment options
- Include links to legal service providers including those who specialize in guardianship issues
- Include links to the education system including special education and Parent Teacher Associations (PTA)
- Suggestion to move the category "Autism Organizations" to the Get Involved section

Training and Development

Include this section Do not include this section

- Include a video glossary and links to existing products
- Include ancillary and incidental information
- Include a category for employers and potential employers
- Include a category for caregivers including daycare
- Include a category for individuals and the public regarding information about understanding and communicating with people with ASD
- Include guides to financial resources / assistance / planning
- Include information about government programs and services
- Include a category for people with ASD including links to good resources including cell phone and web-based safety resources
- Include training on social skills
- Include job coaching skills
- Include a category for schools
- Consider including the capability for webinars

Research

Include this section Do not include this section

- Has to be objective as there is a lot of controversy on ASD
- Consider a link to Pub Med and other reliable sources of research

ASD in the News

Include this section Do not include this section

- No specific comments

Get Involved

Include this section Do not include this section

- Include a section titled "Submit a Suggestion to TARRC"
- Consumers should be able to submit suggestions regarding the website design and content
- Include a section on federal and state legislation both proposed and passed legislation
- Include a legislation analysis and how this might impact the ASD community
- Include information / links to the Texas Health and Human Services Regions



	<ul style="list-style-type: none">• Include a collaboration forum for people with ASD, families and professionals• This section should also include links to research efforts underway and include opportunities to participate in ongoing research
Calendar	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section
	<ul style="list-style-type: none">• Will need to be kept up-to-date
Contact Us	<input checked="" type="checkbox"/> Include this section <input type="checkbox"/> Do not include this section
	<ul style="list-style-type: none">• Include a feedback link for website consumers



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 should be easy to navigate and user-friendly.
- The site should be welcoming.
- The site should not be busy/cluttered.

Table 2: Focus group feedback on example websites

Website Example	Focus Group Participant Feedback
Website 1	<ul style="list-style-type: none">• Do not like the yellow
Website 2	<ul style="list-style-type: none">• Like the format of words across the top and down the left hand side• Like the links to social media sites• Like the search function
Website 3	<ul style="list-style-type: none">• Too busy, too red• Too cluttered

Additional comments related to the design of the website:

- Ensure links work; updated frequently (at least once every four to six weeks)
- Easy to navigate
- Not busy
- Not too many pictures
- Have a heightened sensitivity to parents
- Should not make visitors to the website feel inundated
- Begin with a narrow trunk
- Accessibility
- Not too stimulating
- The main page should be welcoming and provide new parents information on where to start
- User-friendly
- Could have a video to welcome visitors to the site and indicate that a focus is on helping visitors to the website
- Limit the written information on the home page
- Should be family friendly, family positive
- Needs to have navigation to get back to the home page



6 Additional Comments

Participants were asked to share what was most important to them about the website.

- User-friendly
- Focus on family
- Include resources for individuals and families
- Up to date
- Good for families and professionals
- Navigation easy – quick ways to get to the information you like
- Get the website up and running soon
- Useful information
- Professionals needing resources know where to come
- Becomes widely known – includes options for sponsorship
- Comes up when you Google ASD – may have to pay to have it listed
- Includes support for siblings
- Linked to other good resources
- Helpful, accurate and good for individuals
- DADS affiliation needs to be dropped – TARRC should be the prominent domain
- Easy to use; good web resources
- Need a knowledgeable web-designer for key words and linking capability

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
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

