Our Voices: Getting to Know Autism

Katherine Rasberry
Western Michigan University

Follow this and additional works at: https://scholarworks.wmich.edu/honors_theses

Recommended Citation
https://scholarworks.wmich.edu/honors_theses/3637

This Honors Thesis-Open Access is brought to you for free and open access by the Lee Honors College at ScholarWorks at WMU. It has been accepted for inclusion in Honors Theses by an authorized administrator of ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.
Our Voices: Creating an Informative Website for Autistic College Students

Authors: Kate Rasberry¹,³ and Ashley Wagner ²,³

¹Department of Speech, Language, and Hearing Sciences, Western Michigan University

²Department of Marketing, Western Michigan University

³Lee Honors College
Abstract

This study was done in effort to understand the thoughts and feelings of autistic adults relative to life transitions and resources available. We surveyed key stakeholders; specifically autistic students, but also family/caregivers of adults. Six surveys were created, each based upon different themes: camouflaging, life transitions, managing mental health, overstimulation, social communication, and family and caregiver perceptions. Our surveys were marketed on Western Michigan University’s campus and through social media and are still ongoing. Trends in the data, however, suggest that overall autistics have concerns about how their disabilities impact life in or shortly after college. Many respondents expressed they have anxiety and can be related to the fear of asking for help. The limited or lack of availability and access to the support needed for managing mental health and dealing with overstimulation is also a factor contributing to anxiety. Trends in the data on social communication suggest that autistics use camouflaging in social situations, particularly when meeting new people and didn’t find it a negative experience. However, autistics did report that they unmasked when around family and friends. Our efforts to collect and understand insights from autistic adults will be utilized to develop a functional website as a resource tool. We sincerely hope future colleges and researchers will use our data to better serve autistic adults with life transitions and to further the resources available to them.

Keywords: Autism, spectrum, overstimulation, anxiety
Our Voices: Getting to Know Autism

Numerous autistic individuals enter college or the workforce after graduation, yet many are unsuccessful. There could be many reasons for their lack of success and the best method to understand the causes is with research reflecting the voices of autistic adults. Information gleaned from autistic “voices” could be the impetus for providing added resources to campuses and work environments. Resources available for these individuals could impact their experiences and lessen hardships. (Kuder & Accardo, 2017). Autism Spectrum Disorder also known as ASD is defined as “a neurodevelopmental disorder characterized by deficits in social communication and social interaction and the presence of restricted, repetitive behaviors. Social communication deficits are present in various ways and can include impairments in joint attention and social reciprocity as well as challenges using verbal and nonverbal communication behaviors for social interaction. Restricted, repetitive behaviors, interests, or activities are manifested by stereotyped, repetitive speech, motor movement, or use of objects; inflexible adherence to routines; restricted interests; and hyper- and/or hypo-sensitivity to sensory input.” (American Psychiatric Association, 2013). Although limited, the empirical body of research on autistic postsecondary education reveals that college presents daunting challenges to social, and emotional well-being, as well as barriers to independent-living, self-determination (i.e., self-advocacy) both inside and outside of the classroom (Adreon & Durocher, 2007; Gobbo & Shmulsky, 2014), which are largely depended upon communication and higher-order/level language skills (e.g., inferencing, comprehension monitoring, decision making, planning, problem solving). There is limited research on the types of support needed and how to best address these challenges and barriers of post-secondary autistic adults. The critical gaps in literature therefore make it difficult to develop large-scale, evidence-based support for autistic college students (Cox, et.al., 2017). To
understand more about the challenges and barriers postsecondary autistic students face, and to fill critical gaps in the literature regarding any supports to college success, research needs to be informed by the key stakeholders themselves; specifically autistic students, but also family/caregivers of adult autistics (Mallipeddi & VanDaalen, 2021; Coles-White, 2022). By understanding perspectives new resources and strategies can be fabricated to help lessen hardships faced. In this study, we sought out opinions on six topics: camouflaging, life transitions, managing mental health, overstimulation, social communication, and family/caregiver perceptions. We used a mixed methods design comprising both survey and semi-structured interview methodology to obtain quantitative data. Our motive in surveying was to help create a website to help support autistic individuals during transitions and new phases in life.

