

A survey of descriptive language surrounding autistic persons

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Table of Contents

Table of Contents	1
Signature Page	2
Acknowledgments	3
Abstract	4
Introduction	5
<i>Language Surrounding Disability</i>	8
<i>Person- and Identity-First Language</i>	11
<i>ASD Students Transitioning to College Life</i>	14
Methods	16
Results	20
Discussion	21
References	24
Appendices	28

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Abstract

An online survey was distributed to Middle Tennessee State University students who were or are affiliated with someone who is diagnosed with Autism Spectrum Disorder. This was done as a measure to know the campus population's preference between the preexisting person-first (person with Autism) and the new trend of identity-first (Autistic person) language within the demographic. Following the distribution of the survey through willing professors to participants, the data was analyzed using a two-tailed t-test. The calculated $t_{0.05(1.138)} = 0.47$ was not greater than the $t_c = t_{0.05(1)} = 0.712$, therefore the test failed to reject the null hypothesis. The group of Autistic respondents ($m = 0.545$, $n = 2$, $sd = 0.257$) did not significantly differ from the group of non-Autistic respondents ($m = 0.634$, $n = 9$, $sd = 0.141$) in their preference for self-identifying language.

Introduction

Within modern society, most social groups are often well-defined by common in- and out-group definitions. These definitions can be seen either visibly or in what has recently been coined as “identity politics” - the use of specific labels, such as gender, race, or sexuality, that are used by an individual to help identify them with groups the individual feels best relates to them and their morals. Such identification language can commonly be seen throughout minorities within the general populace as a way to identify oneself within what is being presented as an out-group from the culturally accepted in-group. One such group that has coalescence into general knowledge would be the LGBTQ+ groups that advocate for persons whose sexuality and gender identities are outside of the norm defined by heterosexual and cis-gender majority of their community. In this way, there have been words that were used in derogatory contexts, such as homosexual and queer, that have been used to dehumanize and exclude the group (Brueggemann, 2013). There has been a broad movement within the LGBTQ+ groups to reclaim slurs used against them to take ownership of their identity and attempt to humanize the language around them. In this way, the language that has otherwise been used to separate the individual from their humanity has been reclaimed and, in essence, given a face to allow for positive associations on otherwise negatively associated words. Similar movements and semantics have been seen in other minority groups that have been marginalized throughout history, such as with African-American populations in the United States of America. In this way, the change of person- and identity-first language has been wholly dependent on the population that the verbiage describes and the groups’ acceptance that the description given to them as a whole.

There are often differing opinions on topics such as this even within the larger society. These arguments span from the idea that all persons within the group should take control over the words used against them to the thought that the word(s) should be left to the annals of history. In this way, other groups within society can have completely different labels and language around themselves depending on the region and acceptance of their personhood that may differ from the population at large opinion (Rand 2014). The shift within the community can be seen as the out-group becoming an in-group of its own by the community within it being built into an identity of its own. In this way, other labeled groups can be seen to change their accepted labels throughout the years. For instance, the difference between the labelling of children with Autism Spectrum Disorder (ASD) from the 2000's and 2010's have seen a noticeable change by just who is doing the labelling. Because of this increase from the 1990's, groups began to rally around the cause in an effort to raise both awareness for and funds to go toward curing Autism.

In the early 2000's, Autism Speaks was well-known for their advocacy in researching a cure for the children with Autism. During this time, the group offered support for families with a loved one suffering from Autism. However, more recent years have seen a growing dissent within the Autistic community wherein there is a dissatisfaction with whose voices have been heard regarding their diagnosis. Groups such as Autistic Self-Advocacy Network (ASAN) have built stages for themselves to allow their opinions to be heard on how their members want to be treated and addressed as "ASD individual[s]" (Brown, 2011). In this way, there has been the beginnings of a shift within the national stage of self-identification within the Autistic community. The prevalence of this change

and interconnectedness of the Autistic community is more at question, specifically if the idea of identity-first language has become popular within the local community of Autistic individuals here at Middle Tennessee State University (MTSU).

In this way, any shift of the on-campus community's preferred language should be recognized and respected accordingly. Actions like this would better ensure the comfort and ease of transition on-campus for ASD students. On MTSU's campus, the Disability Access Center (DAC) is the primary resource available to students with any disability or need for accommodation ("Accommodation Process", 2018). This group works with physical, neurological, and developmental disabilities of different severities in order to improve the students' experiences on campus to better allow the students the same opportunity to flourish as their cohorts. The staff of the DAC are often the first people that a student must meet with to discuss their needed accommodations for their education. Therefore, this first interaction should be held with the utmost esteem as any discomfort for the student from the faculty could hinder the student's openness when speaking about their needed accommodations. Ways to avoid this conflict at a key time for students could include knowing how students address their disability in relation to their identity. If the student feels that their disability or disorder is a part of their identity, then that should be just as respected as a student who separates themselves from their disability or disorder. By acknowledging and using the student's preferred language, they would perceive themselves to be in less hostile conditions than if being addressed in a way that leaves them uncomfortable.

