Program Evaluation: The Autism Project

PSC 505: Public Program Evaluation

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Introduction

Autism Spectrum Disorder (ASD) is a disorder accompanied by cognitive and social deficits (i.e., lack of visual eye-contact, poor social awareness, and stereotypic behaviors), which in turn hinders functional qualities of independence and social interactions (American Psychiatric Association, 2013). Current reports estimate the number of children diagnosed with ASD as 1 in 68 (Center for Disease Control and Prevention [CDC], 2018), with steady rates increasing over the last 20 years (Neggers, 2014). Moreover, there is a sufficient research pool to be demonstrate concern for quality of life for parents of children with ASD (Khanna et al., 2011). For instance, the process of parenting a child with ASD has been found to positively correlate with higher parenting stress compared to those parents of children without ASD (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005). Parental stress interventions can be delivered in a variety of ways, including but not limited to: (a) parent support groups, (b) parent peer-to-peer mentoring, counseling/therapy, or (c) internet/web-based research and support (Batista, 2016; Marshall, Noonan, McCartney, Marx, & Keefe, 2001; Singer et al., 1999).

The purpose of this paper is to analyze a specific form of support for parents of children with ASD, which is delivered through The Autism Project in Rhode Island. Specifically, this paper will describe and analyze the effectiveness of The Autism Projects' website and programming, with a primary focus on parent perception, satisfaction, and frequency of use. Outcomes will further inform the redesign of the current website. The Autism Project was formed by a group of educators, parents of children with autism, and professionals in 1994 who recognized a need for Autism related resources and training for both schools and the community (The Autism Project, n.d.). The Autism Project received initial funding through the Rhode Island of Department of Education in 1997, however, this funding ended in 2001 (The Autism

Project). Since 2001, The Autism Project has been funded through federal grants, reimbursements through Medicaid, or private payers. Also, through a partnership with Gateway Inc., a Lifespan affiliate, The Autism Project is part of Lifespan and is directly connected with the Rhode Island Consortium Autism Research Team (RI-CART) at Bradley Children's Hospital (personal communication with Joanne Quinn, February 6, 2018).

Program Description

Purpose and objectives of The Autism Project. The Autism project delivers a variety of services to families, educators, and professionals that relate to Autism advocacy, assessment, intervention, and support. The program provides further services for "children and adults with an Autism Spectrum Disorder [ASD], their families, and those who work with them" (The Autism Project, n.d.). Currently, there are five family support specialists who work with families who have received recent ASD diagnoses, or who are looking for additional support for their child with ASD (personal communication with Sue Baylis, February 6, 2018). Pertaining to administrative support and operations, Sue Baylis serves as the director of the family support program and is overseen by the executive director, Joanne Quinn.

Within any given year, approximately 150 parents and 2,000 professionals receive training related to evidence-based practices for ASD treatment and intervention (personal communication with Sue Baylis, February 6, 2018). As such, the targeted populations are those with ASD, their families, communities, and educators/professionals. Funding and location restricts The Autism Project's ability to reach all families who have children with ASD in Rhode Island, such that, rural populations or those of who have not heard of The Autism Project are less likely to be served. Within the past year, the family support team has had the capability to conduct outreach with communities who have populations of Spanish or Asian language speakers, which has subsequently increased the consumer diversity. Overall, a primary objective is to ensure parents are well-supported and less stressed in their interactions with their child with ASD, which potentially may increase the odds of intervention working and improve overall well being for the parent and family (Baker-Ericzén et al., 2005).