**Methodology**

*Design*

The Our Voice research project utilizes a mixed methods design comprising both survey and semi-structured interview methodology. Individual surveys for the two stakeholder groups (i.e., 1- autistic adults, 2- family and caregivers) will be developed and used to obtain quantitative data. Semi-structured interview of the autistic adults will be conducted to obtain qualitative data. Qualitative methods are often considered ideally suited for early inquiries into a new area of research, in which there exists too little theory or prior research to guide hypothesis generation (Palinkas, 2014). Qualitative and quantitative methods will be used simultaneously to provide complementary perspectives on the challenges and barriers autistic adults face in life after high school, specifically post-secondary education and to obtain a depth and breadth of understanding, respectively. The online surveys and the interviews will be implemented in
parallel, and data analyzed independently, allowing for a richer understanding of the phenomenon under study while preserving the integrity and unique elements of each methodological approach (cf, Yardley, 2008; White, et al., 2016; Coles-White, 2022).

**Website Creation**

This website was created with the motive of providing data directly to autistic adults with or without a formal diagnosis or who have similar disabilities. The website is designed to reflect information from data and feedback provided from anonymous survey respondents. This will be easily accessible information that will help current and future generations. After creating the goals and objectives for the website, it was evident that an informational website platform would be created to best fit the research that needed to be displayed. After buying the domain name, gettingtoknowautism.com from Name Cheap, we linked the domain name to a website builder. The website was created through WordPress, which is a website creator that utilizes plugin accessories and prebuilt themes. The first step in creating a trustworthy website was ensuring that every constructed aspect of it was secure. This includes having a URL with https, which means that the website is using a Secure Sockets Layer Certificate or otherwise known as SSL. The website contains four pages: Home, About Us, Autism Research, and Contact Us. Each page was designed in a particular way to direct the audience to either participating in the research through one of six surveys and/or accessing autism related resources.

**Home Page.** The home page contains the project's initial objective, which is to get data from autistic adults and caregivers from six surveys. The surveys are introduced above the scroll to get the intended audience. The rest of the page explains why the website was created.

**About Us Page.** This page gives a brief description of who is behind the design and research of the website. The about us portion of the site gives the website a sense of familiarity
while increasing the confidence of a trustworthy website. The about us page also includes six answers to frequently asked questions.

**Autism Resources Page.** The resources reflect a collection of critical data points from the surveys. The sources are all secondary with various purposes ranging from articles on mental health to supportive articles for family members and caregivers of autistic adults.

**Contact Page.** The contact page design is to send messages directly to the email affiliated with the website. Anyone can send a message directly from the website without having to access a separate window for their email. All responses will go directly to their email promptly. We believe that transparency and authenticity are essential throughout the entire website. Therefore, each website page includes a section with contact information along with a separate contact page.

Once we have sufficient data from the survey, the surveys will no longer be needed as the main focal point of the website. The resource page will be changed to be for current and developing research.

**Analysis**

Survey data analysis will be downloaded from Qualtrics as a comma-separated values file. Data analysis depends on the nature of the questions from the surveys. For example, closed-ended and categorical (quantitative) responses will be cleaned for case mismatch, spelling variants, and typographic errors to prepare for analysis using descriptive statistics. For open-ended (qualitative) responses, natural language processing (NLP) techniques will be applied to cluster responses. Using NLP, responses will be parsed, and synonymous words will be first grouped into word clusters. These word clusters will be further grouped using word similarity measures resulting in semantic word clusters (e.g., two or more successive words belonging to a
specific subcategory). All survey data will be exported to SPSS for further analysis to answer research questions. Data analysis of the interviews for the research project will involve identifying recurring patterns or themes that emerge from data, in the form of words, that describe the participants’ experiences, and that will address the study’s research purpose (i.e., identify the challenges and barriers to post-secondary education autistic adults experience). In this study, data collection and analysis occurred simultaneously, so that the collection could continue, change, or end, depending on if more data was needed, new themes or questions arose, or if there was theoretical saturation. The common themes and categories that emerged will also serve as the content areas for the creation of the website that will feature this study’s findings in the context of evidence-based content (Coles-White, 2022).

**Survey Topics Chosen**

Based on reoccurring issues concerning the lives of autistic adults while analyzing literature reviews, 5 topics were chosen as themes to survey autistic adults on. These topics include social communication, overstimulation, managing mental health, camouflaging, life transitions. We believe having five independent surveys helps the individual partaking in the study narrow in on topics they believe they are knowledgeable about. As well as minimizes the length and time of taking the individual surveys. One additional survey was created for caregiver/family inputs. Each of the six surveys contained the same 11 demographic questions along with roughly 10 combined qualitative and quantitative questions. The qualitative portion of the surveys included open-ended questions, while the quantitative portion of the survey were all in the form of Likert scale style questions.