Language Surrounding Disability

In populations, groups can often be separated into the in-group and out-group model set. An in-group would be defined as a group of individuals whose shared identity is defined by their beliefs, morals, and ideas, thus impacting their perceived worth to the group; Out-groups would therefore encompass all persons who do not match with the in-group's defined identity and thus are perceived as being worth less than those in the in-group. The effect of this perception can be seen oftentimes in the marginalization of the perceived out-groups from the overall community that both in- and out-groups belong to (e.g. town, country, nationality, etc.). Marginalization can be accomplished by many means, spanning from shunning to dehumanization. Because of exclusionary practices like marginalization, the out-group would be spoken of in such a way that they are further excluded by the in-group through the perpetuation of moral superiority and inferiority of the in- and out-groups, respectively. This phenomenon is not new within the scope of social psychology, where othering, the exclusion of those who do not fit in to the identified group, and selfing, identifying with the others with similar thoughts, beliefs, interests, etc., are ways in which people identify groups like and unlike themselves, respectively, and in such a way that the out-group is further perceived as inferior due to their difference from the in-group (Schwalbe et al., 2000). However, to have this othering occur against groups who are being otherwise disenfranchised or prevented from participating in the society at large, leaves a dangerous gap that can be and has been filled by persons from the in-group talking for the out-group and thus pushing the in-groups' thoughts and perspectives on the out-group's experiences.

Furthermore, instances of othering can be seen throughout history in different social contexts. Using just the United States as an example, the Americans with Disability Act (ADA) was put into place by the U.S. Federal government in 1990 and has since undergone several revisions. Most of these revisions have been seen to benefit those whose lives are affected in a negative way by their disability, such as the inclusion of handicap accessibility into all federal buildings open to the public and the mandated inclusion of handicap accessible parking in public areas. However, some revisions have served to benefit those with disabilities by ensuring the inclusion of their presence in society. Such revisions that ensure this integration come from the ADA Amendments Act of 2008 that suffer from diseases such as cancer and epilepsy that leave the individual impaired (Fact Sheet on the EEOC's Final Regulations Implementing the ADAAA, n.d.). However, before the implementation of these expanded definitions, there were and have since been many narrowing's of the definition and allowance for accommodations within the workplace and other public spaces.

Some issues since the establishment of the ADA have affected both employees and caregivers of those with disabilities. Nicole Porter laid out many such issues in her paper, *Special Treatment Stigma After the ADA Amendments Act* (2016), wherein she makes a well-founded argument in the unintended discriminatory effects in labor against those who are or are caring for those who are disabled. By pointing out the perceived "special treatment" given to individuals who would be in a group labeled as "disabled," there is an understanding that coworkers of those given accommodations will feel resentment towards the other group. In this sense, the accommodated disabled person (out-group) is perceived

not only as different by the non-accommodated non-disabled persons, but also as inferior for needing those accommodations and putting more work onto their non-accommodated coworkers. The further implications here are that those who are disabled are perceived by the employer as a potential point of contention in the workplace, the already present in-group, are given fewer opportunities within the workplace or given the expectations to accomplish the same tasks as what is expected of the other employees, regardless of the known abilities of the person who is in need of accommodation.

In this way, those with learning disabilities are given a similar dilemma within their school environment. As an umbrella term, learning disabilities includes challenges in learning due to neurological differences that would impair the child's ability to learn in a typical classroom setting. For the children who fall under this category, children with ASD would be included in having a learning disability depending on their severity and symptomatology. Using the examples by Porter with disability in the workplace, accommodations for children with learning disabilities may be viewed in much the same manner by children without disabilities as the adult counterparts in the previous examples. The perceived difference and "special treatment" of the disabled child would therefore impact the ability of the child to be seen as a part of the in-group by the children who do not have special accommodations to aid in their learning. These accommodations have even been seen to be a detriment to the child, such as in cases where the child is placed in classes designed for passing high school as opposed to classes for college readiness that their cohorts would be taking concurrently (Shifrer, Callaghan, & Muller, 2013). In this way, the accommodations can be seen as an attempt at helping the students already at a

disadvantage due to environmental and socioeconomic factors, but the attempt falls short of bringing the disabled students up to their peers' level. This inequity between the groups would be the disabled children being academically inferior to their peers and may inadvertently create an out-group in the academic setting of a school. The effects of being socially marginalized can be seen through behaviors of peers of the disabled student. Most of these behaviors are seen by the children within the in-group as bullying and the victimization of the students who are given accommodations, with a difference in rates of bullying being dependent on intervention plans put into place by the school (Chen et al, 2015).