Scope of benefits and services. The Autism Project aims to increase the frequency of access to support for families who have children with ASD. Specifically, the parent-training component and school consultation are free for families. In addition, for-pay services are provided in the form of social skills groups among children 10 and under, pre-teens, teens, young adults, or all ages (The Autism Project, n.d.). There is also a summer camp that provides recreationally and social activities in a therapeutic setting and offers scholarships for families unable to pay. In conjunction with these supports, there are free training and workshops that cover a range of ASD topics for parents and professionals. Other training and free resources related to ASD information are offered to schools and teachers as well as an array of and referrals to connect families with services. Moreover, the connection to RI-CART, allows families to gain access to genetic testing, ASD evaluations, and to participate in research projects. Overall, the direct and indirect services to children and families, schools and communities, and professionals has the potential to increase ASD awareness among communities and use of evidence-based training for interacting with individuals with ASD.

In order to implement services at The Autism Project, employees consist of trained mental health professionals, such as, psychologists, social workers, occupational therapists, educators, and educational paraprofessionals. More experienced parents of children with ASD also serve as parent mentors to provide direct support to parents of children with a recent ASD diagnosis. The professions involved in service delivery are Psychology, Social work, Education, Medical Field, and Academia.

Program funding. The Autism Project receives a mix of public and private dollars. Federal grants, submitted by The Autism Project, and Medicaid provide a large source of their income. Also, parents pay for some services that are not covered by Medicaid. The state of Rhode Island, however, does not provide funding for The Autism Project and are continually seeking funding to support their ongoing projects. Related to this evaluation, funding through a recent grant has provided the financial means to pay for website redevelopment.

Problem Analysis

The theory of the Autism Project's program is that services will lead to increased ASD awareness for communities and access to evidence-based treatment and services for individuals with ASD, their families, and educators/professionals. See Appendix A for a logic model that depicts the program theory.

Prevalence of the problem. According to a published RI-CART article (Gerber, Morrow, Sheinkopf, & Anders, 2014), ASD diagnoses have constantly risen over the past decade. In 2013, Gerber et al estimated there were approximately 10,000 individuals with ASD in Rhode Island. Due to the level of need for high-quality supports for treatment and intervention for individuals with ASD to succeed in educational, vocational, and personal domains, the Autism Project mission is warranted. In addition, reaching families from rural or diverse backgrounds is another increasing area of need, such that the Autism Project wants the website available in multiple languages and Americans with Disabilities Act compliant (personal communication with Joanne Quinn, February 6, 2018). The Autism Project continually strives to provide high-quality supports to families with children with ASD and professionals who work with children with ASD but are restricted by limited financial and personnel resources (personal communication with Sue Baylis, February 6, 2018).

In addition to the prevalence of the problem, another way to examine this problem is the need for child or professional input regarding the website. Second, the lack of website redevelopment at a constant rate is most likely tied to inconsistent funding to pay for such services. A serious consequence of not implementing this project is not having a website that provides adequate information and access to resources for families to access at home or during times when the Autism Project is closed (personal communication with Sue Baylis, February 6, 2018).

Values. The following core values listed on the Autism Project's website influence the problems identified:

> a. The Autism Project's supports and programs are accessible to everyone;
>
> b. Individuals with an ASD, their families, those who work with them, and members of their communities are best supported through a model driven by continuous learning and research;
>
> c. The Autism Project provides a welcoming and warm environment where individuals and their families feel safe, respected, and supported (n.d.).

In sum, The Autism Project strives to provide services that increase the well being of individuals living with ASD. An effective and well designed website is one avenue to help achieve this goal.

Evaluation Goals & Research Questions

Within the Autism Project, there are several service components, such as child services, parent, and community-school based services. This program evaluation will focus on the parent support services. Specifically, there is a need to determine if parents are satisfied with the type and amount of training provided by The Autism Project and to determine what, if any, changes to the website are needed.