**Marketing Procedures**
How we were able to create a successful website comes from using many different marketing tactics. The marketing efforts are accompanied by search engine optimization (SEO), keyword research, word of mouth, Google Ads, Facebook groups, and print media. Search engine optimization was widely used throughout the entirety of the content of the website. Not only is SEO low cost, it also has a major impact on where the website will show up in search results. The National Library of Medicine explains that “SEO allows your manuscript to be listed higher on the list of results from search engines. Being higher on the list means that more readers will find your work. SEO is accomplished through use of keywords, best-practice website design, and the very nature of our open-access content” (Cushman M., 2018). To accompany SEO related content, keyword research was done through a platform known as SEMrush to rank higher in search results and increase the performance of the ad sets.

<table>
<thead>
<tr>
<th>Keyword Research Through SEMrush</th>
<th>Keyword</th>
<th>Volume</th>
<th>CPC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>301.0K</td>
<td>$1.39</td>
<td></td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>49.5K</td>
<td>$1.01</td>
<td></td>
</tr>
<tr>
<td>Autism Research</td>
<td>1.0K</td>
<td>$1.92</td>
<td></td>
</tr>
<tr>
<td>Research on Autism</td>
<td>320</td>
<td>$1.92</td>
<td></td>
</tr>
<tr>
<td>Research in Autism Spectrum Disorder</td>
<td>170</td>
<td>$2.47</td>
<td></td>
</tr>
<tr>
<td>Autism Survey</td>
<td>140</td>
<td>$0.48</td>
<td></td>
</tr>
<tr>
<td>Autism Awareness Survey</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism Spectrum Survey</td>
<td>20</td>
<td>$1.00</td>
<td></td>
</tr>
<tr>
<td>Autistic Adults</td>
<td>3.6K</td>
<td>$0.85</td>
<td></td>
</tr>
<tr>
<td>Autistic Burnout in Adults</td>
<td>1.0K</td>
<td>$1.57</td>
<td></td>
</tr>
<tr>
<td>Autistic Adult</td>
<td>880</td>
<td>$0.85</td>
<td></td>
</tr>
<tr>
<td>Autism Camouflaging</td>
<td>90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Camouflaging Autism</td>
<td>40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Camouflaging Autism</td>
<td>30</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Google Ads have the potential to create a significant amount of traffic to the website. However, not all traffic is beneficial to the study. To maintain the right audience, it was important that the ads focus on certain keywords and add any non-essential or potentially misleading keywords to a negative keyword list. This approach will maximize the amount spent per day, while also being able to compete with similar websites.

<table>
<thead>
<tr>
<th>Google Ad Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>Goal</td>
</tr>
<tr>
<td>Landing Page</td>
</tr>
<tr>
<td>Business Name</td>
</tr>
<tr>
<td>Headlines</td>
</tr>
<tr>
<td>Descriptions</td>
</tr>
<tr>
<td>Locations</td>
</tr>
<tr>
<td>Keyword Themes</td>
</tr>
<tr>
<td>Budget</td>
</tr>
<tr>
<td>Clicks</td>
</tr>
</tbody>
</table>

Results

Marketing Results

After launching the Google Ad, it resulted in 13.4K impressions and 533 clicks. By dividing the number of clicks on the website by the number of total impressions, a 4% click through rate was found. While the total cost from running the ad was $146, the average cost per click was around $0.26
Overstimulation Survey Results

While results are still coming in and will be ongoing until the near future, here is some of the data we were able to collect from this survey. In total, there were 5 respondents that included 2 diagnosed autistics and 3 that self-identified as autistic. The majority of the respondents were female and all of which have a co-occurring disability. The disabilities prevalent amongst the respondents were anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), and learning disabilities. The following are a few quantitative questions asked in the survey, all in Likert Scale style formatting.

1. Q11: Are there certain senses that trigger overstimulation (Ex. noise, bright lights, crowds, and texture)?
2. Q13: There are specific locations that trigger my sensory overload.
3. Q15: I have coping strategies for when I am overstimulated
4. Q16: I have tried coping strategies that were not successful with overstimulation.
5. Q18: How often do you experience sensory overload?