Person- and Identity-First Language

Within the history of language surrounding disabilities, there have been many changes and adaptations depending on the groups' preferences at any given time. Due to the fluidity of language over time, the incorporation of adapted terms into a community may occur in staggered stages. Previously mentioned words have been seen to change from prescriptive words, words that are used to separate or prescribe the individual as being affected but separate from their disorder, to descriptive words, words that are used to describe the individual affected with their disorder. These terms go by many names, such as "politically correct" and person- or identity-first language, respectively. Because of the ever-changing environment of language, the preferences of the individuals within the affected group can be seen to differ from the usage of the overall population. Official documents and discussions surrounding the disabled community have been focused on person-first identifiers since the ADA of 1990. Since this implementation, most language

in policies and government surrounding disabilities has focused on person-first language. As discussed in Angelo Muredda's (2012), the inclusion of this language was a profound change from previous derogatory language that labelled disabled persons as "unsightly" or otherwise. Conversely, Muredda later discusses in the same piece how shortly after the adoption of the ADA, many activists began to move from "person with disabilities," the person-first language, towards "disabled person," the identity-first language. In addition, Muredda further speculates as to whether the inclusion of new labels and terms for these groups may suffer a similar fate as previous terms in that the word becomes a euphemism for the public's use in a derogatory manner.

Such concerns can already be seen within communities such as those with Autism Spectrum Disorder. Many people within and surrounding this community still argue about the language used to describe their circumstances. Because the language surrounding disabled persons within their group can help them identify themselves within a group, the choice of language should be left to the individual as opposed to the majority. In this way, person-first language that has been used through the recent history of ASD and disorders like may have been used to remind those within the in-group of the non-Autistic community that those whose lives are affected by ASD are not inherently less because of their Autism. Studies on semantic differences and lexicons for marginalized groups have been studied in recent decades with a noticeable difference of preference even within groups. For instance, a study by Titchoksy in 2001 looked at the use of person-first language within disabled groups, ranging from physical to neurological disabilities. The use of this semantic pattern is noted to detach persons from their disability and thus

separating the dehumanizing aspects of their condition from their overall personhood. However, the use of identity-first language can serve a similar function to persons who have a disorder that they feel is a part of their identity. In this case, the person using identity-first language would be able to argue that their identity within the overall community is defined in part by their disability.

The use of identity-first language can be seen as a reclamation of words that have otherwise been used to dehumanize and other those who are disabled. In this way, the use of semantics that would otherwise other an individual would allow the affected person to “own” this identity and prevent others from defining them out of context (Brueggemann, 2013). Through this reclamation, the ability to push those dubbed disabled into an out-group is mitigated by their ability to form their own in-groups and communities surrounding this label they use. However, this is not used by all parts of the community, regardless of the grouping. For example, the use of the word label “gimp” - a derogatory word that has been used towards handicapped persons with physical disabilities - has not been wholly adopted by those with physical disabilities and thus would still be used to other persons who have not yet reclaimed the word as a way to identify themselves within a smaller community. These differences are best seen as a spectrum within the community and are thus dependent on the different individuals within the in-group to use specific identifiers and markers overall. The effect of this is especially pronounced in groups that are impacted by their disability to varying degrees, such as with ASD.

Specifically, the history of the word “Autism” is key in recognizing what the connotation is when used in either a person- or identity-first context. In either case, the

diagnosed individuals should be able to choose whether to reclaim this identity for themselves. This should be left to the individual rather than the overall group due to reasons such as the person's childhood experiences in reference to their disorder and how their diagnosis might have been used in reference to themselves. When compared to the recent history of the word "Autism," the word "retarded" has been used in such a way that it has lost its original context as a descriptor of a medically recognized set of symptoms because of its use colloquially. The weight of "retarded" as a way to describe specific mental disorder symptoms has changed because of the use in colloquial contexts such that its original denotation has since been subverted and replaced with the connotational meaning. In this way, the use of "retarded" has become an insult to be hurled at someone for doing something that is perceived as being stupid or dumb. Because of this change in use and the way it dehumanizes and belittles those who would otherwise have been medically described as "retarded," groups have come together to advocate for the erasing of this word from common linguistics within the population. Some groups, such as Spread the Word, advocate for inclusive practices and work to better awareness of what this word does to affect others (Schermerhorn, Palumbo, & Shriver, 2019). Much like "retarded," "Autism" has received a similar treatment by society in its transition from a disorder to a commonly used insult that has been separated from the group it described.