The goal of this evaluation is to examine the extent of parent satisfaction (including frequency of use) with the current website content and design, which will provide valuable information to support the redevelopment of The Autism Projects' website. The Autism Project recently received grant will provide funding to pay the website developer and any necessary software or materials. This is the first evaluation completed on the website and will also provide a template for future website redevelopment and design. The following research questions will be answered and are based on the logic model in Appendix A:

Question 1. To what extent are parents satisfied (including frequency of use) with the content and design provided on the current website? Rationale: To date, the Autism Project has not obtained quantitative and qualitative information about parent satisfaction regarding their website design and content (i.e., programming). A well-functioning and easy to use website has the potential to increase frequency of use and satisfaction, which in turn, may increase access to important parent resources as well as a connections to other parents who are going or have gone through similar experiences (Law, King, Stewart, & King, 2002).

Question 2. What other content would parents like to see on the current website? Rationale: Asking parents for specific information about what they would like to see on the Autism Projects' website may have the potential to increase consumer satisfaction and frequency of use. Moreover, ensuring the general voice of parents is heard and represented on a platform used by many might bolster an increased feeling of connectedness to the Autism Project and its mission. Including parent voice in the redevelopment of the website may also increase acceptance of the new website.

Method

Design and Participants

A one-group mixed-method design, with a purposive sample, will be implemented and aims to reach existing consumers of The Autism Project's services. Quantitative and qualitative data will be collected from a survey designed for the purposes of this evaluation (see Appendix B). Surveys are a cost-effective method to gather information (Posavac, 2011). The survey will be available as a paper copy or online. Using The Autism Projects' internal e-mail list the survey will be sent out electronically. At the end of the survey, parents will be asked if they would like to be contacted to complete a focus group lasting no more than one hour. Childcare and dinner will be offered as way to eliminate barriers for participation. A focus group will provide qualitative and process-related information and has the potential to inform ways to better display content and to access resources. Moreover, a focus group can illuminate information that a survey may have missed (Posavac, 2011). For participation in this evaluation, participants will have the opportunity to enter a raffle for a chance to win one of two $25 visa gift cards. Considering research by Singer and Couper (2008) the total amount offered for participation is less likely to be coercive if risks and rights are thoroughly explained to participants. Prior to completing the survey, a paragraph will explain the purpose of this evaluation, such that participant can elect to stop at any time, without losing their chance to be in the raffle or receive dinner during their attendance of the focus group.

Measure

The following measure, *Website and Consumer Satisfaction Survey*, was designed for the purposes of this evaluation. Questions 1 and 2 ask for basic demographic information. Name is an optional category, as parents may feel more comfortable speaking honestly if they are anonymous. The next question asks for the age of the child with autism, which can help provide categorical information to analyze the data. For instance, it would be helpful to determine if there are differences in groups by the age of their child diagnosed with ASD. Next, the following questions (Question 3 & 4), provide a general overview of the perceptions related to programming and the website. These two questions also can provide a global view of whether participants perceive the website and programming are being effectively implemented.

Subsumed under question 5 is a 10-item questionnaire titled the System Usability Scale (SUS) and was modified by a previous author for website ratings and satisfaction (Tullis & Stetson, 2004). Tullis and Stetson found the use of a 10-item questionnaire was found to demonstrate good reliability across their studies, which compared a series of website surveys varying in length. This modified SUS scale is yields a single composite that is a sum of the item scores. A calculation is completed to even and odd items before calculating the final score. Each score ranges from 0 to 4, with odd items score contribution is the scale number marked minus 1 and for even items the contribution is 5 minus the scale number marked. The overall summed score is then multiplied by 2.5; SUS scores ranging between 0 to 100 (Brooke, 1996).

Next, question 6 examines the satisfaction of current programming offered. Parents can elect from three of the categories listed in the first three rows (i.e., Parent Workshops, Community Outings, Summer Camp) or write-in an event not listed. Questions 7 and 8 provide information of the participants' importance and satisfaction of programming aspects. Questions 9 and 10 provide qualitative information that can buttress data gathered in previous items. In addition, some parents may include information that could not be captured by the Likert scale items (Posavac, 2011). Below, the following measurement chart outlines how research questions link to the proposed research method and study concepts.