From the data, we identified the common trends presented from each question. While some of the respondent's experience overstimulation more than others, all answered that they do. Most of the respondents indicated that there are senses that increase the likelihood of overstimulation. We have found that questions related to coping strategies led to a variety of answers, indicating that there could be a need for further resources on this subject if autistic adults would like to use them.
Qualitative Raw Data in this survey was in multiple open-ended questions. A few of these questions, along with the respondents' answers, include:

1. Q12: If so, describe what causes you to overstimulate.
   a. Noise, crowds, scents, tags on clothing
   b. Loud noises, bright lights, crowds, chewing
   c. Crowds noise bright lights any smells

2. Q14: If so, describe a specific location or instance where sensory overload happens frequently.
   a. Office with 3 others, keyboard, telephone, talking.
b. Chewing all going on at the same time I need to leave the room cannot go to movie theatre, 

c. Specifically, grocery shopping and large venues like Costco 

d. Work public places 

3. Q17: If so, describe those strategies that did not work for you. 

a. Reading, meditation, moving into the stimulation 

b. I will sit in the car while my husband finishes the grocery shopping, or we will just leave 

c. Tolerating 

Overall findings from the overstimulation survey suggest that the respondents felt that some environments (classrooms, offices) were overstimulating. We see this in the respondent’s comments regarding overstimulation. Many of the challenges and barriers stem from the environment. From our findings we can suggest that overall overstimulation can be a barrier, including social interaction/social communication. It appears that autistics who answered this survey said their anxiety keeps them from having the ability to self-advocate from supports that they need.

Social Communication/Social Interaction Survey Results 

Currently only 1 respondent completed this survey. Overall findings cannot be drawn from only one respondent; however, the respondent’s answers reflect what we know from the literature on social communication and social interaction. In addition, persistent challenges in this area are a part of the diagnosis of Autism (from the DSM 5). The following are questions and answers from both qualitative and quantitative sections of the survey.

1. Do you think it is hard for autistic adults to communicate?
a. Somewhat agree

2. Give an example of a time when it was difficult for you to communicate?
   a. I find it difficult to communicate when it comes to small talk because I feel lack of control. I can’t anticipate what will be said.

3. When others use irony or sarcasm, how does that make you feel?
   a. Good

4. Do you think it is hard to make eye contact?
   a. Good

5. Describe or tell how you feel when making eye contact with someone?
   a. No response

6. Do others get frustrated if you cannot read their facial expressions?
   a. About half the time.

7. Do you think you offend anyone by trying to be honest?
   a. Sometimes

8. It is easy to form relationships.
   a. Somewhat disagree

**Social Masking Survey Results**

The results from the Social Masking Survey are represented by 2 respondents. The following are quantitative questions taken from the survey. The questions and answers are as follow:

1. Q11: I am likely to camouflage in social situations.
   a. Most of the time
   b. Always

2. Q14: I use camouflaging around my family and those I am friends with.
a. Never
b. Always

3. Q15: I am comfortable not using social masking around new people.
   a. Never
   b. Sometimes

   a. Sometimes
   b. Most of the time

5. Q20: I have a positive view on social masking.

An example of one of the many qualitative questions that were on this survey involves asking the respondents to talk about their strategies when experiencing burnout.
1. Q17: If you experience burnout (from masking), what strategies do you use to destress?
   a. If you experience burnout, what strategies do you use to destress?
   b. Music and coloring
   c. Smoking tobacco

Overall, findings cannot be drawn from only two respondents. However, the respondent’s answers reflect what we know from the literature on social masking or camouflage. Many autistics mask in social situations and most experience burnout.

**Life Transition Survey Results**

From the Life Transition Survey there were 3 respondents. These respondents can be characterized as two formally diagnosed with autism with both having a co-occurring disability. The disability can be ADHD, anxiety disorder, language impairment, and learning disability.

Research and data have been collected from questions that were aligned with the transition and support received from an institution or place of employment.

1. Q11: I am supported by my institution and/or my place of employment.
2. Q12: I am aware of resources and clubs for autism in my community and/or at my institution
3. Q13: I am comfortable asking for help from faculty, supervisors, and classmates.
4. Q16: I have the resources I need to succeed
5. Q15: I share my autism diagnoses openly with others.
6. Q18 - I advocate for myself in work and school settings when needed.
   a. Sometimes
   b. Always
Further questions were in the form of a qualitative analysis to receive further information through multiple open-ended questions.

1. Q17: If you use resources, describe what resource is most useful to you?
   a. DDS Testing accommodations

2. Q19: If you do not advocate for yourself, please explain why?
   a. Tricky for me to explain my needs to people who assume that I am more capable than I am in certain areas due to my abilities in other areas.

Overall findings from the survey on Life Transition suggest that while there may be resources available, some may not be able to access them which may be related to some of the other challenges such as social communication- difficulty self-advocating.

*Managing Mental Health Survey*
The following are some of the quantitative results from the Managing Mental Health survey. There were 3 total respondents; one of those respondents chose not to answer all the questions below.