ASD Students Transitioning to College Life

Within most college campuses, there will be an expectation that some of the student population will have a learning disorder that affects their school life. In this way, MTSU has already put in place some failsafe to assist the students who need help in their transition

into adulthood. The DAC is a prime example of a resource available to assist students who know that they need assistance and exactly what help they need. This dependence on students knowing how to advocate for themselves is beneficial for them both in college and through their life following college but is completely reliant on their ability to recognize and advocate for their needs (Adelman & Vogel, 1990).

By basing the available resources on the ability of the individual to recognize their needs, students who have not had the opportunity to recognize their own needs or learned to advocate for themselves are left behind. Students who were undiagnosed prior to entering college may only begin expressing distressing symptoms once they enter campus life. This may be because of their symptoms not being at a severe enough level to result in diagnosis before entering college, but the result is that the student is not equipped and able to advocate for their needs due to their lack of knowledge regarding their needed accommodations (White, Ollendick, & Bray, 2011). For anyone in an already stressful situation, the onset of symptoms or inability to adapt with previously used coping mechanisms may be missed because of the stress surrounding them. Lack of awareness and access to aid for the student can result in students with disorders struggling to adapt to their new environments. Furthermore, students with pre-existing diagnosis will be able to pull from the Individualized Education Plan (IEP) that was created to aid in the diagnosed students' learning in their primary and secondary schools (Adreon & Durocher, 2007). This benefit would not be afforded to undiagnosed students; therefore, these students would be left without accommodations that would be afforded to them if they were appropriately diagnosed. In this way, the incorporation of awareness for underdiagnosed groups within

the ASD spectrum should be brought up to campus faculty who will be in positions to help guide the students to available resources.

Finally, the awareness of the disorder is alone not enough to aid students in flourishing within the education system unless other factors are addressed. These factors can include the student learning to adapt to the new system, new routines, new living arrangements, and even the new ways of socialization that are associated with campus life. A study performed by Gelbar, Shefyck, and Reichow (2015) found that 61% of students with ASD surveyed agreed to feeling isolated on their campus while 26% reported facing some form of discrimination related to their disorder during their college experience. This could be mitigated through an awareness and understanding towards the Autistic community on campuses. More specifically, an awareness of language and perception by faculty would likely allow for more inclusive environments for students with ASD (Robertson & Ne'eman, 2008). In this way, knowing the preference of individual student's chosen form of addressing their disorder helps eliminate the stigmas that may otherwise be associated with that label for them. Through opening the door for this conversation about ASD in higher education, more people may be able to seek the help and assistance they need in order to achieve greatness in their lives.

Methods

A questionnaire-style survey was used to test the difference in opinion for two groups: MTSU-affiliated persons with ASD as well as with family members with ASD. Five sections were made within the survey: consent, demographics, an introduction to self-descriptive language, emotional response to situation using self-descriptive language, and

a final section allowing the otherwise anonymous respondent to leave a code in case they wish to identify their need to remove their response from the survey at any time.

The consent section required that they be eighteen years of age or older as well as that the respondent consent to their participation before being able to participate. If the participant declined or was not eighteen years or older, then the survey directed them to the end of the survey to thank them for their participation. Each of the question-based sections of the survey had a different focus and format for the questions being asked.

The Demographics section focused on whether or not the participant themselves are autistic or if they were taking the survey as someone who knows an autistic person closely - referred to in the study as a “loved one” - and thus was assumed to either be a partner or family member of the participant. Other questions that were included asked about the Autistic person’s specific diagnosis (i.e. ASD, PPDNOS, Asperger’s Syndrome, etc.) and the approximate year of diagnosis. These questions were used to better gauge the respondent’s awareness of the different diagnosis and the approximate year that the Autistic person was diagnosed. The final question of this section introduced the respondent to the use of person-first and identity-first language regarding themselves. This was accomplished by asking if they are taking the survey as either being related to an Autistic individual or being related to an individual with Autism. The question then transitioned into the following section where the survey focuses on the use of this language.

The Introduction to Self-Descriptive Language section allowed the participant to actively think about what their choice of semantics for different situations would be. While the first question asked the respondent what they believe they choose to say in most

situations (person-first or identity-first), the following two questions tested the consistency of responses in simple situational examples. In these two questions the participant was able to choose whether they preferred to use the example sentence - one of which expressed a person-first format while the other expressed an identity-first format. The end of this section used the same consistency questions to ask whether the respondent would be “bothered” by the way the Autistic individual was referred to, measuring whether the participant felt that the language was othering or not. This question format further allowed for transition into the following section to allow the respondent an opportunity to understand questions in which the context may change connotation of phrasing. Examples of such questions can be seen in Appendix C which contains all questions and presented materials. These questions were loosely structured based upon previous research into emotionally charged verbiage with depression studies.