Research Questions	**Data Collection**	**Study Concepts**	**Survey Question or Question within Dataset**
To what extent are parents satisfied (including frequency of use) with the content (i.e., programming) and design provided on the current website?	Paper or electronic survey Focus Group	Frequency of use and overall satisfaction Perceptions of current website and programming	*Survey questions:* Q3. Q4. & Q5. (Likert scale questions) Q6. Q7. & Q8. Likert scale questions to evaluate satisfaction and perceptions related to programming. Q9. & Q10. Brief qualitative information, with the hope to bolster the quality of quantitative data collected in previous items.
What other content would parents like to see on the current website?	Focus Group	Type of content to display What seems to work Any way to improve	There will be a series of open-ended and close-ended questions presented. Parents will view examples of templates for website displays and have the opportunity to vote on their favorite design.

Conclusion

Providing an efficient and quality designed website is one way to support parents who have children with ASD. As with any website, there is a need to understand from the consumer's standpoint to understand the most beneficial information to include as well as determine what information is displayed on the website is useful. An ongoing need to of The Autism Project is to ensure the majority of Rhode Island residents have the option to participate in all aspects of programming and services, with the hope that supported parents will demonstrate increased parenting competency and decreased stress. In sum, this evaluation will take the information gathered to further improve upon the quality and design of The Autism Projects' website, while making sure there is emphasis parent satisfaction and need.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Autism Project. (n.d.). Retrieved February 19, 2018, from http://www.theautismproject.org/

Baker-Ericzén, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, *30*(4), 194–204.

Batista, M. (2016). *Exploring the impact of parent mentoring programs on Latino parent engagement and empowerment*. California State University, Northridge. Retrieved from http://scholarworks.calstate.edu/handle/10211.3/174073

Brooke, J. (1996). SUS-A quick and dirty usability scale. *Usability Evaluation in Industry*, *189*(194), 4–7.

Center for Disease Control and Prevention. (2018). Data and Statistics | Autism Spectrum Disorder (ASD) | NCBDDD | CDC. Retrieved February 17, 2018, from https://www.cdc.gov/ncbddd/autism/data.html

Gerber, A., Morrow, E. M., Sheinkopf, S., & Anders, T. (2014). The Rhode Island Consortium for Autism Research and Treatment (RI-CART): A New Statewide Autism Collaborative. *Rhode Island Medical Journal (2013)*, *97*(5), 31–34.

Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *41*(9), 1214–1227.

Law, M., King, S., Stewart, D., & King, G. (2002). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, *21*(2–3), 29–48.

Marshall, N. L., Noonan, A. E., McCartney, K., Marx, F., & Keefe, N. (2001). It takes an urban village parenting networks of urban families. *Journal of Family Issues*, *22*(2), 163–182.

Neggers, Y. H. (2014). Increasing Prevalence, Changes in Diagnostic Criteria, and Nutritional Risk Factors for Autism Spectrum Disorders [Research article]. https://doi.org/10.1155/2014/514026

Singer, E., & Couper, M. P. (2008). Do Incentives Exert Undue Influence on Survey Participation? Experimental Evidence. *Journal of Empirical Research on Human Research Ethics : JERHRE*, *3*(3), 49–56. https://doi.org/10.1525/jer.2008.3.3.49

Singer, G., Marquis, J., Powers, L. K., Blanchard, L., DiVenere, N., Santelli, B., … Sharp, M. (1999). A multi-site evaluation of parent to parent programs for parents of children with disabilities. *Journal of Early Intervention*, *22*(3), 217–229.

Tullis, T. S., & Stetson, J. N. (2004). A comparison of questionnaires for assessing website usability. In *Usability professional association conference* (pp. 1–12).

Appendix A

Program: The Autism Project

Situation: The Autism Project would like to redesign their website and gain parent perspective about the redesign.
Program Evaluation Goal: To what extent are parents satisfied with the current website? Specifically, what type of changes would parents find beneficial to their overall parental support?