1. Q11: Do you feel anxious when talking to others?
2. Q13: There are certain atmospheres that make me feel more comfortable than others
3. Q14: Do you feel that you have a good friend group?

The purpose of including opened ended questions for this survey was to receive direct feedback on how autistic adults are feeling mentally. An example of this type of qualitative question refers to asking the respondent to describe what they do when they are feeling anxious.

1. Q12: Describe what you do when you feel anxious.
a. Self-isolation, take a long hot shower, cry

b. Be alone

Overall findings suggest that anxiety is a prevalent co-occurring condition of autistics. However, there is not enough evidence from the low number of respondents to form a conclusion at this time. This survey will continue to be monitored and tracked as new data is formed.

**Chosen Resource Topics for the Website**

Based off the data from the six surveys, we were able to create six topics relevant to the responses. Data from each ongoing survey is continuously monitored and gathered to maintain relevant resources for the website. The chosen survey themes are as follows:

- Social Communication- Finding it hard to make eye contact, lack of control when talking.
- Overstimulation- overstimulation in the grocery store, overstimulation in an office environment.
- Managing mental health- Strategies to improve mental health, isolation tips.
- Camouflaging- Learning to unmask.
- Life transitions- understanding it’s okay to ask for help.
- Family/caregiver- misunderstandings.

In total there were 69 responses to the surveys. 4 of those responses were from caretakers/caregivers. The survey with the most responses was overstimulation, with the least responses being from the parents/caregiver survey.

**Discussion**

After analyzing the data collected from our surveys it is evident that there are areas of support that can be implemented to ameliorate various aspects of autistic adults' lives. The survey results from life transitions, overstimulation, and camouflaging support this claim with
pertinent concepts occurring including self-isolation, not asking for help, and anxiety. Many of these challenges and barriers experienced by autistic adults are largely dependent on communication and higher-order level/language skills (e.g., inferencing, comprehension monitoring, decision making, planning problem solving) (Coles-White, 2022). From the responses, the data concludes that autistic individuals use camouflaging in social situations and almost always use it when meeting new people. However, those that use camouflaging are comfortable with not masking around family. From the responses, using masking techniques was not viewed negatively. In the study, “Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew”: Defining Autistic Burnout, Raymaker et al. (2020) states “participants described an exhaustion of internal resources—physical, mental, emotional, or social—as a key feature of their burnout. Participants characterized this directly as feeling “tired” or “exhausted,” but typically went on to frame it more specifically as a depletion of energy from overextending themselves in daily life.” Not everyone who uses masking experiences burnout. Knowing that individuals are diverse in their needs, we looked for resources that were inclusive to everyone. Our website provides resources based on the viewpoints we collected and that have applicable tips to address the difficulty that autistic individuals may face.

Limitations and Directions for Further Research

This thesis is limited to the data we collected during our research. We experienced deadlines when conducting this research and were not able to independently interview those who agreed to one in the surveys before the defense of this thesis. We also would have liked to be able to develop our own resources based on the data collected in this study. This thesis presents other opportunities for research by inviting others to share their experiences during transitions as
an autistic adult. This thesis also creates new independent resources to give to higher education institutions or work environments. In the future, we would like to further our research of autistic adults and focus on how autism is perceived from various cultures and demographics. This is an area of focus that is commonly overlooked and would be beneficial to future research studies.

**Conclusion**

As these surveys are still ongoing and will continue to create new data, the current responses have formed multiple conclusions. Even though the data is small and ongoing we can say that yes, there are challenges and barriers to being successful in post-secondary environments as someone with ASD. From a neurodiversity perspective, autistics will always find some environments and interactions difficult because the current world we live and interaction in is designed to accommodate neurotypical individuals, or people who are not autistic. Classrooms and offices are bright and noisy and expect everyone to socially communicate the same, and everyone to be able to self-advocacy sufficiently for the things they need. Autistics experience pressure to behave like others. This pressure can bring the need to mask which may lead to anxiety and other mental health issues. Continued research in this area will hopefully shine a bigger and brighter light on these challenges and barriers so that teachers, administrators, and other stakeholders concerned with student success, especially autistic students, can find ways to support them. The findings helped us to narrow in on resource topics to promote on the website created: eye contact difficulties, lack of control when talking, overstimulation in the grocery store, overstimulation in an office environment, strategies to improve mental health, isolation tips, learning to unmask, asking for help and navigating misunderstandings. Our website is still
in production and will be created to help empower autistic individuals in different areas of their lives.
References