The Emotional Response to Situations section of the survey asked participants to assess their discomfort with situation-based context to their preferred language pattern. Five questions were given in this portion to assess for consistency of the respondent with certain situational responses. The assumption was made that a respondent would be more bothered by the language pattern unlike their own being used in the context provided - e.g. person-first preference respondent reading a situation that uses identity-first language within the example would be more bothered by the example than a respondent whose preference is identity-first. Within these questions, participants were able to gauge how uncomfortable a scenario’s language made them on a scale of one to five with five being very bothered. Each scenario either presented a situation where person- or identity-first

language was presented. The examples were presented in a nonspecific order to avoid any priming effects for the participants.

An online survey was the decided mode of distribution for this questionnaire. This choice was made for both ease of access for individuals and to ensure anonymity of the participants overall. MTSU's Institutional Review Board's (IRB) approval of both format and platform was needed before the survey was able to be distributed. This was achieved by filing for an Expedited Review, as seen in Appendix A. Once approval was given, participants were able to volunteer after receiving an email containing a link to the survey and a copy of a pre-approved flyer containing the same information as stated in the email (Appendix B) from one of their professors whom had been contacted by the primary investigator. All professors were spoken with in person regarding their willingness to distribute emails to their students. These emails were sent through an official institution email host with only students and faculty being encouraged to participate. The link provided in the email took the potential respondent to the survey being hosted on the Qualtrics website where all responses were kept and analyzed.

The exclusion of responses was limited to the following: lack of consent, being under the age of eighteen years, and not being or not knowing an Autistic person. The requirement of consent and the requirement of being the age of majority are due to limitations in the study's scope in working with needed consent and inexperience of the principal investigator with minors in research. The requirement that participants either know or are an Autistic person was deemed necessary to the responses of this survey due to the small population on-campus. Other unanticipated exclusion factors to occur included

blank responses - a risk of opening the link and exiting out of the tab that the Qualtrics survey is in without putting anything into the survey. Qualtrics automatically submits incomplete responses after a period, regardless of answers or lack thereof. A non-excluded response that may otherwise be an outlier would be respondents answering as both an Autistic individual and as a loved one of an Autistic individual. In this instance, the individual would be counted in both categories as their interpretation would affect both groups.

When analyzing the data for any difference between the Autistic and non-Autistic groups' preferences for identity- and person-first language, a non-directional two tailed t-test was used. When analyzing the test, a $\alpha=0.05$ was considered to test for significance of the results. In this experiment, there is an expectation of preference for either identity or person first language between the groups. This is due to the preexisting preferences of those tested in regard to the connotations surrounding the verbiage.

Results

The final number of responses was eleven respondents following the exclusion of two respondents who met the appropriate criteria and the inclusion of one respondent into two categories. Four responses were purged - one due to an incomplete form and the other due to neither being or knowing an Autistic person. No participating respondents that completed the survey answered as both someone who is Autistic and knows someone with Autism, therefore no responses were counted towards both groups.

Values were assigned to the Self-Descriptive Language questions answers' such that the values would fall on a spectrum from identity-first = 0 to person-first = 1. Emotion-based questions were appropriately scaled (e.g. five choices had a range of 0-1 with increments of 0.25).

Two respondents identified as being autistic while nine others responded as knowing an autistic person. Following the independent samples t-test, the group of Autistic respondents ($M= 0.545$, $n=2$, $SD= 0.257$) did not significantly differ the group of non-Autistic respondents ($M= 0.634$, $n= 9$, $SD= 0.141$) following the cumulative response for both self-descriptive and emotion-based responses. Within this measure, Levinne's Test was failed by the measures provided, indicating that unequal variance must be assumed. For a test using unequal variance, $t_{0.05(1.138)} = 0.47$ while $t_c = 0.712$, thus failing to reject the null hypothesis.

Discussion

Neither group of participants had a statistically significant preference for either person- or identity-first language when referring to people diagnosed with ASD and related disorders. These results were definitively influenced by sample size and thus may not appropriately represent the Autistic community of MTSU. The study should therefore be repeated at a larger scale for a better comparison between these groups. However, the shared ambivalence of those surveyed does not indicate that a lack of awareness of verbiage would be a benefit to anyone in trying to better accommodate and support students with ASD on-campus. Rather, more research should be put into the comfort and preferences of

this and other groups on-campus so that the campus is perceived to offer more accommodation to students who need them.

Furthermore, the lack of preference by ASD students at MTSU within this survey should not be extrapolated to larger populations in the Middle Tennessee area. Rather, these results may be more indicative that students who participated in the survey being less aware of the context of language around the word “Autism” or a disconnect from an Autistic community that they can relate to. In this way, they may use other identifiers that link them to their own in-groups, such as religion or community. Similarly, the lack of preference from the non-Autistic participants may indicate a disconnect from the broader Autistic community's perspective. This disconnect could be linked to a lack of public awareness of connotation of the word “Autism” in a colloquial sense.