Inputs	**Outputs**		**Outcomes – Impact (The incremental events/changes that occur as a result of the outputs)**	
	Activities	*Participation*	*Short*	*Long*
Funding Sources (public, private, federal grants, Medicaid) Materials Website/Software Staff (parent coordinators, therapists, paraprofessionals, etc.) Community partners (RI-CART) Facilitators (Parent Mentors)	Needs and Resource Assessments Parent Training School and Parent Training Marketing/ Communication Community activities (Summer Camp)	Parents Children Agencies that provide services to families with disabilities Stakeholders	Access to parental supports and information through the Autism Project website. Parent satisfaction with the website. Increased ASD awareness and training for individuals with ASD, their families, educators/professionals, and communities 80% of those surveyed will respond to the website satisfaction survey.	Greater ability to participate in all aspects of The Autism Project's programming and services. Increased parenting competency and decreased stress, as a result of participation and access to The Autism Project's programming and services. Parents' satisfaction scores will demonstrate improvement as compared to those assessed prior to website redevelopment.

Assumptions

1. Parents use the website frequently and are aware of what they would like changed or added.
2. Parents will want to respond to help improve the website.
3. Access to computers, smart-phones, or Internet is available to families.
4. Adequate website use and presentation will foster connectedness and support for parents of children ASD.

External Factors

1. Potential budget cuts could affect payment for website redesign.
2. Not enough parents respond to the survey to provide adequate information for website redevelopment.
3. State does not provide consistent funding.

APPENDIX B

The Autism Project - Website and Consumer Satisfaction Survey

Thank you for taking the time to complete this survey. Our goal is to use the following information to understand better ways to deliver information through the Autism Project's website. With your assistance we can integrate your feedback into the redevelopment process of the current website.

1. Name (Optional)

2. How old is your child with ASD?

3. How would you rate the programming overall at The Autism Project?

Unacceptable	Somewhat Unacceptable	Neutral	Somewhat Outstanding	Outstanding

4. How would you rate the current website?

Unacceptable	Somewhat Unacceptable	Neutral	Somewhat Outstanding	Outstanding

5. With the current website in mind, please answer the next series of questions:

	Strongly Disagree 1	2	3	4	Strongly Agree 5
a) I like to use this website frequently.					
b) I found this website unnecessarily complex.					
c) I thought this website is easy to use.					
d) I need Tech Support to be able to use this website.					
e) I found that the various functions on this website were well integrated.					
f) I thought there was too much inconsistency on this website.					
g) I imagine that most people would learn to use this website very quickly.					
h) I found this website very cumbersome to use.					
i) I felt very confident using this website.					
j) I need to learn a lot about this website before I could effectively use it.					

6. Overall, how satisfied are you with the types of programs you attended?

	Very Satisfied	Satisfied	Neutral	Unsatisfied	Very Unsatisfied	Not Applicable
Parent Workshops						
Community Outings						
Summer Camp						
Other:						
Other:						

7. Please tell us which of these are important to you.

	Not at all important	Slightly important	Neutral	Important	Very Important
Scheduling					
Variety of program topics					
Quality					
Knowledge of staff and trainers					
Energy and passion of the presenter					

8. What is your current level of satisfaction with the following?

	Very Satisfied	Satisfied	Neutral	Unsatisfied	Very Unsatisfied
Scheduling					
Variety of program topics					
Quality					
Knowledge of staff and trainers					
Energy and passion of the presenter					

9. In a few words, please tell us what you think about The Autism Projects' website?

10. In a few words, please tell us what you think about the type of programming offered?

Thank you for your participation! If you would like to be apart of a focus group to help better understand what information should be presented on the website, please click the following link to enter in your contact information:

https://goo.gl/forms/602wkrNZVbwtTV1p1

Or, if you are completing this survey on paper, please e-mail Sue Baylis at sbaylis@lifespan.org.