The school officials of MTSU will be more equipped in addressing this topic with students who are diagnosed with ASD when they know how the student addresses the disorder's effect on their life. In this way, student-specific accommodations may be better incorporated into the student's time on campus and thus may allow for an equal opportunity to the student to flourish under the same system as other students. Accommodations are already being made for other students whose disorder has impacts on their abilities in classes such as separate testing rooms and extended examination periods for students who need this. The incorporation of an individual student with ASD should not be seen as anything different. Rather, the assistance of encouraging self-advocacy from individual students with ASD would likely see long-term benefits after their time on campus. Assistance in self-advocacy alone for those who are seeking aid and accommodations in

education because of their disorder would transfer into the positions that these students will take on after MTSU. Because of this, there should be more research into helping students learn the best practices when advocating for their needs both on-campus and in life.

In future studies, there would be more benefit to expanding the length of the study once validity of the survey is established. This could be improved by providing the survey in-person which would therefore encourage respondents to fully complete the survey as opposed to an online survey that may not keep the participants' attention as well. Alternatively, improving the in-test validity and methods of asking these questions should result in more consistent and nuanced answers from participants. Accessibility and likeliness of response was considered to be a higher priority in this initial study, thus the length of the survey was kept to a minimum. If the survey had been performed in-person or with incentives, the response rates may have changed enough to allow for a longer survey. This may be used in any expansions on this study to attain more accurate results. Further research on the awareness of this type of language usage may be required to ensure that the population tested would be first aware of what is being asked. Because of this, the surveyed population on MTSU's campus may have not been inclined towards either person- or identity-first language, as indicated by the mean scores falling close to the middle of the tested ranges. The lack of statistical significance for the results does indicate that there can be no firm conclusions drawn from this survey alone.

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Appendix A

IRB
INSTITUTIONAL REVIEW BOARD
 Office of Research Compliance,
 010A Sam Ingram Building,
 2269 Middle Tennessee Blvd
 Murfreesboro, TN 37129



IRBN001 - EXPEDITED PROTOCOL APPROVAL NOTICE

Tuesday, October 30, 2018

Principal Investigator **Elizabeth Kobeck** (Student)
 Faculty Advisor Tiffany Rogers
 Co-Investigators NONE
 Investigator Email(s) *erk2u@mtmail.mtsu.edu; tiffany.rogers@mtsu.edu*
 Department Psychology

Protocol Title ***The effect of self-descriptive language on autistic individuals***
 Protocol ID **19-2056**
 Funding Information **NONE**

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU Institutional Review Board (IRB) through the **EXPEDITED** mechanism under 45 CFR 46.110 and 21 CFR 56.110 within the category (7) *Research on individual or group characteristics or behavior*. A summary of the IRB action and other particulars in regard to this protocol application is tabulated below:

IRB Action	APPROVED for ONE YEAR		
Date of Expiration	10/31/2019	Date of Approval	10/30/18
Sample Size	200 (TWO HUNDRED)		
Participant Pool	Primary Classification: Adults (18 or older) Specific Classification: A combination of healthy adults, adult individuals with autism or adult individuals who know someone with autism		
Exceptions	Approved to administer consent online (restriction below)		
Restrictions	1. Mandatory active informed consent; the participants must have access to an official copy of the informed consent document signed by the PI. 2. Identifiable personal information must not be retained beyond the data processing stage. 3. Inclusion/exclusion criteria must be followed as proposed. 4. Identifiable information that includes audio/video recordings and handwriting samples must be deidentified as proposed in the protocol.		
Comments	Alexander Jackson is permitted to access research records		

This protocol can be continued for up to THREE years (**10/31/2021**) by obtaining a continuation approval prior to **10/31/2019**. Refer to the following schedule to plan your annual project reports and be aware that you may not receive a separate reminder to complete your continuing reviews. Failure in obtaining an approval for continuation will automatically result in cancellation of this protocol. Moreover, the completion of this study **MUST** be notified to the Office of Compliance by filing a final report in order to close-out the protocol.

Post-approval Actions

The investigator(s) indicated in this notification should read and abide by all of the post-approval conditions imposed with this approval. [Refer to the post-approval guidelines posted in the MTSU IRB's website.](#) Any unanticipated harms to participants or adverse events must be reported to the Office of Compliance at (615) 494-8918 within 48 hours of the incident. Amendments to this protocol must be approved by the IRB. Inclusion of new researchers must also be approved by the Office of Compliance before they begin to work on the project.

Continuing Review (Follow the Schedule Below):

Submit an annual report to request continuing review by the deadline indicated below and please be aware that **REMINDERS WILL NOT BE SENT.**

Reporting Period	Requisition Deadline	IRB Comments
First year report	9/30/2019	NOT COMPLETED
Second year report	9/30/2020	NOT COMPLETED
Final report	9/30/2021	NOT COMPLETED

Post-approval Protocol Amendments:

Only two procedural amendment requests will be entertained per year. In addition, the researchers can request amendments during continuing review. This amendment restriction does not apply to minor changes such as language usage and addition/removal of research personnel. .

Date	Amendment(s)	IRB Comments
NONE	NONE.	NONE

Other Post-approval Actions:

Date	IRB Action(s)	IRB Comments
NONE	NONE.	NONE

Mandatory Data Storage Requirement: All of the research-related records, which include signed consent forms, investigator information and other documents related to the study, must be retained by the PI or the faculty advisor (if the PI is a student) at the secure location mentioned in the protocol application. The data storage must be maintained for at least three (3) years after study has been closed. Subsequent to closing the protocol, the researcher may destroy the data in a manner that maintains confidentiality and anonymity.

IRB reserves the right to modify, change or cancel the terms of this letter without prior notice. Be advised that IRB also reserves the right to inspect or audit your records if needed.

Sincerely,

Institutional Review Board
Middle Tennessee State University

Quick Links:

[Click here](#) for a detailed list of the post-approval responsibilities.

More information on expedited procedures can be found [here](#).

Appendix B

RESEARCH PARTICIPANTS NEEDED

Middle Tennessee State University Honors College

10/30/2018

Investigator: Elizabeth Kobeck
 Study Title: The effect of self-descriptive language on autistic individuals
 Protocol ID: 19-2056
 Expiration: 10/31/2018
 Approval: 10/30/2018

Study Description

With this survey, there will be questions regarding how a diagnosed individual feels about the discussion of their diagnosis. These questions refer to whether or not using the word "Autistic" as an adjective is acceptable to those with the diagnosis. Oftentimes, there are debates within the community over whether or not a proper way to refer to a diagnosed individual would include this sort of language. In this survey, the use of person-first language (i.e. "I am a person with Autism, Asperger's, etc.") is to be compared to identity-first language (i.e. "I am an Autistic, Aspie, etc person.") to better understand the use of this language by those on the Autism Spectrum and their support groups.

Target Participant Pool

If you or someone you are close to or related to are autistic, then you are eligible for taking this survey.

Additional Information

This survey should take under twenty (20) minutes to complete. Some questions may be uncomfortable to answer since it is not common to discuss the semantics of discussing diagnosis. By completing this survey, your answers help to define how people within the MTSU autistic community feel about being called by their diagnosis.

Contact Information

If you wish to contact the primary investigator, email the following address: erk2u@mtmail.mtsu.edu

INSTITUTIONAL REVIEW BOARD

Middle Tennessee State University, 2269 Middle Tennessee Blvd, Murfreesboro, TN 37129
 URL: www.mtsu.edu/irb – Tel: 615 898 2400 – Email: irb_information@mtsu.edu

Appendix C

The effect of self-descriptive language on autistic individuals

The following information is provided to inform you about the research project and your participation in it. Please read this form carefully and feel free to ask any questions you may have about this study and the information given below. You will be given an opportunity to ask questions, and your questions will be answered. Also, you will be given a copy of this consent form.

Your participation in this research study is voluntary. You are also free to withdraw from this study at any time. In the event new information becomes available that may affect the risks or benefits associated with this research study or your willingness to participate in it, you will be notified so that you can make an informed decision whether or not to continue your participation in this study.

For additional information about giving consent or your rights as a participant in this study, please feel free to contact the MTSU Office of Compliance at (615) 494-8918.

Duration:

Between 5-10 minutes

Purpose of the study:

You are being asked to participate in a research study because of a perceived lack of discussion within the Autistic community around use of self-describing language. This study acts to help clarify the descriptive verbage used by autistic individuals in reference to themselves.

Description of procedures to be followed and approximate duration of the study:

Follow the directions provided for each section of questions. The study should take no more than twenty minutes. Please answer all questions to the best of your abilities.

Expected costs:

There will be no costs accrued through participating in this study.

Description of the discomforts, inconveniences, and/or risks that can be reasonably expected as a result of participation in this study:

Some questions may be uncomfortable to answer due to their nature in discussing vernacular used within the autistic community. There are minimal to no risks in participating in this survey.

Compensation in case of study-related injury:

MTSU will not provide compensation in the case of study related injury.

Anticipated benefits from this study:

- a) The potential benefits to science and humankind that may result from this study are to measure the current awareness and perception of descriptive language around and within the autistic community.
- b) The potential benefits to you from this study are to further explore your own perceptions and positions in how you talk about yourself and/or others.

Alternative treatments available:

N/A

Compensation for participation:

There is no monetary compensation for participation.

Circumstances under which the Principal Investigator may withdraw you from study participation:

Should you answer questions indicating that you are not and do not know anyone who is autistic, your answers will be dismissed from the survey. If for any reason you wish to withdraw from the study, you will be able to contact the principal investigator to ask that your answers are dismissed. While privacy is protected and no identifying information is gathered, an opportunity to include a key code at the end of the survey will act as your way of identifying your answers should you wish to no longer participate in the survey.

What happens if you choose to withdraw from study participation:

There are no penalties for withdrawing from or having your answers dismissed from the study.

Contact Information. If you should have any questions about this research study or possible injury, please feel free to contact Elizabeth Kobeck at erk2u@mtmail.mtsu.edu with reference to the study.

Confidentiality. All efforts, within reason, will be made to keep the personal information in your research record private but total privacy cannot be promised. Your information may be shared with MTSU or the government, such as the Middle Tennessee State University Institutional Review Board, or Federal Government Office for Human Research Protections if you or someone else is in danger or if we are required to do so by law.

Q1: Do you give free and willing consent to participate in this survey?

- I do consent and wish to participate
- I do not consent nor do I wish to participate

Q2: Are you 18 years of age or older?

- Yes
- No

This section is for basic information regarding demographics. Please be aware that all answers given will maintain anonymity. Your name and proof of diagnosis, such as the doctor who made the diagnosis, will not be required.

Q3: Are you autistic?

- Yes
- No

Q4: Do you have a loved one who is autistic?

- Yes
- No

Q5: When were you or a loved one diagnosed?

Month and date are less important, as long as the year of diagnosis is correct.

Q6: What was your or your loved one's diagnosis?

Examples include: Autism, Asperger's Syndrome, etc.

Q7: Are you taking this survey as:

- An Autistic individual
- An individual on the Autism Spectrum
- A family member or loved one of someone with Autism
- A family member or loved one of an Autistic individual

How one identifies regarding their diagnosis can tell a lot about how they perceive the diagnosis's affects on the individual. Person-first language refers to instances where the diagnosed individual's personhood comes before their diagnosis. On the other hand, identity-first language is used when the individual describes themselves by their diagnosis.

In this section, choose the answer that falls closest to how you would say the answer.

Person-first: "I am a person with Autism, Asperger's, etc."

Identity-first: "I am an Autistic, Aspie, etc person."

Q8: When discussing your or your loved ones' diagnosis, how do you refer to being on the Autism spectrum?

- Person-first
- Identity-first

Q9: When someone refers to you or your loved one by their diagnosis first, do you feel upset?

Ex. "Susie is an autistic girl."

- Yes
- No

Q10: When someone refers to you or your loved one with their diagnosis as an aside, do you feel upset?

Ex. "Susie is a girl with autism."

- Yes
- No

Q11: If someone were to refer to you or your loved one by your diagnosis, how bothered would you be?

1 3 5

Not bothered

Very bothered

Q12: If someone were to ignore your or your loved one's diagnosis when referring to you, how bothered would you be?

1 3 5

Not bothered

Very bothered

Oftentimes, diagnosed individuals find that their use of identity-first and person-first language is dependent on situations. This final section has described scenarios where someone else is talking to you or your loved one about someone in the Autism spectrum. On the scale, indicate how much or how little you are upset by the handling of the scenarios. If any of these questions confuse or make you uncomfortable, feel free to skip the question.

Note: The scale listed below is on a one (1) to five (5) range where one (1) is scored as being *not bothered* while five (5) is being scored as *bothered*.

Q13: When talking with a friend, you hear them complaining about how much time their parents had to put in for another sibling. After some time talking with your friend, they finally state that their sibling "has Asperger's Syndrome." In regards to their wording, you feel:

1 2 3 4 5

Not bothered

Very bothered

Q14: You are talking with some friends at a party. During the conversation, the topic of Autism comes up. One friend is explaining how they often forget that you are Autistic.

1 2 3 4 5

Not bothered		Very bothered
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Q15: When visiting your grandmother, she has friends come over. She insists that you join in for the visit with her friends so you oblige. While she's introducing you, she mentions that you are her "autistic grandchild."

1 2 3 4 5

Not bothered		Very bothered
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Q16: A large organization has begun a campaign to raise money to help cure Autism with a slogan, "Help children with Autism." In regards to the wording alone, you feel:

1 2 3 4 5

Not bothered		Very bothered
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Q17: Your participation in this survey is extremely appreciated by the investigator. Please feel free to skip the following question if you do not wish to have any contact or questions for the investigator. If you feel that you may have questions or wish to be withdrawn from the study after submitting it, please include a five character "keyword" that you can remember in case you want to be withdrawn.

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